ENHANCING THE HEALTH OF INFORMAL CARERS:

IMPLICATIONS FOR GENERAL PRACTICE,
POLICY AND PUBLIC HEALTH
IN THE 21st CENTURY.

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Research Thesis submitted for the award of the degree of
Master of Medical Science
June 2002
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ABSTRACT

'ENHANCING THE HEALTH OF CARERS: IMPLICATIONS FOR GENERAL PRACTICE, POLICY & PUBLIC HEALTH IN THE 21ST CENTURY'

This study examines four main areas: the impact of caring on the health of the informal carer; general practice as the key to carer health enhancement; and informal caregiving as population health and public policy issues under the wider rubric of public health.

3.4-4.2% of informal carers were caring for chronically ill, disabled or frail aged individuals during the past decade in South Australia, however this was at a personal cost to the health of at least a third of family carers. Despite provision of support services for carers, a clinical model of care for carers is absent from policy and care planning. Therefore proactive General Practitioners are vital for both the well being of the carer and the cared for person at home but GPs have needs too when trying to assist carers. Few carer studies have sought a GP perspective.

[Phase one]: The health and social needs of carers were examined in the general practice domain with 22 carers and 25 GPs [using focus groups, interviews and questionnaires] in the mid 1990s. [Phase two]: Population surveys of over 6000 people [using the SA Health Omnibus Survey] to compare health status between carers and non-carers were conducted in 1994 and 1998. Carers consistently had lower scores than non-carers in all health dimensions of the SF-36. Females' scores were lower than males, and up to a half of all carers reported their caring role negatively impacted on their physical and emotional health to the point where the individual's social and emotional functional capacity was significantly limited.

This research concludes that carers may actually be prevented from achieving their optimum health status due to the restrictions of their caring roles and lifestyles and therefore recommends specific carer health policies be developed. Future care planning, training curricula, and carer policy requires an ethical framework of caregiving to better address the individual health and clinical needs of the carer - in parallel to service needs associated with the caring role and relationship. Improved integration of general practice with all carer support and community care initiatives is urgently required.
STATEMENT

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

I consent to this copy of my thesis, when deposited in the University Library, being made available for loan or photocopying.

Signed: Anne F. Stacey

Date: 19 Nov 2002
ACKNOWLEDGEMENTS

A special mention is made of the following people who made this research possible. Without their help and enduring support I would not have been able to complete the tasks over past years. First, sincere thanks to my Supervisor, Dr Neville Hicks, Department of Public Health Adelaide University, for his wisdom, patience, encouragement and understanding during the latter difficult years. To my earlier supervisors, the late Professor Chris Silagy, then at the Department of General Practice, School of Medicine, Flinders University, and Dr Alan Stewart, Department of Primary Health Care, Flinders University, for their confidence in me and assistance at the start of this project. I thank my initial academic advisors Dr Malcolm Bond, Flinders University, and particularly Dr Justin Beilby (Flinders University and Adelaide University) for their field support. Also I appreciated the backup support of all the Departmental staff involved at both Universities.

I acknowledge the support of the Royal Australian College of General Practitioners, SA and NSW Branches, as well as the Management Committee and GP members of the (Adelaide) Southern Division of General Practice, and the Australian Medical Association (SA Branch). Other organisations that have been central to this study include the Centre for Population Studies in Epidemiology, Department of Human Services, South Australia, with special thanks to Anne Taylor and Catherine Chittelborough, for their invaluable assistance, (and earlier in the project Dr Melanie Wakefield, Behavioural Epidemiology Unit, SA Health Commission). Also to staff of Harrison Health Research, Adelaide, SA.

Carer and community agencies to whom I am indebted include the Carers Association of South Australia, the Southern Carer Support and Respite Centre, the Alzheimers Association (SA), Stroke SA, Parkinson's Society, Mental Health Education and Resource Centre, (SA), to name a few. Further afield are the Carers Association of Australia, and the Carers National Association, UK. I thank Pat Smytherman of the Carer Support and Respite Centre for her liaison and skilled facilitator roles in this project and I pay tribute to the busy carers and GPs who both as advisors and participants, so generously gave of their time to share their knowledge and experiences for my research.

Lastly I thank my parents and extended family for their steadfast support and encouragement during the past decade, and dedicate this thesis to my mother and late father who died during the period of my candidature.
I would like to preface my thesis with some explanatory comments on the timeframe of this research and about the actual research journey itself.

Within the time constraints of most research projects, other than one conducting a longitudinal study, it is unusual for a researcher to have the opportunity to review the findings and conclusions over an extended period. That however was the case with my part-time research work which unexpectedly was to span the years of 1994 to 2001. It is also unusual for the researcher to seemingly step inside and start to live one's research. By an ironic twist of fate, that happened to me.

My research journey was initially straightforward. It commenced in earnest in 1994 as a simple, preliminary descriptive study that focused on the needs of informal family caregivers in the general practice setting. Working in association with a newly established Division of General Practice and a university general practice department, by mid 1995 I had developed the project, completed the field work, data collection and prepared an interim report on carer needs and GP perceptions about carers and community services. I had also acquired some survey data on carer health status that revealed surprisingly clear results. I then transferred to a department of public health so that I could consolidate my research work by exploring the population and policy implications of the research findings. That led me further afield, to look more closely at the health of carers, from public health and policy aspects.

But before I could complete this thesis, my life was transformed from that of a researcher of carer issues, to become a carer myself. I was to experience first hand, the dramatic impact of taking on such a role in the family home. My new caring and home nursing roles started slowly at first, but from 1996 were to intensify and dominate my life to the point where I had to give up paid work and most of my research and studies, so I could nurse my father at home in Adelaide. He fought a valiant but dignified battle against
cancer and Alzheimers Disease over the ensuing years and finally died peacefully at home with his family in mid 1999. Our efforts were not in vain and there was a great deal of satisfaction in knowing that my father had had the best care possible, and he had been happy at home to the end. Providing that level of care however was the hardest job I had ever taken on and it took many months for me to recover to a point where I could return to work on my thesis at university. This included re-assessing those earlier findings and reflecting on my preliminary conclusions and recommendations.

Prior to the experience of caring for my father, my approach to this research about carers was very much as an investigator examining a poorly defined but huge map of the informal caring environment. I proceeded as any explorer might move into unknown regions - inspecting the map to gain a better idea of the caring terrain, reading about the area, interviewing 'the locals' and documenting their comments. This I had done when I rigorously conducted the focus groups and interviews with carers and GPs. I carefully analyzed their comments and endeavoured to come to an understanding of their circumstances and needs in the general practice setting. That was in late 1995.

Within twelve months of adopting my carer mantle, I no longer looked from the outside onto that featureless map. Instead I found myself plunged into its very epicentre and enveloped by the caring experience. I soon realised as "a carer" myself, trying to survive on a daily basis, I had became part of "the territory" of caring. Not only did I get to know the map's borders and environs, which I had skirted around earlier as a researcher, but most importantly I learned very quickly what it meant to live in the territory and interact with others located inside that map. Nearly four years after becoming my father's caregiver, I had not only explored the boundaries of the phenomenon of caring, living the day and night life of a carer, but could now fill in many more of the gaps of that complex canvas of life which the carers and GPs in my study had tried to explain to me several years earlier. My own experience, in conjunction with this research, had demonstrated for me very dramatically the contrast between 'the map' and 'the territory' of caring, especially from the carer perspective.

It also illustrated the urgent need for further work with GPs as they are constantly expected to cross the divide between their own territory of general practice into the realm of the home based carer. This enabled me to see the benefits of both "carer-aware" and
"GP-friendly" solutions to the many dilemmas within community care today. I will be describing some of those possibilities in the text of this thesis.

I present my research data and facts quite objectively in the body of this thesis, but my final deliberations are based on realism gained from my own caring experiences, rather than academic and political rhetoric that punctuates so much of the home based and community care literature. As it happened, around the time of caring for my father, there were also major state and federal government carer initiatives occurring in Australia. These included the introduction of more generous Commonwealth carer pensions and financial supports, extended emergency respite care, new state Carer Resource and Respite Centres which were established to provide information and better integrated regional home care services. Due to my long term research links with Carer Associations at the state and federal levels, and serving as a Director on the Board of one of those Associations, (1999-2001) I was able to observe the unprecedented expansion of carer support from an administrative point of view. I have also been able to follow the progress of these new initiatives both with carer and General Practitioner representatives.

I have therefore been part of the bigger, more 'abstract' picture of health and aged care as well as personally trying to cope, both before and after the government strategies and benefits were introduced. It was certainly not my original intention that this research should incorporate any personal narratives of my own, but under the circumstances, my experiences and observations have provided me with an invaluable insight. I believe that having this dual viewpoint adds an important extra dimension to the study. What I was not to know however was that my caring role would not end with the loss of my father. Like so many other carers, in reality it had just started. This thesis, through the contributions of the caregivers and GPs is testament to the efforts of so many carers who have gone before me.
SECTION I
SECTION I

UNDERSTANDING INFORMAL CAREGIVING
[A review of the literature]

Introduction
Background to Research and Rationale
The Health of Informal Caregivers
An Epistemology of Informal Caregiving
Formal and Informal Care
Ethics/Conceptual Framework of Informal Caregiving

METHODOLOGY AND METHODS

An Approach to Methodology - Literature Review
Study Design
CHAPTER: 1 INTRODUCTION AND RESEARCH RATIONALE

Overview of research
The central focus of my inquiry and its long term aim is to consider the enhancement of the health and well being of informal carers in the 21st century. It is anchored within the domestic realm of family and home care but extends into the domains of general practice and public health. The latter is approached from both a population health level and a public policy perspective.

I have identified three overarching research issues which underpin this study of carer health. They are (1): Informal caregiving as a health risk to informal carers; (2): Informal caregiving as a General Practice issue; and (3): Informal caregiving as a Public Health issue, all of which I have incorporated into an analytical framework. This in turn translates into four main conceptual pillars on which I base my research project. Working within this framework has enabled me to build a theoretical model around carer health enhancement.

Initially, I focused my research in the general practice domain where I established there was inadequate research in Australia on the health and needs of informal family (and non-kin) carers from both carer and GP perspectives. Very little additional research has been carried out on the needs of GPs themselves to better support family and other informal caregivers. Secondly under the wider rubric of 'public health', I sought a 'population health' approach, initiating two surveys of the health status of carers in South Australia. Following this I reviewed the 'policy' aspects of caregiving, particularly in relation to carer health and involvement of general practice in policy development.

Structure of thesis & analytical research framework: The 4 conceptual pillars
Four conceptual pillars set the boundaries for this analytical framework within which I have developed a number of research questions for each main area of interest. See conceptual outline and list opposite.

1st CARER HEALTH @ INDIVIDUAL LEVEL
Caregiving as a health issue for the INDIVIDUAL informal carer

2nd INFORMAL CAREGIVING AND GENERAL PRACTICE: CARER/GP NEEDS
GENERAL PRACTICE as the key to carer health enhancement

3rd CARER HEALTH @ POPULATION LEVEL
Informal family caregiving as a POPULATION health issue [SF-36]

4th INFORMAL CAREGIVING, CARER POLICY AND CARER HEALTH
CAREGIVING AS A PUBLIC HEALTH ISSUE: An overview and discussion
Chapter 1: Introduction

This thesis is presented in five sections. The first section of the thesis opens with an overview of published evidence on the impact of caregiving on carer health drawing on reports of carer health from Australia, Britain and the United States. Discussion follows on the epistemology and concept of caring then I describe the key ethical elements of informal caregiving.

1st Conceptual Pillar: Informal Caregiving as a health issue for informal carers. [This is based on the notion of caregiving as a risk to carer health.]

Carer health at the Individual level
The first conceptual pillar of my analytical framework is the notion that informal caregivers may experience extra health problems associated with their caring role and responsibilities. This idea emerged during the 1980s and early 1990s, when a trickle of academic papers were appearing in geriatric and psychology journals about emotional and physical health problems experienced by informal carers of the frail elderly and severely disabled. Commentators were suggesting there could be a link between the impact of the caregiving role on health problems reported amongst the family caregivers. However such a link could not be firmly established as there was only limited evidence to suggest causality between caring and carer ill health. Based on the notion of informal caregiving impacting on carer health my research questions under the first pillar are:

1.1 Does caring impact on the health of carers?

   In what ways/how is informal caregiving perceived as detrimental to health of family/informal carers?

1.2 What effects does caring have on the health, well being and lifestyle of informal carers?

   1.2.1 Carer Perceptions:
   What do carers themselves have to say about their experiences of caregiving roles and responsibilities.
   What are their perceived needs and general effects of caring on carer health.

   1.2.2 GP Observations:
   What do local GPs say about carer health and their related needs?
   These issues and questions are raised in Sections I and II of the thesis.
Chapter 1: Introduction

2nd Conceptual Pillar: Informal Caregiving and General Practice

The second concept underpinning this research is based on the notion of General practice as the key to the enhancement of carer health. GPs are the pivotal health profession with whom carers have most regular and prolonged contact. Before suggesting a broadening of the GP role in supporting the health and social needs of caregivers, I wanted to know if GPs themselves would be amenable to a more pro-active approach to informal caregiving. What did GPs think about supporting carers in the future? I address these four key questions in Section II.

2.1 Do GPs understand informal caregiving, carer roles and responsibilities?
[Compare GP comments with carer views of their own experiences]

2.2 What did GPs have to say about supporting carers?
Would GPs themselves be amenable to a more pro-active approach to informal caregiving in the future. [1994/5]

2.3 What is happening in general practice in southern Adelaide about carer issues?
I ask selected GPs from across the southern region.

2.4 GP Experiences: What problems have GPs had in trying to assist carers?

This refines my analytical framework so I can pursue the crucial role of GPs in the early identification and support of carers' health and caregiving needs related to their caring role. The relationship between carers and GPs was referred to in references about carer well-being in reports released through fledgling carer and consumer organisations in Australia and Britain. They included broad and somewhat vague suggestions that carer health issues and other needs could be better addressed within General Practice. Carer representatives and academics, particularly in the UK, emphasised it was the GPs who functioned as gatekeepers to the rest of the health care and community support systems, and this was especially relevant to the roles of informal family carers. This second issue thus revolves around 'good practice' for carers in general practice.

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Chapter I: Introduction

For the majority of GPs to adequately meet the needs of family carers in twenty first century general practice, GPs have to be seen as an active part of "the caring equation" by the other providers and educators in the community care sector. This was not happening in the early nineteen nineties when I was developing the field research project [later described in the methodology chapter], and certainly not prior to the introduction of Divisions of General Practice throughout Australia. A minimal interest in carers occurred with the Federal Government's Coordinated Care Trials which commenced in the mid nineteen nineties, but it was not until the recent introduction of the Enhanced Primary Care Initiatives since 1999-2000 that GPs and carers were both seen as an active part of the 'caring equation'.

If general practice is to support carers more comprehensively, strategies that provide adequate remuneration for GPs are also needed to encourage the local doctors to identify and build relationships with informal carers. The GPs themselves will require more direct assistance to help them deal with the very complex and cumbersome structure, funding and distribution of community services for carer support. GPs' self-conception on these matters are least well known and hardest to find out. Harvesting rich, qualitative information from GPs, involves time consuming research within general practice and is a difficult task for investigators, both inside and outside the profession. I have attempted to examine this on a small scale through my study with twenty five local GPs in the southern region of Adelaide and the Fleurieu Peninsula.

3rd Conceptual Pillar: Informal caregiving as a population health issue.
The third conceptual pillar takes a societal and public health approach to caregiving observing 'Carers' health at the population level as a group potentially at risk. This section focused on re-defining informal caregivers as a group at risk of health problems due to their demanding caregiving activities and lifestyle.

Four questions emerged:

3.1 Do informal carers at the population level perceive their health is affected by their caregiving role? and

3.2 What proportion of these caregivers report they have health problems?

3.3 Can it be shown there are any measurable differences between the health status of caregivers and non-caregivers at the population level?

3.4 If it can be shown informal caregivers have a lower health status, what particular areas of their health and well being are affected?

Section III explores these questions.
This moves the focus of my inquiry from the individual carer perspective, to a population dimension. It attempts to redefine informal carers as an identifiable group at risk of health problems that are related to their demanding caregiving "work". Taking a wider view of carers provides a way of contrasting the health status of carers with non-carers within the population raising the question of whether the health status of carers as a group might be different to that of the non-carer population. This approach was designed to help me establish if there was a case for viewing caring as a public health issue, particularly if any of those health problems could be prevented.

I also explore in this thesis the idea that the caring role might prevent some carers from achieving the optimum health standard enjoyed by non-carers. This phenomenon along with details of the SF-36 results of carer health, suggests that the difference between being a carer compared to being a non-carer, might be described as the difference between having or not having a chronic disease. Asked more simplistically, does it suggest that the impact of caregiving on the carer is like the carer having a chronic illness himself or herself? These results and interpretations of the surveys of carer health, together with a growing body of research over the previous two decades, now provide compelling reasons for members of the health profession and GPs to take a more proactive approach to assessing and addressing carers' health needs.

4th Conceptual Pillar: Informal Caregiving- Carers & Public Policy.

Central to the whole issue of carer health are the politics and policies driving the trend towards home-based and community care. Shifts in the locus of care and greater emphasis on the informal carer have occurred in parallel with the groundswell of consumerism and carer movements voicing the rights of the aged and disabled people to live independently and apart from institutions. Also, as health services are put under increasing pressure, family carers have less confidence in the "system" to care for loved ones- especially in the longer term. Carer advocacy groups have vigorously supported the home care preferences of families to care for their dependent relatives at home, and perhaps by default, have supported 'public policies' that paradoxically have resulted in increased burdens on informal family carers in the family home. Unfortunately, increased home based care has

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4 At the same time there has been a declining confidence of families in the ability of the health system to offer adequate long term quality of care for chronically dependent and disabled relatives, especially parents of disabled and chronically sick children, rather than "leave them to the mercy of an already overstretched system". Family members readily, but not always willingly, accepted the responsibility of taking on the care of their loved ones at home as there seemed no other choice but to care for their relatives home.
become so overwhelming for some families and other informal carers, that governments have had to introduce additional public policies to fund community services to assist carers and attempt to solve 'private' troubles.

Examining carer issues at the societal level thus shows how carers' private problems are transformed into community-wide needs that require public solutions through political and policy initiatives. One is prompted to ponder however what comes first for carers - the public policy or their personal problem? It is a 'catch-22' situation! Thus this line of inquiry prompts questions about the impact, both positive and negative, of public and social policies on personal lives of informal caregivers, their health, quality of life and autonomy. The moral imperatives associated with public and institutional policies in relation to informal caregiving are explored in the light of these paradigmatic and ideological shifts in community care which have prevailed over the past two decades.

Building on the findings of my own population health surveys described in Section III, as well as results of carer surveys through the Australian Bureau of Statistics and other surveys of carer health, the main research questions in Section IV first ask: -

4.1 How well does Australian public policy address carers' health?
4.2 Are GPs adequately integrated into Government carer policy.
4.3 Are carers integrated into General Practice policy?

Informal Caregiving- Caregiving as a Public Health Issue.
In the final part of the thesis I address the main issue of whether informal caregiving can be viewed as a public health issue.

The conceptual framework outlined above provided me with a very comprehensive structure for my research project, around which I designed my methods, collected and interpreted my data. The research expanded accordingly and resulted in a reasonably large project. Since quite a few years have elapsed from the time I collected my data in 1994/5 to present day, I will not be presenting details of all my data in this thesis. There have been many changes in the types of community services available and the introduction of carer specific services since 1996.
CHAPTER 2
BACKGROUND TO RESEARCH

Introduction
The genesis of this research for me links back to a brief undergraduate project I undertook towards the end of my nursing degree in 1992. I was at that time considering "dimensions of care" within the health care system in the context of formal and informal care. Having worked as a registered nurse within Adelaide hospitals over the previous twenty years, in between studying medicine for a short time at university, I was interested in exploring aspects of informal family caregiving in the community, an area I had had little contact with professionally. I was surprised to discover how much informal family based care of complex chronically sick and severely disabled people occurred at home and especially concerned at the intensity and protractedness of that work load on family carers.

The phenomenon of informal caregiving and home based care was occurring as a result of late twentieth century economic, political, social and demographic changes acting as catalysts to governments, prompting politicians and bureaucrats to rethink and restructure the way health and related social services could be funded and delivered. Pressure on informal carers became more acute in the late 1980s and early 1990s with further changes in hospital and health care that allowed even sicker patients to be discharged home requiring ongoing personal care at home. An additional dilemma surrounded children and adults who would have, a few years previously, died as a result of trauma and disease. Today they are surviving through the benefits of medical, pharmaceutical and technological advances. Many however were, and still are, sent home in various states of mental and physical dependency to the long term care of parents, partners or adult children. Most significantly, the family carer was usually expected to provide 'informal' nursing level care for increasingly complex and sick individuals in the home, 'work' which was not necessarily shared with other informal or formal carers. It appears little attention was given to the assessment of the carer's own willingness, wellness or capabilities, nor was the potential impact of that long term caring considered in terms of the carers' own health.

During the late 1980s large numbers of family carers remained unidentified and unprovided for in the family home, despite the earlier introduction from 1985, of the Australian Home and Community Care Program which was established to support frail aged and disabled individuals outside of institutional care. At the same time there was
increasing support and recognition of carers in Australia and Britain, fuelled by a growing trend by feminist and social science scholars who redefined family members, relatives and close friends - simply as 'carers.' Carer advocacy and lobby groups had been formed in Britain in the late 1980s, emerging as a strong political force presenting a voice for carers in their own right. Much of the impetus for the carer movement in Britain was in response to the controversial Community Care Act\(^2\) proposed for enactment in that country initially for 1990. There was so much public disquiet that the introduction of the Bill was delayed until 1993.

In Australia during the early 1990s, the Commonwealth Government took a very proactive approach to community care. It funded the establishment of state carer associations which embarked on awareness raising campaigns on the special needs of this growing but 'invisible' army of family caregivers. Through the early work state carer associations in NSW, Victoria and South Australia in particular, there was an improved recognition of 'carers' by professionals. As more care was transferred from health institutions to 'the community', additional government funding (carer pensions and payments and extra respite services) was requested so to as to provide better support for carers.

**My first conclusion**

My short undergraduate study on the informal dimensions of care and the caring roles of family relatives was primarily from a nursing perspective and at the end of my investigation in 1992 I came to two conclusions. Firstly, carers required dedicated clinical attention to their own health needs during all the stages of their demanding caring role. Despite the nursing profession's obvious empathy with and commitment to family caregivers, the one and often the only health professional with whom the carers were in regular contact over periods of five, ten, even twenty years for example, was their local General Practitioner. The family doctor was usually the first to have contact with relatives who were entering into a caring relationship or were already caring for sick family

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1 The term 'carer' had started to emerge within British and Australian governments and in social policy documents during the late 1980s but the term 'carer' was not used in the United States in this way. In North America, the emphasis was specifically on 'family caregivers' and remains so today. Australian authors tend to use both terms, adopting the American version of 'family caregivers' when referring specifically to relatives, then using the broader British term of 'care' that also includes non-kin informal caregivers who take on caring roles involving close friends. For example one well recognised group on non-kin carers were the partners of patients with AIDS who became very vocal during much public debate surrounding care of HIV and AIDS patients during the 1980s[mention my early paper]. I shall be using both the 'care' and 'caregiver' terms in a similar manner in this thesis.

2 *National Health Service and Community Care Act, UK 1990 and 1993*
members at home. During these extended periods of time, carers are less likely to maintain ongoing and stable relationships with any other local community health care professionals.

The dilemma is that some GPs do not always recognise 'carers', tending to see them as the family member, next of kin or significant other. Nevertheless, what I concluded was that carers sought, valued and trusted their family doctor, choosing them as the preferred health care professional for advice and help. As a central tenet to this carer research, I argue that whether the GP realises it or not, from a carer point of view, the local family doctor is very much a part of that family's caring equation. In this thesis I suggest it is the carer's preference for GP involvement which will be the driving force for a more comprehensive approach to carer enhancement and support within general practice in the future.

**Carers and GPs - partners in care**

At first glance, the deliberate coupling of family caregivers and general practitioners as partners in home-based care may appear rather incongruous. Family caregivers and GPs occupy opposite ends of the formal - informal care spectrum. It is however, well accepted that informal family caregivers and GPs are both pivotal to the *continuity of care* of 'patients' who are cared for at home. If one sees the carer and GP roles from their respective positions of responsibility for the long term support of a sick individual in the home, the link then becomes much more meaningful and logical. Further, if one considers the role of GPs in terms of 'care of the health of carers', the link becomes crucial.

Continuity of care and sustained co-ordination of care through general practice is therefore vitally important for carers especially those whose caring responsibilities continue over many years. The family doctor's intimate medical and social knowledge of the family's life, about the caring relationship and cared for person at home, placed the local doctor in a unique position to be the preferred contact and advocate\(^3\) for the carers. The family's close proximity of a medical practice within their local suburb or town was, and remains an important factor for carers.

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\(^3\) This scenario does need to be tempered with some qualifying remarks. The picture of the smaller personalised general practices of recent years may not be accepted as 'the norm' in the light of a decade of reform and restructuring of general practice. With dramatic changes impacting on general practice as we enter the 21st Century, the reality of tomorrow's local family medical practice might not quite fit this image. There is a trend for increased mobility amongst General Practitioners and as medical practices are encouraged to amalgamate, enlarging into more business oriented groups, one cannot assume that one's regular GP will always be there as was the expectation of past generations.
Despite GPs' close and frequent work with families in both Britain and Australia, there was scant information available during my preliminary research during 1994-5 about general practice supporting carers' roles, or GPs monitoring the health and well-being of the carers themselves.\(^4\) That was not to assume General Practitioners within the profession were ignoring carer issues at that time, but it indicated there was a real need to pursue a research project that coupled GPs and family (informal) carers. When I initially tried to find research that specifically focused on carer-GP interactions and evidence on whether carers \textit{per se} were recognised within general practice, I found no useful studies in Australia. There was some isolated activity in Britain in the early to mid 1990s, through the Kings Fund Centre in London where a number of projects were funded to strengthen the carer-GP link at a service level. The only other research project that was GP initiated was through the University of London with Dr Jeanette Naish\(^5\).

**My second conclusion**

The second conclusion from my brief nursing study on different dimensions of care was in relation to the actual role of the informal caregivers at home. Reviewing their caring tasks and activities carried out by family caregivers at home through the eyes of a health professional, I was concerned that many family caregivers were more than 'just helpful relatives' providing mere basic personal care for sick and dependent people at home. A proportion of carers were giving quite detailed, 'nursing type care', supervising and 'specialling' sick, severely disabled, or terminally ill relatives at home. In many instances the informal care was of a similar nature to that rendered by trained nurses in the hospital environment. Examples include care for those who elected to die at home or chronically ill adults and children requiring regular home renal dialysis, laryngeal suction, parenteral feeding and bowel management. Few authors have acknowledged this blurring of roles between the formally trained nurses and informal carers, even to the present day.\(^6\)

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\(^4\) I refer here to the Enhanced Primary Care RACGP Standards and Guidelines for Health Assessments, Care Planning and Case Conferencing, which recognised carers and the effects caring can have on carer health. GPs are now encouraged to assess carer health as part of the Enhanced Primary Care program for Australians over 75 yrs.

\(^5\) This was a joint academic project through the Academic Department of General Practice and Primary Care, Medical Colleges of St Bartholomew's and the London Hospitals at Queen Mary and Westfield College, Mile End Road, London, UK

Carers 'alone at home'

An additional concern of mine was that family carers were mostly functioning alone at home, not only without optimum equipment and facilities, but without adequate preparation and training. In addition, many carers especially those in rural areas, were without back-up of paid relief carers (personal assistants and nurses). This is incongruous when contrasted with the numbers of workers that trained/paid nurses have on call to assist them in their daily work in institutions. It seemed to me unacceptable that these same 'patients', who when hospitalised required rotating teams of trained personnel to care for them, were discharged home to family members to manage. The assumption was 'a carer' would be available and able to continue to provide constant nursing care, general maintenance and in some cases, rehabilitation therapy. Many relatives were given no choice but to provide care and support for sick and dependent individuals on a non-stop, around the clock basis, enduring broken sleep, going without regular days off or 'recreation leave' that is a pre-requisite for all paid employees. For some family caregivers these caring duties continue for decades. For example in the case of parents with severely disabled or brain damaged children who then tend to age earlier, or for spouses and other family members caring for frail or relatives with neurological disorders and other chronic illnesses. For some the caring role is destined to continue unabated for half a life time, usually increasing in intensity as both the cared for person, and the carer age.

Wearing the hats of both a trained nurse and later that of a carer myself, I found this practice of transferring such heavy and intensive care from formal to informal carers ethically questionable. This was heightened by the introduction of early discharge and 'hospital at home' programs for post-operative patients, introduced throughout the health system by mid 1990s. The ethics of caring at home remains an underdeveloped area. It requires much closer scrutiny with the aim of developing guidelines and protocols to prevent formal institutions from failing to fulfil their duty of care in today's so called seamless health care system.

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7 Although patients have been carefully selected for such Hospital at Home programs thus far, there is potential for increased use of this approach to post-operative care which could place inappropriate burdens and worries on family members who already are carers of chronically ill persons.

8 The fact that within such hospital at home programs trained nurses visit the patient at home on a daily basis for half an hour or so, does negate the fact that the informal carer [usually the spouse] still has the responsibility and workload of caring for the 'patient' for the remaining 23 hours of each day.
These conclusions highlighted for me the unfair pressures, unjust and unethical burdens placed on relatives, (and sometimes on very close friends), by a financially stressed health system and government ideology that was condoning the transfer of patient care onto unpaid informal caregivers under the guise of improved patient care in the community. In reality, one has to question how much of this new approach is implicitly dollar driven to help solve government problems like institutional funding shortfalls and bed closures across hospitals and nursing homes, staff shortages. Without doubt it is associated with a declining welfare state, as well as the prevailing economic rationalist policies.

My Argument

As many governments have pursued the economically appealing idea of care in the community, some even adopting the slogan of care by the community, it has been at the expense of the family caregiver - of whom two thirds are women. Some are children and teenagers functioning as unpaid carers. I strongly agree with several other researchers like Julia Twigg that the idea of 'community care' and policies promoting 'care in the community' are seriously flawed in the expectation that an arcane faceless, unidentifiable 'community' can take responsibility for the health and personal care of a chronically sick, frail or disabled individual who is incapable of self care. I argue that in reality the responsibility for care is in the hands of individual caregivers [the mother, wife, daughter, in-laws or sometimes the husband] - but usually one family member who takes on the role of the primary carer.

In some cases the less than optimum circumstances surrounding caring for relatives and loved ones at home has the potential for carers to take on unhealthy 'work loads' and lifestyles. This has been exacerbated by expectations placed upon them by all levels of society, from governments, the health carer system, and from family members themselves. Expectations of carers is particularly high in ethnic communities and amongst certain cultures.

Carers and GPs and a clinical approach to carer health

My wider concern however is about the culmination of the effects of a decade of carer and community care policies on society in general which have been developed mostly outside clinical or medical paradigms. Although significant advances have been achieved for carers at the service and support level using a social health model, there has been a serious

9 This reference is applied mostly to the British government's 'Care in the Community' initiatives of the 1990s.
absence of a clinical based programmes relating specifically to addressing carer health issues. I therefore suggest the possibility of reconsidering the health needs of carers from within an integrated carer health policy and a clinical model of care that is based within general practice. I further suggest that from an ethical perspective it is vital not only to protect 'at risk' carers from harm at both the individual level and as a group at the public health level but also include active clinical measures [eg early clinical intervention] to tend to those carers who may succumb to the strains and stresses of their caregiving workloads. GPs are one of the few groups of health professionals who are in frequent enough contact with the carers to monitor them. GPs also have the training to do so.\textsuperscript{10} It is well accepted that there is potential for pro-active intervention by the GP, so that many carer crises and health problems can be circumvented or prevented from occurring. It should be acknowledged that this already occurs in many practices where carer-aware' GPs are giving considerable time and effort to support family carers in need. This has been further enhanced through the recent Enhanced Primary Care Initiatives, introduced in 1999/2000. However not all GPs recognise carers in the context of that shared responsibility, or the need to monitor carers as people specifically 'at risk,' which was one of the main reasons for my first initiating this research project.

\textbf{Rationale for first stage of Research Project}

To gather local information about these issues necessitated a qualitative study to find out what was already happening in the field of general practice, and what carers and GPs thought might improve outcomes for carers, those they cared for and for the GPs. Descriptive data was based on the perspectives and experiences of carers, as well as from GPs through their observations of carers associated with their own practices. The bulk of this research predated the Co-ordinated Care trials which involved Australian General Practice during the late nineteen nineties. It was also more than five years prior to the Federal government's EPC initiatives however brief references will be made to the place of carers within both programs.

If I were to suggest a broadening of the GPs' role in supporting carers, especially their health, I wondered if GPs themselves were going to be amenable to a more pro-active /

\textsuperscript{10} As a caveat, I add that there is potential for medical specialists from many fields to identify carers at risk and initiate follow-up through the GP. Geriatricians and palliative care specialists are already sensitive to carer circumstances but is it still not adequately dealt with at the clinical level ie where carers own special health needs associated with the caring role are assessed and offered health care for themselves.
preventive approach with informal caregivers. Working and consulting with GPs in a Division of General Practice, I was aware of the growing pressures and frustrations inherent in practicing family medicine already impacting on GPs in the early to mid 1990s. What about their perspective? Might GPs themselves have unmet needs which should also be addressed? We don't know what GPs actually think about their role in helping family carers as GPs are rarely asked, which perhaps is the crux of the problem. The GP perspective is the missing voice! One of my main objectives in developing this research in 1994 was therefore to actively include GPs in my study on carer needs and health, to seek GP experiences and suggestions on what might assist them with supporting carers. This was to yield both useful and revealing information. The doctor's own comments suggested that GPs themselves responded as "consumers" and strongly identified with family carers when trying to access community, carer and social support services for their patients and family carers.

Initial Research Issues and Problem Statement
I chose two main issues about carers within general practice in the early 1990s and I identified two problems for follow-up in the first stage my research project. To my surprise I find these issues remain problematic at the practice level a decade later. These were integrated into my initial Research Problem Statement (before the field research in 1994/5) which read:

The health and related social needs of carers are not always adequately recognised and managed at the primary care level (either by the family doctor or by the carers themselves) and problems often continue unresolved until a crisis point is reached. This not only puts the health and quality of life of the carers seriously at risk, but may compromise the continuity of care of the person being cared for. The health system may then have two patients to provide for.

The General Practitioner is in a unique position as the most frequently consulted health professional in the community, who can readily identify, support and advocate for people who are carers. With appropriate pro-active intervention by the GP, many carer problems can be prevented... What then do carers and general practitioners have to say about this?
Research Purpose Statement
Thus the purpose of the initial study was to access General Practitioners and people in an informal caregiving role (carers), firstly to draw together their comments and ideas;  
*To explore the meaning of the role of “carer”,* and secondly;  
*To gain an overview of the broad needs of carers in their interactions with their local GP or family doctor.*

The Research Objectives relating to GPs -
To explore their understanding and perceptions of the role and responsibilities of carers and the major needs of carers. Also the impact of caring on carers and their health which GPs had observed in their practices. GPs were asked about their own needs and invited to give suggestions of what would help them provide improved carer support.

The Research Objectives relating to Carers -
To explore with carers, their understanding and experiences of their role as carer, the responsibilities associated with being a carer, and their perception of the general effects caring might have on their health & well being. Carers were asked how GPs could provide more comprehensive support...

Findings from the early stages of my research allowed me to take the next step from considering GPs’ support roles with individual carers to explore broader public health issues relating to population health and policy. Service provision, preventive and health promotion initiatives dedicated to enhancing the health and well-being of informal family caregivers are also considered. I now present a brief overview of the literature on carer health.
CHAPTER: 3
THE HEALTH OF INFORMAL CAREGIVERS

Introduction
It is most interesting when reviewing the literature on the health of informal caregivers to note the evolution of this topic over the last two decades. Having made yearly searches on carer issues over the past eight years, I have seen informal and family caregiving emerge from the point of obscurity to a subject in its own right and noted some important trends on how research on carer health is advancing and changing. I refer to recent discussion of carer mortality in relation to the impact of caregiving on older individuals caring for their spouses. Prior to 1999, caring had never been reported in terms of increased mortality amongst carers. That study will be discussed shortly.

Carer Health - Early literature review: Carer morbidity
In 1994 I prepared the following summary after a fairly extensive review of the literature on the health of informal caregivers. (I repeated my literature searches on carer health in 1996 and again in 2000.) I noticed in the literature from the 1980s there was more interest on the actual impact of caring on carer health, than emerged in the 1990s. This latter decade produced a regular sprinkling of articles on studies featuring carer health, especially from North American investigators. However the dominant area of interest by researchers during the 1990s was service related, especially from the British academic community. There has been growing volume of research internationally (1985-1995) into the effects of the caring role on the health and well being of caregivers.\(^1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12\). Much focused on the psychological morbidity of caregivers, for example

stress and depression, particularly amongst those caring for the elderly and patients with dementia. Most British and North American studies have consistently reported stress, depression, sleep problems and psychological morbidity as the predominant effects of caregiver burden, especially on female or spousal carers. Other frequently reported effects are hypertension, heart palpitations, back and musculoskeletal injuries, arthritis, gastrointestinal disorders, ulcers, anaemia and dizziness.  

A 1989 survey by the Southern Community Health Services Research Unit (in the southern region of the Adelaide metropolitan areas of Marion, Brighton and Glenelg), compared the health status of carers versus non carers and found that non carers of both

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12 Schofield, H., Murphy, B., Herman, H., and Singh, B. 1993, Carers of People with disabilities compared with carers in the general population. Paper presented at the Scientific Meeting, Department of Psychiatry, Royal Melbourne Hospital, March.
sexes reported less illness than resident carers. In addition, carers reported experiencing many health problems in the previous twelve months. Stress and depression was more evident amongst resident carers than non-resident carers or non-carers. This is consistent with many overseas studies. It was found in the same survey that a greater percentage of resident carers were experiencing conditions like arthritis, rheumatism, stress and allergies. Also sleep problems, lack of energy, physical mobility problems, back trouble and blood pressure. This was similar to some American studies referred to above which also reported specifically on the mental and physical impacts of spousal caregiving of people with Alzheimers. Female caregivers in particular were found to report higher incidence of headaches. Snyder and Keefe listed hypertension and back problems, depression and mental exhaustion in their study. Some British studies also reported carers suffering from back problems and musculo skeletal injuries, while Davies commented that the caring role has a high cost to the carer, with physical, emotional, financial or all three. Among carers aged 45 or over, almost half report poor health.

The 1989 Southern Community Health Services Research Unit study concluded that carers, suffered from lack of energy and had sleep problems. This was compounded by the fact that many carers were over 60 years old themselves and had physical mobility problems related to their age. Interestingly, amongst this group, 93.3% of resident carers reported having consulted a GP in the past year. This was very close to general population trends with 94.1% of non carers also consulting a General Practitioner in the same time period.

In another report for the Southern Domiciliary Care and Rehabilitation Service (SDCRS), Kalucy referring to the 1988 ABS Survey of Aged and Disabled Persons, commented that more than half of the SDCRS carers have considerable disability and/ or health problems themselves, and experience stress through their situations. These findings therefore link the role of carer with poor health status.

26 ibid
Chapter 3: The Health of Informal Carers

Carer health-later literature review: Caregiving and carer mortality

It is only very recently, since 1999/2000 for example, that mortality has been linked to informal caregiving suggesting how mental or emotional strain, or 'the caring role' in itself, can be seen as an independent risk factor for mortality. It is acknowledged by Schulz and Beach, "...the caregiving-mortality link applies only to a subset of the caregiving population". However after a four year longitudinal study they found that those participants in their sample "...who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non-caregiving controls". This was after adjusting for sociodemographic factors, prevalent disease and subclinical cardiovascular disease. In addition Schulz and Beach reported, "...a third of strained caregivers with prevalent disease ... died within 4-year follow up period".

Another group of researchers supporting the research of Schulz and Beach, suggested linking family caregiving and chronic stress with mortality in older adults. In their 1999 article, Kiecolt-Glaser and Glaser provided data and proposed additional links between caregiving stress and clinical illness, stating that "caregiving can accelerate mortality". They added that:

'...the mortality data are likely to underestimate significantly the actual risks associated with caregiving for a severely physically or cognitively disabled spouse'.

and highlighted:

"...the growing body of evidence that has implicated caregiving as a risk factor of health", and the importance of assessing both psychological and biomedical risk factors."

These studies both represent, I believe, groundbreaking work which goes well beyond previous morbidity focused research about carers, as most studies since the mid 1990s featuring informal caregivers, had been based on either physical and psychological morbidity. Prior to that, mainly up to the early 1990s, the physical effects of caring were less often reported and the literature was dominated by research investigating the impact of caregiving mainly on the psychological morbidity of family caregivers. Much emphasis in the past has been placed on burden, stress and depression in carers.

This study focused on elderly caregiving spouses who were living with the care recipient.
33 ibid
It is noteworthy that the majority of this research on the psychological aspects of caring originated in the United States, some of which has attracted criticism from both British and Australian researchers. Although the preoccupation with the psychological impact of caring still persists, (which cannot be ignored), I notice a trickle of broader based health studies and surveys of carers are now emerging across the literature. This suggests a possible paradigm shift in the way society, especially the academic community, now perceive carers. For example the somewhat restricted view of family caregiving at the individual level that has been confined to the realms of primary health care and 'community' oriented paradigms, is now moving towards a broader public health approach to caregiving. Researchers, since 1999, are also presenting more compelling evidence on causitive relationships between informal caregiving and ill health. Some are suggesting with more confidence that being a carer can be a significant predictor of major health problems, especially for women. Carers such as those with competing roles and those in younger age groups are also considered to be at risk of increased stress. This is evidenced in my own study.

Co-morbidity of persons being cared for

One notices in the literature that the bulk of research articles over the past ten to fifteen years have broadly categorised caregivers of people with predominantly physical or cognitive impairments, or those with a mental illness. In reality, co-morbidity is more common amongst dependent young and older persons who may also have multiple physical and mental disabilities, intellectual impairment or cognitive problems like dementia. This is in addition to sensory, degenerative and chronic health problems

34 Julia Twigg was particularly critical of American research.
35 Schofield et al were also critical of the emphasis on caregiver burden as a form of carer assessment. After a very thorough and useful review of caregiving instruments related to dementia care, the preference of these authors was for a needs based model and the stress paradigm as a useful conceptual framework for caregiving research.
Murphy, B., Schofield, H. and Herman, H. 1992. 'Developments in the Study of Family Caregiving: A Review of Caregiving Instrument Related to Dementia'. Prepared for the World Health Organisation Project on Mental Health and Ageing. Vic Health Foundation, November 1992. This was part of a large project 'The carers' Program'. Carers of people with disabilities: Research and health promotion program, funded by the Victorian Health Promotion Foundation.
36 Henwood remarks on the significant physical and mental ill health among carers which exposes them to the risk of becoming increasingly unwell.
occurring in older aged persons. Mental illness may co-exist with any of the above combinations. Family caregivers have to deal with the care of their loved ones with multiple health and disability problems on a daily basis, but too often it appears that researchers avoid such complex subjects for their studies.

With a global focus on the demographics and care needs, and associated costs of caring for, an ageing society, it is not surprising that it has been the family caregivers of the frail elderly and carers of those with dementia who have consistently received the most recognition by researchers. Those caring for disabled adults or parents caring for children with disabilities have attracted less attention. Hence there is a serious gap in knowledge about the experiences, needs and support of family caregivers caring for chronically sick and dependent children and adults who do not fit into neat research categories. (Despite much academic and practical interest in palliative care over recent years, there is a surprising paucity of research into the care of carers of the terminally ill. Textbooks too on palliative care are dismally brief about health and clinical needs of carers). Researchers over past decades have enthusiastically studied the health of many different types of carers categorised by their age, sex, marital status, employment status, race, ethnicity and many other distinct characteristics, including co-residence and use of services or availability of informal social networks. Investigators have extensively researched carer well-being according to specific conditions affecting the cared for persons, so despite the gaps in knowledge mentioned above, we now have a wealth of information from a large number of small-scale studies examining a wide range of carers in various caring situations and relationships.

A generic and population view of family/informal caregiving

One type of research data that has been slower to emerge is from large population surveys in which carers are grouped together 'generically' by virtue of their caregiving role. This is irrespective of their own characteristics or whether the person being cared for is chronically sick, disabled, young, old, terminally ill, or frail aged. From the late 1980s and during the 1990s, carers in Britain and Australia in particular, have been identified in their own right in census surveys (as in the UK). Firstly they were seen as people with specific needs arising from that family or informal caregiving role, and more recently as 'a group' within the population whose health may be at risk due to their ongoing responsibilities and heavy caring workload. National government bodies have funded
surveys in the UK\(^{39}\) and Australia\(^{40}\), while some Australian state governments have, with gentle prompting, included carers as part of their state-wide health surveys\(^{41}\), all of which have reported differences in the health of informal/family caregivers when compared with non carers.\(^{42}\) This data was not available when I started on my research project in 1994. I have since found that it parallels my own results from the 1994 and 1998 Health Omnibus Surveys reported in this thesis.

What a decade and a half of research confirms is that the informal caregiving role has clearly been shown to impact negatively on both the morbidity and mortality of family caregivers, posing a potential risk to the health of a third to half of informal carers, especially those with pre-existing medical conditions and of those who are themselves ageing. Survey\(^{43}\) results show that carers of the physically impaired are more prone to injuries, musculo-skeletal strains, and in some cases fractures due to unsafe or excessive lifting of disabled adults and children or frail elders.

Caregiving in general is seen as "a significant risk factor for the development of depressive symptoms". It is suggested that:

\(^{39}\) A British household survey was the first major review to specifically include 'carers' as an identifiable group within the general population. This survey was the forerunner of a number of significant documents on carers in the UK and beyond. In 1993 another General Household survey was conducted which also included 'carers'.

\(^{40}\) As at 2000, to my knowledge, the Australian Bureau of Statistics have not yet included 'carers' as an identifiable group in a national household census, but have instead conducted smaller population surveys targeted at the aged and disabled, for example-

\(^{41}\) Australian Bureau of Statistics 1988, Carers of the Handicapped at Home, Australia 1988 Cat. no. 4220.9, ABS, Canberra.

\(^{42}\) For example Carers and their needs, were included as survey participants in the 1995 Regional Health Survey SERCIS telephone surveys by the South Australian Health Commission.

Chapter 3: The Health of Informal Carers

"...depressive symptoms are associated with development of ischaemic heart disease... Chronically depressed mood... is linked to cancer risk in older persons".44,45

Twenty years of research suggests that in general, carers of persons who are cognitively impaired or mentally ill, have been found to be more at risk of emotional and psychological related health problems, especially related to prolonged stress and exhaustion dealing with unpredictable and unusual behaviour. It should be emphasised that a proportion of these carers may also be at risk of physical injury from uncontrollable behaviour or physical violence inflicted by those they are caring for. The opposite situation, where the carer may be perceived as abusing the dependent person, for example with 'elder abuse', should always be investigated first to ascertain the level of carer stress and diminished coping abilities. Research indicates that many instances of this type of abuse are a cry of help from an overburdened or very distressed carer who cannot cope with the caring relationship or responsibilities involved in supporting a complex or difficult sick dependent on their own.

It has been consistently reported that many carers are at risk of social isolation and many become financially disadvantaged causing further stress and worry which can impact on their health and wellbeing. Informal carers are indeed "the hidden patients", experiencing poor health, which they often ignore.46 Most try to keep going in an effort to sustain the caring role, as was highlighted by Cahill and several international authors.47 This latter group of carers constitute a large number of untreated "patients", who often postpone their own health care until a crisis arises, at which point their health may be seriously compromised. Caring therefore, according to Rosenman's research with older women, "...not only has the potential to exaccerbate existing health problems, but by the time treatment can be arranged, serious health problems may have worsened".48

45 ibid
46 Australian researcher Suzanne Cahill and Margaret Shapiro featured the earlier work of Fengler and Goodrish (1979) on hidden carers.
In 1998, in a British study, Henwood also highlighted that lack of attention at an early stage to physical and mental ill health among carers. She concluded,

"...exposes carers to the risk of becoming increasingly unwell and ultimately unable to continue with their caring responsibilities. The public health agenda must recognise that carers are a group potentially at risk".  

At this point one cannot help but question why this dedication to 'duty' affects the ability of carers to see to their own health needs. It was while I was visiting England on study leave in 1993 that I came across an interesting paper that gave me one possible reason for carers' self-sacrificing behaviour. At that time there was an active carer support unit at the Kings Fund Centre in London which meant that Kings Fund Library offered a rather unique collection of publications specifically on carer needs and well being. There I found Angela Spackman's 1991 research paper on the Library data base. One aspect she raised in terms of defining and measuring health status concerns the "yardstick" a carer may use to assess their own health status. Spackman takes a functional approach, which she suggests refers to as "...the extent to which a person's activities are restricted by whatever condition he or she has". She states that "...carers might feel unwell but because of their responsibilities they are not able to give up their usual activities and adopt the so-called 'sick' role." Many carers, she says later, "feel that they give up the right to be ill when they assume the carer role", a comment from carers I have since read in other many research reports.

What Spackman next suggested however was more significant. She explained that "the individual initially needs some lay measure of the extent to which his or her symptoms constitute 'ill-health'. Many yardsticks are available like one's normal level of health, or as compared with others of the same age and sex. Spackman suggests:

"...it is possible however that carers use a further yardstick and compare their health with that of the dependent person they are caring for. The carer, she continues, "...could feel that his or her own condition is insignificant...", and "...a carer might decide that certain symptoms do not qualify as 'illness', whereas a non-carer might decide otherwise."


50 These publications were not available on the usual databases I was accessing in Australia as many were specific to current Community Care legislation proposed for introduction into the UK in 1993. Also this pre-dated our current global information network through the internet. If I had not travelled to Britain personally in 1993 and again in 1997 and searched Libraries of Kings Fund Centre, and the National Carers Association in London, it is unlikely I would have found such helpful references. These key organisations have only recently established their own websites but even now few of the references are available through the internet.

In short, Spackman says carers and non-carers "...might have different perceptions of the severity of an illness...". This seemed a cogent argument at the time of which I made note, and wondered if a carer's isolation of carers could have some influence on a carer's perception of their health. It was not until I too became a carer that I personally experienced this confounding logic first hand and found that I purposely delayed seeking medical attention for myself. It was with some surprise that I realised my decisions were based on what I perceived as my own 'trivial' needs opposed to the severity of my father's declining and serious health problems. Isolation did not help, but I also realised there were other more compelling reasons for keeping the status quo at home. It was to protect the cared for person from 'the system' or even more serious, the fear of losing touch with him or her if the carer was to be separated from the cared for person due to failure of the carer to keep going.

Physical health of carers
By the very nature of caregiving which occurs in the family home, carers endure the strain of prolonged periods of day and night supervision and support of sick, disabled and dying individuals. Recent research on carer physical health describes the associated impact of the stresses and strains of caregiving on carers. For example Schulz and Beach\(^52\) refer to carers who may become "physiologically compromised" and remind us other researchers have suggested:

"... that the combination of loss, prolonged distress, physical demands of caregiving and biological vulnerabilities...may compromise their physiological functioning and increase their risk of health problems".

The impact of caregiving on the immunological system, cited by several authors\(^53\) ... shows '...decrements in immunity measures compared with controls...', and also "slow wound healing". Kiecolt-Glaser and Glaser\(^54\) refer to:

"Chronic stressors such as caregiving that evoke prolonged distress which can influence cardiovascular, immune and endocrine function. These alterations are sufficient to enhance a variety of health threats particularly among older adults."

They cite for example: "...two studies which showed that spousal caregivers evidenced poorer immune responses to influenza virus than well-matched control subjects". Due to

\(^{53}\) ibid
their demanding caring roles there is also some reported reduction in caregiver physical functioning, especially with older carers. My survey using the SF-36 later showed this.

The most common complaints from carers are related to chronic tiredness and exhaustion, lack of energy and confusion often due to broken sleep getting up to attend to the sick person night after night, year after year. Other negative affects consistently reported in surveys on the physical health of carers range from neck, back and shoulder complaints and other musculoskeletal injuries due to frequent lifting of disabled and other 'heavy patients' at home on their own. Existing physical conditions of arthritis, rheumatism, hypertension, coronary heart disease, gastro-intestinal disorders and many other chronic or degenerative conditions that accompany the ageing process, are repeatedly reported as being worsened by caregiving roles.

The emotional and psychological well-being of carers
Research on the emotional and psychological well-being of carers paints an even more vivid and acute picture. Researchers consistently report the burdensome, stressful impact of this lifestyle. Again Schulz and Beach's 1999 study and interpretation of their findings are very significant when they suggest that "caregivers who report strain associated with caregiving are more likely to die than non-carers". Their findings also showed that "...trasted caregivers compared with age-and sex matched non-caregiving controls" had significantly higher levels of depressive symptoms, higher levels of anxiety and lower levels of perceived health. They were "...also much less likely to get enough rest in general, have time to rest when they are sick or have time to exercise." Schulz and Beach state that all of these factors just described, and others not assessed in their study, "..are possible mediators of the association between caregiving and mortality." The emotional and psychological well-being of carers.

Schofield et al discussing the associations between carer overload and the poorer health status and emotional well-being of carers, give examples of overload as greater responsibility for household tasks, diminished life satisfaction and perceived social support

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57 ibid
and health problems. This leads the authors to suggest 'interventions of a practical kind' which might also:

"...include working with GPs and other health professionals to promote awareness of the potentially deleterious effects that caregiving can have on the health and well-being of their patients".

These authors recommend GPs and other health professionals: "...inform carers about community services and make referrals". Surprisingly at this juncture in their report, nothing is mentioned about the imperatives of further assessing the health status of each carer and implementing interventions of a clinical kind.

The consequences for the carer's longer term health, even after they cease their caring role also needs to be considered. The research by Schofield et al\textsuperscript{59} provided some interesting results in relation to relinquishment of the caregiving role when carers were studied over a period of years. The authors reported improvement in the health and well-being of carers, enhanced life satisfaction ... and diminished overload after ceasing caring 'at time 1' in comparison to "the decreasing life satisfaction of continuing carers". However:

"...while they reported that the well-being of carers did not deteriorate further relative to that of non-carers", they stated that, "...the poorer physical health and well-being of carers evident at the first interview did not dissipate with time".\textsuperscript{60}

Other authors show from their research that 'past' carers still had a poorer health status than non-carers. This suggests, even after relinquishment, the longer term impact of caring in many individuals may an enduring one and perhaps in some, be irreversible, leading to premature death. Findings from the literature, much of which was published after I had collected the data for my own study, complement my research quite closely on the impact of caring on the health of carers. In fact the consistency of the evidence has been quite unexpected. Before presenting how I did my field research and what I found, I first want to turn attention to the concept and ethics of informal caregiving. There is still much confusion on these topics in the literature and is generally very poorly presented.

With such dilemmas consistently experienced by my peers I concluded that even after two decades of research on the topic, no clear academic 'map' existed to help guide the reader across the constantly blurred and changing territory of what we refer to as the informal care sector. My starting point for understanding care and 'informal caregiving' therefore is not

\textsuperscript{59} Schofield et al, 1998, p. 117.
\textsuperscript{60} Schofield et al, 1998, p. 119.
Chapter 3: The Health of Informal Carers

about who the carers are, who they are caring for or what they are do - all of which will be included in later chapters. Rather I first seek to explore the epistemology of 'informal care', concentrating on the knowledge base underpinning the topic of 'caring for others'. It was only when I focused on the basics that the topic took on some form, structure and meaning for my reading and research. Moving the concept of 'caring' from the privacy and obscurity of the domestic sphere into the academic and public realm was tantamount to unlocking pandora's box, generating confusion and conflicts between theorists, ethicists and researchers - but at least stimulating a closer scrutiny. Without a deeper understanding of this phenomenon, we cannot adequately understand who the carers are, their experiences and why they continue to care at such costs to themselves. Only then can we address individual carer health and develop more appropriate public policy that has the potential to enhance carer health.
CHAPTER 4
AN EPISTEMOLOGY OF INFORMAL CAREGIVING

Introduction
At the start of my research about carers and their health, it was first necessary to clarify the nature of caring, to search for 'the essence of informal caregiving' as it was evolving by the end of the nineteen eighties. Viewing the concepts of 'care' and 'family caregiving' through a wider intellectual lens allowed me to take an epistemic approach and place pertinent ideas about 'caring' within an academic frame of reference. Initially I had to do my own philosophical and theoretical groundwork, but I owe much of my enlightenment on the concept of informal care to four authors and their colleagues. From the UK, they are Gillian Parker, Julia Twigg, writing throughout the early 1990s and later in that decade, to Ann Brechin et al; and also from the Australian authors, Schofield et al, based in Melbourne, Victoria.

The concept of 'care' has both universal and personal dimensions which are so broad and convoluted they are usually incompletely dealt with in the literature. By the mid 1990s, despite the growing rhetoric endorsing the importance of informal care, there still did not appear to be a clearly articulated or accepted 'world view' on informal care or family caregiving. Twigg and Atkin for example referred to their efforts towards the mid 1990s, to bridge the gap in knowledge in this area of informal caregiving as "mapping a new intellectual territory " and added, "... caring as we understand it now, was absent from the analytic agenda: an academic subject that simply did not exist." 

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2 Twigg was involved in at least 3 major works published in 1990, 1992 and 1994
5 About informal care in chapter 1 the authors were referring to the position of carers within the service system.
7 Writing in her opening chapter of a 1992 publication summarising research and practice on the topic of carers, Julia Twigg wrote: "Ten years ago this book could not have been written. Twenty years ago no one would have thought of writing it."

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These sentiments were echoed by an Australian research team (Schofield) examining the concept of family caregiving in the mid 1990's. They found the term too general and that it did not "...recognise the complex and variable experiences of caregiving," They suggested we need to understand family caregivers "...as opposed to the professional and the volunteer to assist them in their role."

**Feminist writing fills in theoretical gaps on the map of family caring**

Reviewing theoretical progress on the topics of 'informal care' and family caregiving in the late 1990s, I was constantly frustrated by a lack of theory or paradigmatic clarity. For example prior to the 1980s, there seemed to be a theoretical void about informal caring, and no established ethical theory that applied to family or informal care of the sick or disabled. There was however extensive documentation and dogma surrounding formal care. For all its well used philosophical scaffolding, it seems 'old ethics' has failed to address the reality of the new domestic issues emerging around the home based care by family and friends.

From the 1980s onwards, discussion of 'informal care' issues was being energised and driven by feminist scholars, many of whom were from social science disciplines. They offered very different views of informal and family caring to that from the health sciences which at the time did not yield any useful definitions on informal care). The feminist approach and vocabulary was much more expressive and particularized - at odds with the dry and impersonal language of ethics that enveloped most aspects of formal care in the health system. In fact a feminist interpretation of care sometimes seemed to fall outside the map of 'traditional' justice based ethics as we know it. Interestingly informal caregiving rarely appears on those traditional ethical landscapes. As Australian ethicist Helga Kuhse concedes, the "....concept of care - never played a prominent role in mainstream western ethics, in the way freedom, justice and love have done".

By the end of the 1980s and early 1990s a trickle of publications discussing care in terms of 'care theory' and an 'ethic of care' appeared with a revitalised discourse. A new
gendered phraseology was introduced which was incorporated into a 'morality of care', some of which was based on virtue theory.\textsuperscript{10} However as an example of the state of play within the development of care theory at the time, a title used for one major publication was "The chaos of care and care theory".\textsuperscript{11} The question must be asked why there was such a theoretical vacuum surrounding informal care prior to the 1980s in contrast to the steady stream of publications that appeared during the following twenty years. What I soon realised was that the actual process of developing a theory of knowledge, in this case a theory of care, depended on the inquirer,\textsuperscript{12} himself or herself, and of course on the paradigmatic boundaries that guided or limited their intellectual inquiry. What I had not appreciated was that until a body of feminist scholars presented their own epistemology of informal care,\textsuperscript{13} there was in fact no identifiable or equivalent treatise within formal ethics.

What evolved from the feminist writings on care theory and care issues was the creation of a new epistemology and gendered orientation on care and family caregiving, a subject matter which was previously missing from the 'established' philosophical and ethical literature.\textsuperscript{14} It appeared there had been few inquirers within traditional epistemology who had recognised or explored the deeper significance of family care issues, especially from the carer or female perspective, and until then it could not be adequately interpreted. Thus it has been the feminist movement which appears to have made the greatest inroads into the hitherto hidden domestic sphere concerning women, spouses and other family members caring for others. This occurred in parallel with active 'carer movements' involving fledgling carer advocacy groups which had gained momentum by 1990 in both Australia and the UK. They too brought with them a fresh and contemporary vocabulary to describe

\textsuperscript{10} Virtue theory used to describe care refers to a 'cluster of virtues'. The debate between using the virtue of justice or the virtue of care was discussed by Veatch in the article: 'The chaos of care and care theory'. Little, M. O. and Veatch, R. M. [Eds.] 1998, 'The chaos of care and care theory', Journal of Medicine and Philosophy, April, vol. 23, no. 2.

\textsuperscript{11} Veatch emphasises that a final possibility of positioning care (or care theory) on the map of ethical theory is to add to that map. Veatch disagrees with pitting care against justice.


Larrabee, M J. (Ed.) 1993, An Ethic of Care: Feminist and Interdisciplinary Perspectives. Routledge, NY. [Refer chapters 10 and 15 on Gilligan].
the roles, responsibilities and repercussions of caring on family members and other informal 'carers'.

A new language for caring

The feminist contribution to understanding informal care has dramatically changed late twentieth century philosophy on care and the language used to describe it. It moved away from the traditional approach to family issues which confined them to the domestic domain. Using a feminist perspective and language 'exposed the gendered nature of informal care' and gave a more compassionate and individualised orientation to caring.

For example it is well documented that in the wake of feminist thinking there was a transformation of the old notion of 'family duty' to the concept of 'kinship' obligation.

The feminist approach therefore politicized informal caregiving. 'Caring' became gender specific and 'carers' in the late 1980s were swept into the political limelight with their feminist proponents challenging the assumptions inherent in newly drafted British community care policies, in particular, that women would be available in the home to provide the care. This was seen as 'female discrimination' that would lead to the 'oppression of women as carers'. As Twigg commented earlier, "...the feminist impact freed analysis of family obligation from its conceptual straightjacket". It examined ways kinship rules were negotiated, researched the impact of caring on women, including those of different race and class, and it - "created a change in academic understanding - a new orthodoxy - and debate on informal care."

The focus on women's roles in informal care partly explains why in the last two decades of the 20th century, this 'new orthodoxy' has provided the catalyst for the production of a new body of knowledge on informal and family caring. It has remained predominantly feminist in its ideology, interpretation, language and voice during the 1990s. The subtle changes in language also altered the way family was perceived, challenging "the traditional...".

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sociology of the family" and its obligations. 18 'Caring' could then be analysed in terms of: its emotional, physical and financial costs to family carers which saw certain burdens as "beyond normal expectations". Twigg points out that -

"...carers in this tradition are not perceived so much as women, but people whose lives were significantly disrupted by caring," thus providing "a different emphasis for the debate". 19

With carers' special burdens needing to be alleviated, the discourse adopted the language of justice, which in turn called for public intervention and support. 20 Personal difficulties of family carers were no longer seen only as private troubles. They became public issues. 21 Thus the modified language of care not only reflects dramatic changes in philosophical approaches to the 'care of others', but also mirrors major shifts across the political arena which occurred during the closing period of the twentieth century. These ideological currents have greatly influenced social and health policy-making during the 1990s and all these factors combined to impact on the domestic domain and thus on private caring issues in the family home. 1985-1995 represents a watershed in how society viewed 'the family' dimension of the informal sector.

The 'new age' approach to informal caring: A double edged sword for carers
As this thesis explains, the feminist perspective has dominated recent academic literature, colouring our interpretations of carer experiences and prompting different and dynamic solutions to their problems. The emergence of a liberated and expanded philosophical base that embraced women's roles in family care spawned a wealth of additional ideas from a generation of feminist scholars and researchers who have continued to contribute richly to the literature on care and caring. I suggest however that in parallel with this phenomenon there have been a few unexpected disadvantages, some of which relate to a lack of action on addressing carer health issues in particular. Also focusing on caring within the context of women's issues overlooked and isolated men as carers, but fortunately that division is slowly being bridged and caring is no longer seen as just affecting women. In fact it is now well recognised that men constitute up to a third of all carers in most statistical

18 Twigg et al, 1996 p. 3
19 Twigg et al, 1996 p. 4
20 Twigg et al, 1996 p. 4
21 On the important disjunction between troubles and issues refer to: Mills, C. W. 1960, The Social Imagination, Open University Press. NY.
surveys that have been conducted in Australia and the UK.\textsuperscript{22} Men are now acknowledged as carers and better catered for in carer support groups, especially in Australia.

What I see as a more important consequence of this 'new age' approach to informal caring, has been the separation of carers and caring, from so called 'sickness' models, to escape past trends towards the over-medicalization of care. I believe that by trying to avoid pathologizing\textsuperscript{23} care for groups like the disabled, mentally ill and some elderly, carer issues have inadvertently moved too far beyond the clinical orbit in a valiant endeavour to offer them a greater diversity of holistic support. This I believe this may have perpetuated the ideological split which already existed and has had far reaching ramifications on health care for the carers themselves.

**Absence of clinical model of care for carers**

Despite the very impressive social progress that has been made in supporting carers over the past decade in Australia and the UK, the one area where there remains a serious gap is in the absence of a clinical model for the medical and preventive health care of carers in their own right. Much has already been achieved towards supporting carers within the caring relationship, but I am concerned that if informal care and carer well-being is not better incorporated into the traditional medical model the barriers between carers and clinical care may impact on carers' health. This barrier between informal carers and health professionals already occurs throughout the health care system, especially in hospitals, at community and practice levels and at some levels of policy-making.\textsuperscript{24} Examining the difference between formal and informal care may explain some of those barriers and how today they appear more blurred. It would be useful to pause briefly to examine the concepts of informal and formal care. I outline them in the next chapter.

\textsuperscript{22} This has been reported in ABS population surveys on Disability, Ageing and Carers, as well as surveys of the Carers National Association, UK and the Carers Association of Australia.


\textsuperscript{24} In recent years there have been encouraging signs that the carers' voice is better represented during government policy formulation. Most recently there have been some innovative developments with general practice launched as the Enhanced Primary Care in 2000.
CHAPTER 5
CONCEPTS OF INFORMAL AND FORMAL CARE

Introduction
The interpretation of informal care I provide offers a contemporary view of a postmodernist society rather than a 'historical' description of the caring landscape and family care as is evolved over past centuries. The descriptions of 'caring' I include below highlight a number of different aspects of informal care. For example I begin with Gough et al1 who suggest:

"The majority of caring takes place in the home, known in policy terms as the private domain, and in the literature is often referred to as informal caring. Only a small amount occurs in the public domain, such as hospitals, community homes and hostels - this is referred to as formal caring."

British author Julia Twigg writing in 1990 about informal caring stated: "The word informal is used to distinguish it from similar care provided in the formal sector: that is provided on an organised and paid basis." In a later publication Twigg added that

"...informal care by contrast normally occurs in the context of family or marital relationships, and is provided on an unpaid basis that draws on feelings of love, obligation and duty."

Qureshi and Walker5 offered a slightly different angle when they described differences between the formal and informal sectors in caring for the elderly in Britain, by looking at the differences in the criteria for eligibility for services:

"...informal care is directed towards a particular person on the basis of their social relationships with others - care for a mother, a sister or a friend, for example - whereas formal care is organised to be delivered to all people in particular, defined categories of need."

5 This is a particularly useful reference for differentiating between carers, informal carers and informal care [See the opening chapter].
6 Qureshi and Walker provide useful discussion on the formal and the informal systems of care.
8 Again this reference to the earlier work of Abrams [1978]
Brechin et al also describe the informal sector as being 'personally directed' with 'no formal procedures'. These four statements represent useful but rather simplistic approaches to informal care. Nevertheless they become significant when considering both a conceptual framework and an ethical model of informal care. When reviewing the literature one finds that the definitions of informal care are many and varied, with authors using the terms informal 'sectors', informal 'care', informal 'support' and informal 'assistance' interchangeably. Taking a different tact Brechin et al, equate informal care directly with the 'family' realm contrasting the relationships between the two. I find their description most appealing, ie:

"In family care, it is the relationship which determines the care. In formal care, it is the provision of services which creates the relationship."

Earlier references to family caring in the 1970s represented what Dalley referred to as a 'familist' approach that was part of 'a golden age of family support'. As already outlined, it held a limited and narrow interpretation of family and kinship obligations. A re-appraisal of the concept of family obligation by feminist scholars, made a distinction between household duties and family obligations. It .."freed the analysis of family obligation" to view it instead as "kinship obligation" as was highlighted earlier in Twigg's work.

It should be remembered that 'community care' has evolved as a combination of both formal and informal care and crosses the boundaries of both private and public realms. The blurring of these boundaries contributes to the ongoing confusion and complexity associated with identifying and accessing community care services throughout many countries today. Interestingly despite the differences between their national social policies, informal care is the predominant pattern whether in Australia, Britain, Canada, Scandinavia or the United States.

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8 ibid
11 Twigg & Atkin 1994, p. 76.
Care and caring relationships

Qureshi and Walker wrote that Adam\textsuperscript{12} had "...expounded the theme that care provided by the informal sector is qualitatively different from and superior to formal sector care". He had argued that "...because informal care is embedded in pre-existing social relationships it has a different meaning [from formal care] for recipients." This is an important core aspect of caregiving which most modern social researchers have continued to support. For example focusing on the family and relationships Shiela M Pearce\textsuperscript{13} commented:

"...most informal caring relationships take place within contexts which are shaped by family histories, shared experiences, attachments and emotional commitments. They are commonly affectional relationships, but in most cases also highly instrumental, requiring practical tasks to be undertaken in order to meet daily needs".

Twigg\textsuperscript{14} had emphasised that:

'Informal does not imply that the care is provided on a casual or easy going basis. Caring is often very hard work and can be emotionally draining'.

The significance of acknowledging informal or family care in terms of the relationship on which it is based is pivotal to understanding the meaning and morality of caregiving as well as the special needs of informal carers. Several British authors, like Julia Twigg and Gillian Parker (writing independently of each other), have contributed to a greater appreciation of the informal caring relationship regarding its meaning, and carer needs in terms of service provision.

Limitations of neighbourhood care

In the literature and also in many policy documents, some authors interpret the meaning of 'informal care' beyond immediate family and close friends to include neighbours or 'communal relationships'. Other commentators extend this even further include informal care under the community care paradigm. For example Parker and Lawson\textsuperscript{15}, acknowledge that the greater part of 'the support and assistance provided on an informal basis to disabled and older people living in the community, usually by family members and


\textsuperscript{14} See Ch 8: Caring in Place by Shiela M Pearce, Care Matters.


close friends'. Qureshi and Walker\textsuperscript{16} differentiated between formal and the informal systems of care and the informal sector adding that:

"the world of relatives, friends and neighbours is distinguished most sharply from the other sectors both in terms of principles of organisation and also its suitability for fulfilling different types of need".\textsuperscript{17}

Twigg commented on this expanded view of informal care which included neighbours.\textsuperscript{18}

She observed:

"...there are structural limitations in the level of substitution one can expect between for example the tasks performed by friends and neighbours and distant kin.\textsuperscript{19}

She added,

"While not discounting the support given by neighbours and distant kin, such support tends to be circumscribed in character".

Twigg's main reason was the realisation that:

'Keeping an eye out for a neighbour or fixing a nail, though useful in themselves, do not constitute the real business of caregiving. Moreover, attempts to widen the conceptual scope to include the informal sector as a whole can lead to a systematic blurring of the real policy issues, whereby the realities of informal support to dependent people are lost in over-optimistic accounts of the community and its caring capacity. [Allen, G 1983]. The heart of the problem of informal care concerns carers.'\textsuperscript{20}

I have taken Twigg's ideas a few steps further to discuss different caring capacities of neighbours and friends, in contrast to the caring capacities of family caregivers, by drawing on the work of Barbara Misztal in her recent book on 'Informality'.\textsuperscript{21} Although her discussions are not specifically about carers, her concepts are applicable to informal care. Misztal identifies three different types of patterns for people "being together" in society today. The three main patterns of interaction between individuals she suggests are 'Encounters', 'Exchanges' and 'Pure Relationships', ranging from the least intimate to the most intimate. Misztal goes on to identify three styles of interactional practices that occur between people within each of these three social realms. She suggests they are 'civility' (in encounters), 'sociability' (in exchanges), and 'intimacy' (in pure relationships) respectively.


Here the authors are discussing the formal and the informal systems of care.

\textsuperscript{17} Twigg, J., Atkin, K., Perring, C. 1990 \textit{Carers and Services: A Review of Research}. SPRU [Social Policy Research Unit, University of York], HMSO, UK, pp. 3-6.

Twigg used the same quotation as Qureshi and Walker: 'Involves world of relatives and friends and neighbours'.

\textsuperscript{18} Twigg was referring to other work by Pancoast and Collins 1976; Litwak and Kulis 1983; Finch 1989 from her own text.


Applying Misztal's dimensions to Twigg's comments about keeping an eye out for a neighbour, can now be re-interpreted and described as *exchanges* occurring between the neighbours or friends. These exchanges are usually manifest in interactional practices on the level of sociability, not intimacy. Misztal explains that sociability exists within certain social realms and so has its limitations. In contrast, "the real business of caregiving" as Twigg puts it, is based on what Misztal refers to as 'pure relationships' between individuals where *intimacy* is the interactional practice. Intimate 'pure relationships' involve "close and continuing ties" in the domain of family, marriage and very close friendships. These reflect a "deep knowing and understanding, private, even secret, communication, shared commitment, shared values, information where the participants exhibit the capacity to 'trust utterly'. Here Misztal refers to partners, friends and lovers as examples of those in pure relationships, which she says are 'ruled by particularist obligations.' These are the types of relationships that Schofield and al. would perhaps describe as 'reciprocal' with 'mutual dependence' for the participants. Therefore it can be argued that the realities of informal support can place significant restrictions on the types of caring tasks neighbours, friends (or even distant kin) can perform or are capable of because of the barriers imposed by the social realm in which they interact. The actual personal tasks to be performed in the caring role may require a level of intimacy that does not exist between neighbours, friends or distant relatives. The individuals would first need to develop a closer, more 'pure relationship' before that could happen. I suggest that would entail a transformation of the helping role based on sociable interactions, to those of an intimate nature. This would complete the transformation of a loose social relationship to a caring one.

I suggest this observation raises two issues. Firstly neighbours as carers can not be expected to substitute for persons in close relationships. I believe caution is required when discussing neighbours, friends or distant relatives in the context of informal care, or their role as carer. Today's 'generic' approach to defining carers which incorporates both kin and non-kin, including carers at the neighbourhood level, often fails to make that distinction clear. Secondly it is important not to assume too much of those who do not have intimate caring relationships in the first instance. Authors like Schofield and Herrman, who have specifically defined informal caregiving, point out that in family

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caregiving relationships there is an *imbalance of dependence* and a 'transgression of normal expectations.' They emphasise that in comparison to non-family caring there is often no *choice* for family caregivers. I will return to their ideas shortly when discussing the elements of informal caregiving.

Although it is a social reality that non-family members and friends do take on caregiving roles in our community providing a very important stop gap, I find this problematic when considering long term care of aged sick individuals with complex co-morbidity. Caring arrangements and caring capacities based on intimate, pure relationships, are quite different when contrasted with communal or neighbourhood exchanges based on relationships that are drawn from the wider community. These are more in keeping with interactions that reflect reciprocity based on 'sociability' rather than 'intimacy'. Having made this distinction one can move on to a discussion about the elements of informal caregiving.

**Key Elements Of Informal Caregiving**

This thesis is based on an understanding that 'being a carer' exists by virtue of a person's caring relationship with the chronically sick or significantly disabled person who needs and receives personal care that they cannot do for themselves at home. Following on from Twigg and Mizstal's ideas described above, it is clear that the caring *relationship* with its associated *responsibilities* and *roles* are the main elements which distinguish people as carers 'from the broad realm of the "caring people"' referred to by Schofield et al. Further, the special character of a caring relationship only exists because of the associated caring role and responsibility involved. Julia Twigg, clarifies this position stating that... "caring takes place in a relationship" and therefore, "as important as the carer", "is the cared-for-person"... She says about the persons being cared for ... "They, after all, are the reason why the caring exists, and it is the presence of the difficulties that transforms a family or social relationship into a caring one."  

*An overview of the caring relationship - how it develops*

Whether a caring role is taken on by choice or default, providing personal caregiving to persons who lack the capacity for self care, or need nursing level care at home, is very different situation to the normal reciprocity. The latter is seen amongst well adults within relationships or parenting of well children within families. For individual families and

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other close social relationships this creates a new caring situation\textsuperscript{25} which has been described by Schofield to as 'a transgression of customary expectations within relationships beyond what might be expected.\textsuperscript{26}

This in turn leads to a 'transition' of the responsibility for these dependent people to informal family caregivers in the home and community\textsuperscript{27}, a transition I suggest that requires complex moral decision making and many different actions on the part of the caregiver. I therefore suggest that it is by this stage the transformation of marital, family and social relationships into caring ones has occurred, and through that transformation a very different relationship emerges for each participant, creating a relationship that has the capacity to generate new problems and difficulties for both carer and cared for person [the patient]. Such an 'imbalance in dependence\textsuperscript{28}' may lead to further changes within relationships associated with 'caring for someone with a long term illness or multiple complex disabilities. It usually leads to the carer shouldering 'an increased level of responsibility' for the health and well being of the cared for person.

Having established a clearer differentiation between informal and formal care, in the next chapter I briefly refer to what I found to be the most useful building blocks each author has provided for assembling the actual meaning of informal care and how it appears to have emerged in stages during the late 1980s and 1990s. I propose at least eight main components for my framework. They include the caring relationship, responsibility for the cared for person, the caring role (tasks and tending), capabilities and competencies of the carer to perform the caring tasks, accountability of the carer and the consequences.

\textsuperscript{25} Focusing on the concepts of caring situations & caring relationships is the result of my compilation of the ideas of several leading authors whose work has been published on caring and carers over the past decade. Searching for texts and reports about "informal caring", prior to the internet, lead me not only to visit interstate Australian libraries and agencies, but beyond our shores to personally visit libraries in the UK in 1993 and again in 1997. It was in Britain I discovered invaluable resources through the Kings Fund Centre, London which at that time had a well staffed unit dedicated specifically to addressing carer issues within health and social services. This Unit was unique, not only to Britain but probably at an international level at that time. I was also able to follow up the pioneering advocacy work of Jill Pitkeithley and other researchers at the Carers National Association based in London. These organisations and a number of Social Policy Research Units across Britain [like the SPRU at York University], could be likened to an epicentre for the growing interest in informal caregiving, not only in the UK but for fledgling carer organisations in many other countries - like Australia.


\textsuperscript{28} Schofield et al, 1998, p. 11.
of caring efforts on the caregiver. I also include the element of recovery, referring to the rehabilitation that is often necessary to restore the carer to their optimum health, well being and independence. For some individuals they never regain their health and well being. Below I summarise my interpretation of the evolution of the caring relationship, which I expand from an ethical perspective in the next chapter.

A summary of how the caring relationship evolves

This thesis is based on an understanding that being a carer 'exists by virtue of a person's caring relationship with the frail, chronically sick or significantly disabled adult or child who needs and receives personal care that they cannot do for themselves at home. Without that caring relationship the 'carer's role' does not exist. Therefore one can explain the creation of a caring relationship as an evolutionary process involving the following steps.

Firstly, becoming a 'carer' involves the transition of the responsibility for sick, disabled or frail dependent (patients') to family members or other informal caregivers in the home setting. This in turn results in the transformation of marital, family and social relationships into caring ones.

However providing personal care to persons who lack the capacity for self care is very different to the normal reciprocity seen amongst well adults within relationships, families or parenting of well children within families. As a result of the increased level of responsibility carried by the carer there is a transgression of customary expectations within those relationships, beyond what might be expected. This type of personal caregiving therefore has the potential to create a new 'caring' situation and an imbalance in dependence which may lead to further changes and difficulties within those relationships.

In summary it is the caring relationship, and the associated responsibilities, roles and caring tasks which are the main characteristics in distinguishing people as carers 'from the broad realm of "caring people". Thus the central concept of informal caregiving is not simply having responsibility for someone else, but being responsible for that person beyond what might be expected in that relationship.

CHAPTER 6
A CONCEPTUAL / ETHICAL FRAMEWORK FOR INFORMAL CARE

Introduction
As mentioned in the previous chapter there were several key elements of informal caregiving which continued to feature strongly in texts describing home-based caring by family caregivers and other informal carers. Recurring elements throughout these texts were the caring relationship, the obligation to care for kin and very close friends, as well as the responsibility of providing the care for a sick or dependent person. In her book¹, Twigg emphasised carers' "feelings of obligation, love and duty" and expanded her earlier ideas on the nature of caring to mean "emotional labour," very hard work' and 'unpaid work' for the carers. She also described how the 'material aspects had impacted on their situation'. Caring activities were discussed in terms of 'a range of relationships' and she introduced a 'generic' approach to caring. Here she was referring to a 'common core of experience that transcends such divisions', but recognises 'differences in their circumstances and expectations made on them' [ie made on the carers].

Describing caring 'tasks' was also a very popular way of differentiating carers and their roles, up to and including the early 1990s. This is how Twigg and Atkin presented 'caring' in their 1990 book², a very useful literature review of the subject up to that time. Twigg reported 'caring' in terms of 'supportive tasks' and 'caring activities' of carers who were seen to be in an ambiguous position, particularly in terms of the British health care system. By 1990 carers were well recognised as those people providing 'most care to the cared for person'. Twigg described carers as being in 'obliged social relationships' involving 'close kin and familial relationships'. Twigg and Atkin strongly linked responsibility for the dependent person with 'emotion'.

A Typology of Caring
It was through Twigg's book (mentioned above) I learned of Gillian Parker's typology of caring activities based on 8 tasks and 6 patterns of care³. This typology of caring activity associated with family caregiving was 'based on instances of caring relationships between


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caring tasks." Parker and Lawson analysed different sorts of caring activity or behaviour on a spectrum of caring, making a very important contrast of personal care tasks with domestic household tasks. Their spectrum of care ranged between concern at one end and tending at the other end.

Following up Parker and Lawson's very analytical approach, it was clear the focus was on the different categories of care in terms of the provision of help and support and protection to the dependent person requiring the care. From their analysis of the literature, the nature of caring was divided into four dimensions of caring - who does it, for whom, why and what is done. They reported that Ungerson in 1987 had proposed another typology of carers that attempted to categorise informal carers in terms of their motivation to care - why they care. Ungerson had suggested this was best discussed in the context of the carers' position in the lifecycle.4

Parker and Lawson's analysis of the literature revealed an emphasis on who the carers are (eg parents, daughters, spouses) and the nature of the relationship. In terms of the provision of informal care, Parker suggested formal service providers need to know four main characteristics about carers in parallel to the four dimensions of caring about - who they are, whom they help/ support, what they do and the impact of caring on their health.5 Other discriminating variables used within their typology included the sex and age of the carer, the sex and age of the cared for person, as well as the nature of the impairment. It also considered the number of hours of help given to the cared for person, whether the carer lived in the same house as the cared for person (co-residence) and the level of responsibility involved.

Main ethical components of informal caregiving
With the input of these and many other authors, the main components of caring and a possible structure of caregiving was starting to take shape in my mind by the mid 1990s. However on tracing these explanations, I still believed that it lacked reference to crucial aspects like the health status of the carer. The next stage of my building a deeper

4 Anna Howe also focused on a "lifecycle" approach at the 2nd International Conference on Caring, [Share the Care], 29-31 March 2000 in her paper: 'The Lifecycle of Caring.' - Printed version of Conference paper was not available.
5 Parker and Lawton reported that the literature described carers by 'knowing what they do which provided 'support shaped relevance', and 'knowing who they are' by 'distinguishing characteristics of carers and those they help - this revealed 'different levels of involvement and need'. Parker, G. and Lawton, D. 1994, Different Types of Care, Different Types of Carer: Evidence from the General Household Survey. HMSO, London.
understanding of caregiving came again through the work of Twigg & Atkin. Their next book took a policy perspective in the context of the new service developments for carers throughout Britain after the introduction of the Community Care Act of 1993. In this landmark book, Twigg and Atkin 'opened up new intellectual territory on the map of informal caregiving', offering a moral dimension to service provision for carers. They were the first authors I had read who cited clear ethical and policy reasons 'to treat carers as a category in their own right'. They emphasised 'caring' as being:

"...embedded in the relationships of obligation", and that 'carers were "constituted as a subject by the relationship of obligation and care that they have with disabled person". Hence, carers feature in public policy, "...by virtue of that relationship."

Further, they added that carers were bound into relationships... which means that 'they don't give up'. They (the carers) '...carry on against their own interests' - a crucially important area that comes up again in the carer and GP data. It therefore has important ethical implications for general practice and policy development.

Twigg again took a 'generic' approach to caring when referring to it as a 'role'. Twigg and Atkin proposed five distinct elements of the concept of caring which involved first, the performance of tasks of a supportive character where these go beyond normal reciprocities common between adults; second, kinship obligation; third, emotion and love; fourth, co-residence, and fifth, a feeling of being responsible. In their following section they emphasised that caring takes place in a relationship which although could be seen to link with kinship obligation, I thought they could have included as an additional element. Their work on this aspect of caring enabled me to expand my own conceptual framework of caring. Most helpful was their overview of "the debate" surrounding informal caregiving. They described the six strands of the caring debate which revolved around kinship obligation and feminism, which I have already referred to in my earlier chapter. Also discussed was the influence of the new right on the welfare state; rationalisation of community care and the more contentious "disability debate" of the mid 1990s.

Although the work of Australian carer associations at state and national levels has been impressive, it was the VICHealth team of Schofield et al that provided me with the most

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7 Twigg, 1996, pp 5-7

realistic and comprehensive view of family caregiving. In contrast to the rather constrained research produced by their American colleagues, the Victorian multi-disciplinary research team working on this major VIC Health research project about carers produced the most realistic results. This longitudinal study not only provided comprehensive overview of carers' social and health characteristics it also involved for the first time GPs and pharmacists. Unfortunately it did not extend to including any qualitative feedback on their reactions or needs.

In their first chapter on 'What do we mean by a family caregiving?', they referred to Twigg's work and also Graham's two components of caregiving 1983, namely the caring activity and caring emotions. Schofield et al's notion of caregiving explains that caregivers are under a kind of obligation to care... because of, and I here summarise their points, the close kinship, and the emotional bond to the care recipient. These in turn involved issues of responsibility, choice that also involve customary expectations in relationships. Adding the work of Schofield, Herrman et al to that of Twigg, enabled me to develop my own interpretation of the creation of the caring relationship. I also expanded the main elements of informal caregiving, including an ethical overview of caring. This however was an even more arduous search as the 'moral' territory of informal caregiving was relatively uncharted until viewed through the feminist lens as I discussed in the previous chapter.

It was during my visit to the UK when I was studying moral philosophy at a Cambridge University summer school that I finally discovered two authors - Carol Gilligan and Susan Mendus who offered a different approach and 'voice' on caring. Gilligan's Theory

9 Comparing British and US work on informal caregiving.

Whilst the British authors were producing conceptual, service and policy related literature on caregiving, the other group of contributors were North American researchers who seemed to take a narrower view of family caregiving. The US studies were dominated by disciplines of psychology and geriatrics that maintained a strong focus on caregiver burden. There work was not so service oriented, and applying it was problematic in that there was no equivalent public health or social service in the United States which equated with the 'community care' approach evolving in Britain and Australia.

The only significant references to carers I could find by the mid 1990s in Australia with equivalent or useful reviews of informal caregiving were those associated with the Carers Association of Australia, and a number of key staff of the Commonwealth government's Carer Support Unit. Some Australian authors and researchers of note on carer issues during the 1990s were Howe, Brimbaite, Schofield and Hermann et al, Schultz and Schultz. Some of them like Anna Howe and possibly the Schofield research team acting in an advisory capacity to the Australian Federal government in their developing carer sensitive policies within the HACC programme.

10 The VicHealth project was based in the University of Melbourne's Department of Psychiatry

Chapter 6: Conceptual / Ethical Framework- Informal Care

of Moral Concern was grounded in the idea of "responsiveness to others" while Mendus focused strongly on the issue of the choice to become a carer. However it was not until several years later that I came across related texts following up Gilligan's Theory of Care, which gave me well reasoned criticism and comments on the theory. In particular it was Tronto's Theory of Morality on the moral dimension of 'caring for others' which enabled me to further expand my own conceptual framework of informal caregiving. Tronto developed a theory of care (instead of an ethic of care) and proposed four ethical elements as part of her Theory of Care: They were attentiveness, responsibility, competence and responsiveness, in that order. While responsibility remained the element common to most of the authors I have already quoted, I was interested in Tronto's attentiveness and responsiveness as process issues involved with a range of decisions and actions of the caregiver at different stages of the caring cycle, rather than as additional key elements.

Tronto's idea of competence prompted me to think more about the caregiver's competencies for which there is an element of 'accountability'. This in turn may be affected by each carer's overall 'capacity' to function as the informal caregiver. Capacity in this context not only refers to the ability and skills of the carer to perform caring tasks and activities in their home environment, but each carer's willingness, wellness or health status to take on, and continue with the caring role. At any this point of the caregiving experience, the demands and expectations of caregiving may go beyond the level of the carer's competence and capacity. This led easily onto serious consequences of the caring demands on the carer. "Capacity" therefore became the important ethical and moral component of my conceptual framework. In addition the caring lifestyle can lead to loss of income, independence and health, eventually creating a dependency of the carer on public support for services and financial assistance.


15 I have prepared my own version of the stages of caring, from both the literature and from data from carers participants in my study. See Appendix: 1. 'The 6 stages of caring.'
### SUMMARY OF KEY ELEMENTS OF INFORMAL CARE

#### CARING RELATIONSHIPS:

The transformation of family, marital or social relationships into caring ones. This involves relatedness, emotion, reciprocity and often co-residence (but not always).

#### RESPONSIBILITY: Kinship obligation to others

Attentiveness to another's needs and taking on the caring role.

First level responsiveness - Decision to accept that responsibility for the person and for meeting their needs.

#### CARING ROLE: Context & practicalities of the caring environment

Second level responsiveness - Fulfilling the caring role

Doing for dependent people - both children and adults - what they can't do for themselves

The caring role can be described in terms of caring tasks and tending:

- **a. TASKS** [activities according to the dependency of the adult or child and the environment in which the care occurs]
- **b. TENDING** [as a type of nursing or supervision of the sick, frail, disabled or dying individual]

#### CAPABILITIES OF THE CARER:

Caring tasks and tending require competencies, skills and capabilities, including the health capabilities of the carer to continue caring.

The carer is accountable for the well being of a dependent person

#### CAPACITY OF THE CARER TO CARE:

Capacity not only refers to the ability and skills of the carer to perform caring tasks and activities in their home environment, but each carer's wellness, health status and willingness to take on, and continue, the caring role.

#### CONSEQUENCES TO THE CARER: [Restrictedness + dependency for the carer]

There can be physical, emotional, social, and financial consequences to the carer from informal caregiving. The caring lifestyle can thus be associated with loss of independence, health and eventual dependency of the carer on both private and public services and financial assistance.

#### RECOVERY, REHABILITATION OF THE CARER

The carer may require a time for personal recovery after the caring ceases, for his/her own rehabilitation and renewal. Not all carers recover their health, or social and financial independence.
Conclusion
There have been major shifts across the political arena in the public support of informal caregiving and today a new language surrounds family caring (now referred to as kindship obligation). In this first section I have described a typology of caring, how the caring relationship evolves, investigated the key elements of informal care, and proposed a conceptual and ethical framework for informal caregiving. I have also examined the literature on carer health and well-being and described how informal caregiving has been seen as a risk factor, as well as a predictor of a range of health problems amongst carers as a generic group. Carers have consistently been shown to suffer increased physical and psychological morbidity. Most recently, lack of rest when the carer was sick and lack of lifestyle activities has been associated with increased mortality in carers, not acknowledged in carer research before. Despite their reported lower health status, carers may maintain a different perception to their own illnesses and see their own condition as insignificant in comparison to the persons they are caring for.

With the blurring of formal and informal care in the home and community setting, attention to carers has focused on their caring role and service needs, virtually to the exclusion of their individual clinical care. Therefore for my study the role of the General Practitioner in protecting carer health has been emphasised, and in the following chapters I explore how I went about devising my research project at a time when there was no paradigmatic or theoretical frameworks available for my study that linked carers with General Practice. These challenges are addressed in the next two chapters.
THE 4 PILLARS OF CONCEPTUAL FRAMEWORK
RESEARCH QUESTIONS

[1] First conceptual pillar: CARER HEALTH @ INDIVIDUAL LEVEL
Caregiving as a health issue for the INDIVIDUAL informal carer

1st conceptual pillar is based on the notion of informal caregiving impacting on carer health.
1.1 Does caring impact on the health of carers? 
   ie In what ways/ how is informal caregiving perceived as detrimental to health of family / informal carers? [ Literature Review ]
1.2 What effect does caring have on the health, well being & lifestyle of informal carers?
   1.2.1 CARER PERCEPTIONS. What do carers themselves have to say about their 
           experiences of caregiving roles and responsibilities.
           What are the needs and general effects of caring on carer health.
   1.2.2 GP OBSERVATIONS- What do local GPs say about carer health and related needs?

GENERAL PRACTICE AS THE KEY TO CARER HEALTH ENHANCEMENT

2nd conceptual pillar is based on notion of GPs as the pivotal health professional 
with whom carers have most regular and ongoing contact.

Before suggesting a broadening of the GP role in supporting the health / social needs of caregivers, I
wanted to know :
2.1 Do GPs understand informal caregiving, carer roles and responsibilities?
2.2 What did GPs have to say about their supporting carers? 
   Would GPs themselves be amenable to a 
   more pro-active approach to informal caregiving in the future. [1994/5]
2.3 What is happening in general practice in southern Adelaide re carer issues? 
   I ask selected GPs from 
   across the southern region.
2.4 GP EXPERIENCES: What problems have GPs had in trying to assist carers?

[3] Third conceptual pillar introduces: CARER HEALTH @ POPULATION LEVEL
Informal family caregiving as a POPULATION health issue [SF-36]

The 3rd conceptual pillar focuses on informal caregivers as a group at risk of health 
problems across various populations.
3.1 Do informal carers, across a population, perceive their caregiving role has affected their health?
3.2 What proportion of surveyed caregivers report they have health problems?
3.3 Can it be shown there are any measurable differences between the health status of caregivers 
   and non-caregivers surveyed at the population level?
3.4 If it can be shown informal caregivers have a lower health status than non carers and/or the general 
   population, what areas of carer health and well being are most affected?

[4] Fourth and final conceptual pillar - examines CARER HEALTH & CARER POLICY 
& CAREGIVING AS PUBLIC HEALTH ISSUE - An overview and discussion

I: Theoretical and Ethical Context for Policy-Development for carers.
   - Transformation of domestic needs of carers into public policy
   - Concept of Community Care. Where does General Practice fit in?
   - Carer Policy within an Ethical Justice Framework

II. Australian public policy, carers' health and GPs
4.1 How well does Australian public policy address carers' health?
4.2 Are GPs adequately integrated into Government carer policy.
4.3 Are carers integrated into General Practice policy? (RACGP )

III: Is informal caregiving and carer health to be viewed as a public health issue?
CHAPTER 7
MY APPROACH TO THIS INQUIRY AND ITS METHODOLOGY

Introduction
This chapter is a preamble to the methods chapter. Details of the final research design, actual methods and techniques used and how I conducted each phase of the study are described in full in the following chapter. My methodological approach to this study follows the conceptual framework already outlined.

CONCEPTUAL FRAMEWORK FOR RESEARCH PROJECT

First conceptual pillar: Caregiving and carer health at the INDIVIDUAL level
Exploring the meaning and experience of informal caregiving; Also an overview of published evidence about impact of caregiving on carer health.

Second conceptual pillar: Caregiving in the GENERAL PRACTICE domain
Exploring carer and GP perceptions of the health of carers at the individual level; as well as the needs of both carers and GPs

Third conceptual pillar: Carer health at the POPULATION level
Comparing the health of carers with non-carers at the population level

Fourth conceptual pillar: Caregiving and carer health as a PUBLIC POLICY issue.
Considering policy issues that relate to informal caregiving, carer health and GP involvement.

Under the four pillars of the conceptual framework there were four main questions attached to each pillar, with each pillar representing a different domain of interest in relation to informal caregiving. Constructing my study in this way generated more than a dozen main questions. Keeping in mind the golden rule of research that methodology and methods must match the research question(s). I spent quite some time reviewing the research on what methods (tools) would ensure my questions were answered.

The purpose of this chapter is to illustrate the broader methodological and paradigmatic challenges I faced in 1994. Many researchers are able to build on the research...
methodologies applied by other investigators within their own discipline and in their own area of interest. That was not to be the case for my study. For instance there were three aspects of my research topic which differed from most other studies from the early 1990s that impacted on the development of my research design and methodological approach.

Firstly my inquiry was not about patients as was the norm in medical, general practice and health research.\(^3\) Mine was specific to the health and needs of those family members giving informal care to the patients or disabled persons at home. The second variation was that General Practitioners were also sought as information rich participants. Usually general practice research is clinically oriented where the GP remains at a distance in the role of the investigator while studying cohorts of patients with specific medical conditions or requiring specific interventions. The focus of this study was therefore in stark contrast to the bulk of research reported in general practice and family medicine journals. I was investigating both carers and GP problems.\(^4\) Seeking out the voices of these two groups of people meant my study needed to draw on descriptive qualitative methods that were holistic, naturalistic and exploratory.\(^5\)

As a non-GP researcher, my foray into the territory of general practice was to bring some additional challenges for me. This was despite conducting most of the research project under the supportive umbrellas of an academic Department of General Practice and working with a Division of General Practice at the time. As is often the case with novice researchers, which I was at the time, one can become buoyed by one's own success. During the piloting of the GP questionnaire, (which went extremely well with very cooperative participants ), I decided to widen my plan of action to include a greater number of GPs from the southern region of the Adelaide environs - using the same questionnaire. However the randomised survey of 100 GPs, did not yield the anticipated responses. How

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\(^3\) Considering carers were well recognised by members of the health professions and politicians for their important roles in maintaining chronically ill patients at home - in particular keeping the elderly out of hospital, it seemed ironical that there was so little formal academic interest shown in carers by the profession closest to family medicine within Australian general practice research.

\(^4\) Other than a few isolated general practice studies which utilised interviews, focus groups and surveys, there were few methods I could draw on to assist me with my research design that focused on the GPs themselves. During the 1990s, some studies (and projects within Australian Divisions of General Practice) started to explore consumer and community health issues while others probed the GP-patient relationship. They rarely addressed doctor-caregiver interaction. In fact I could not find any.

\(^5\) In 1994 when preparing my research design I could not uncover in the literature any similar academic studies with GPs which might serve as a more detailed template for my research. Nor were there any published accounts of carer-GP projects within Divisions of General Practice, which were still in developmental stages in 1994. From my own experience of working in a Division at that time, the emphasis was on consumer and community based research, not carer specific projects.
I responded to that setback, and the lessons to be learned from the process are important and have been addressed in this thesis.

The third aspect of my research that differed from most other studies was the population based review of carers and non carers health utilising the Australian version of the SF-36 health questionnaire to collect the data. From my background reading, I understood the SF-36 had not been considered before for studies with carers. Few socio-demographic and service related surveys of carers had been explored in Australia up until 1993 when the ABS conducted carer specific surveys on disability and ageing.

**Pardigmatic and Methodological Dilemmas**

*Lack of paradigmatic and theoretical frameworks*

A further dilemma for me was finding an acceptable theoretical framework or dedicated family caregiving paradigm on which I could base my research. Paradigmatic development in the area of informal caregiving over the past ten to fifteen years has tended to see-saw between the individualist (self care) or patient-centred paradigms. These included mechanistic, biomedical or psychological theory/frameworks for examining effects, variables, interventions and outcomes. Some were 'systemic' paradigms that blended family with formal care systems.

Little progress had been made by the time I launched into my own research project. It was not until I resumed formal study of the topic in the late 1990s that I found that paradigms and theory in relation to informal care had been explained quite comprehensively in an earlier book edited by David Biegel and Arthur Blum. They offered a potpourri of theories, methodological frameworks and models for informal caregiving which mirrored

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6 The SF-36 was new to Australia. It had only recently been validated and approved for use in the Australian context.


This book offered a predominantly North American perspective on both caring and ageing. eg: Ch. 1 was especially helpful and very enlightening by Schultz: Schultz, R. 'Theoretical Perspective on Caregiving. Concepts, Variables and Methods'. Part I of the book on Theory, Conceptual Framework and Methodology, includes excellent discussions on the caregiving paradigm and a critique of research methodologies used for caregiving research (mainly from the United States). Despite the fact this book is now dated, over a decade old, I still commend any future researchers of caregiving topics to read this book from cover to cover before they attempt any new study. I have not found there to have been much progress on caregiving paradigms, equivalent theory development or methodological refinement in the intervening years.
the rather indecisive state of the subject at the time. So it was no wonder that all my searches for a well defined theory had been frustrated.8

Over the past decade there has been a gradual global transition from welfare paradigms to community care to the market paradigms of the later 1990s. All these models and theories have been imported from a range of disciplines, for example from nursing, medical, social and the political sciences, each bringing their own repertoire of "isms", sets of ideas, values, belief systems and analytical constraints. None can claim to be truly focused on the informal caregiver's world or territory. Therefore in 1994 I had no choice but to return to 'square one' - exploring the meaning of the inquiry paradigm and applying it to my own proposed study. These aspects of my research meant that I was entering uncharted waters where very few had gone before.

In choosing the most appropriate methodological approach for my research project, I first reviewed the basic but important concepts of the research process, refining my understanding of scientific and inquiry paradigms, various theoretical directions and orientations available for research. For this I initially drew on the works of the published doyens of early 1990s qualitative research, namely Norman K Denzin9 and Michael Quinn Patton.10 I took time to reflect on what these and many other authors11 had to say about research paradigms and what approach would best fit my research about carers, GPs and carer health.12

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8 From my ongoing literature reviews I learned later of other interesting work done on The Theory of Care, which I described in an earlier chapter, but that was more philosophical and ethical and so lacked the methodological components of applied science which might have helped me.
11 I read extensively on this fascinating but frustrating topic of paradigms with many different interpretations. Denzin and Patton, and other helpful authors are listed below - many of whom were social scientists or nursing researchers.
12 Denzin described research as 'gendered' and "multiculturally situated which -
Ch. 7: My Approach This Inquiry And Its Methodology

Paradigmatic and theoretical relevance
The challenge with academic paradigms is that they may be all very well among a community of scientists, but what is deemed as important and reasonable within the parameters and variables of a socially constructed realities, may be quite unimportant and irrelevant to those carers being studied. Therefore I felt it important to recognise that carers are strongly influenced by the family 'culture', not necessarily one that is characterised by any particular paradigm, different languages or religious traditions. Each family unit generates its own culture and relationships, embracing multiple perceptions and sets of ideas which impact on family members. This is especially so for the person being cared for and the carer in their own caregiving situation. Denzin reminds us that,

'Any gaze is always filtered through the lenses of language, gender, social class, race and ethnicity'.

Hence certain dominant paradigms and theoretical models, (like those of the medical and nursing sciences which are patient-centred), may not necessarily provide the ideal lens through which to view and analyse the complexities and problems associated with the caring role in the carers' world. In the area of informal caregiving we also need a world view - from the carers' own perspectives.

Locating paradigmatic and theoretical frameworks in General Practice
In the general practice and family medicine literature, in comparison to the huge volume of research on the patient, there is a paucity (if not a total lack) of studies examining the phenomenon of informal caregiving in parallel with patient care. Family based care in general, and family carers specifically, have been are poorly recognised and researched. This however does not reflect a lack of 'family' oriented theory in General Practice

"...approaches the world with a set of ideas, a framework" (referred to as theory or ontology), that separates a set of questions (epistemology) that are then examined involving (methodology and analysis) in specific ways."

Similarly Patton wrote that paradigms were-
"...a set of propositions that explain how the world is perceived, a way of breaking down the complexity of the real world, telling researchers and social scientists what is important, what is reasonable".

Carers are not ignored however and there has been since the late 1990s, a more sustained recognition of family carers and a need to better support them and include them in patient care plans. It is most likely an indirect consequence of the Coordinated care trials, the restructuring of Australian General Practice and most recently the Enhanced Primary Care Initiative involving the aged and chronically ill.

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epistemology. McWhinney,15 a highly regarded educator in General Practice in the 1990s, included in his book examples of paradigms, systems, models and pathways which were inclusive of "the family" and therefore available to be used in family medicine. I note however that none of the models illustrated in his books, specifically highlights informal or family 'carers' as a separate entity. McWhinney nevertheless mentions people with caring roles, in particular those family caregivers of patients with Alzheimer's Disease16 and mental illnesses like schizophrenia. What I could not find in his text was the application of these paradigms, systems and models to research that was inclusive of informal/family carers. All the dominant paradigms in family medicine, including the biopsychosocial model of illness focused on disease processes and remained patient-centred.17, 18, 19 In one short paragraph in his chapter on The Family Health and Disease, McWhinney acknowledges that:

"we know very little about how family physicians work with families".20

15 McWhinney includes an excellent chapter on the Philosophical and Scientific Foundations of Family Medicine.


McWhinney's book is of one of the mandatory texts for registrars studying the RACGP Training Programme [previously the Family Medicine Programme of the College]. Although McWhinney is Canadian, writing from a North American perspective, there appear to be enough parallels between the Canadian and Australian cultures and backgrounds in general practice to see how this academic treatise was adaptable to our own in the early 1990s. Whether that remains the case in 2002 and beyond is debatable.


17 Even when referring to family carers in the areas of aged care and palliative care, the research methodologies remain patient-centred.

18 I later reviewed Moira Stewart's text on this subject and was disappointed to see that despite a chapter which took a holistic approach to the family, it did not adequately recognise the caregiver, either in circumstances when the patient him or herself was the patient, nor did it seek out the carer perspective of a chronically ill or disabled patient.


I also make reference to Murtagh's text books here as they are also widely used within GP training curriculum. Murtagh is an Australian GP who very purposely provides a practical rather than an academic viewpoint of general practice. Surprisingly even in that very hands on context, the family carer is barely mentioned in any chapter.


19 Extending my search for carer specific theories to nursing based epistemology I was also surprised to note an absence of informal carers within that profession's theoretical frameworks and conceptual models. Some mention was made of 'family' in a few of the nursing care models and there were many nursing articles written by nursing practitioners working with carers in the field, but that interest was not translated or fed back into theory development.

20 Although this is in the context of the Canadian health system, family physicians can be considered equivalent to General Practitioners in Australia and the UK.

He continues:
"Almost certainly family physicians do help families ... by providing information and support at times of vulnerability, and by helping family members towards self-knowledge."

He concludes,
"Only long term descriptive studies will tell us how this is done and how effective it is."

This was the closest I was to come to any reference to research about family carers within the popular textbooks (and journals) on family medicine/general practice.

At the professional level I did not find any suggestions about exploring the experiences and perceptions of the physicians themselves in their efforts to support families or caregivers. This aspect is even more important in view of the major changes that have occurred in family medicine over the past decade. With the significant restructuring of General Practice in Australia and further changes expected (through corporatisation), we are witnessing ongoing paradigm shifts within the profession. Such instability challenges earlier theory on which general practice and family medicine is based although I personally believe some of the earlier concepts should be modified and enhanced rather than jettisoned at the expense of losing any more of the family focus.

These issues were uppermost in my mind when designing my research strategy. Several times I revisited the concept of paradigms with Denzin. Like Patton, Denzin raises the thorny issue of the influence of values and belief systems which colour how both investigator and participants make sense of their or other peoples' worlds. Mostly, they are limited to mere images of other people's worlds. For my study I wanted to feel confident that I could see and conceptualize the separate worlds of carers and GPs that was as true to their changing reality and experiences as my own observations. This required that I explore a little deeper into the realms of the inquiry paradigm with Denzin who says:

"...the basic beliefs that define inquiry paradigms can be summarized by the responses ... to 3 fundamental questions, which are interconnected in such a way that the answer to any one question, taken in any order constrains how the others may be answered."

Because of this interconnectedness of the three generic activities of the research process where the answer to one question depends on the answer to the previous question, Denzin proposed that the knower (the researcher) answer them in a logical order. First one

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21 Denzin described them as "a set of beliefs (or metaphysics) that enable the inquirer to see and conceptualize the world". Denzin, N. K. and Lincoln, Y. S. (Eds.) 1994, *Handbook of Qualitative Research*, Sage Publications, California, p. 107.
addresses the **ontological** question, then the **epistemological** question and finally the **methodological** question. I will briefly revisit how I rationalized and worked through Denzin's preliminary questions. In this way I hope to illustrate the pathways of my own logic in deciding on which methodology and methods were preferable for this study.

**The ontological question - for the first phase of my research**
Firstly I examined the ontological question which asks about 'the form and nature of reality'. Ontology means focusing attention on 'the real world' which in my case is the real world of family members or very close friends committed to providing sustained care for sick and dependent others at home. Specifically, I wanted to explore the reality of the carers when they entered the domain of general practice, seeking help from the local doctor.

Secondly I needed to understand what is the reality for GPs as they assist carers within the sometimes restrictive parameters of their own general practice domain. I include the GP visiting the family home as well as seeing carers and their patients in the doctor's office. Once I had teased out the realities for each of the different groups of participants, my next step was to address Denzin's epistemological question in terms of the purpose and objectives of my inquiry.

**The epistemological question - for the first phase of my research**
The epistemological question in research methodology is a tricky one to explain. Put simply, it establishes the investigative posture the researcher is to adopt for his/her inquiry. According to Denzin, the epistemological question explores the nature of the relationship between the knower (ie myself as the researcher) and what can be known. It is not so much a matter of what I should ask to discover new knowledge about the reality experienced by carers and GPs, but how I should ask it. If a "real reality is assumed", says Denzin, "...then the posture of the knower must be one of objective detachment or value freedom in order to be able to discover "how things really are and how things really work". 'Not just any relationship can now be postured", Denzin points out.

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22 When preparing a paper on carers in Palliative Care some years later I was able to portray the real world of carers (developed from the carers data) in two diagrams called "The Carer's Universe". [See Appendix 2. ]

23 The purpose of my study was to explore (1) the meaning of the role of carer, and (2) the broad health and social needs of carers in interaction with GPs [GP needs included as well]. The overall aim of my research was to explore (and possibly provide a framework for) the enhancement of carer health and well being.
This was the important decision I had to make on what stance to assume as the inquirer. Should it be one of objective detachment or value freedom? As I wanted to reveal new knowledge about individual carer health and more broadly at a population level, I would need a different approach and posture for that second aspect. For the first phase of my inquiry exploring the experiences and perceptions of carers and GPs - (how do things really work for carers and really work for GPs?) it clearly needed to be less objective. Thus for most of the first phase of my study I was committed to adopting a more subjective and "warm" approach to my research.24

A population view - for the second phase of my research
In describing the second phase of my study, I need to revisit both the ontological and epistemological questions. Focusing on a population requires that one takes a different 'world view' - moving ontologically from the reality of the individual to a collective reality of a large group, or a cohort within a population. However conducting a survey of the state's population is too complex and expensive an exercise for a individual research student like myself to carry out. Thus in phase two of my research plan, the nature of the relationship between the knower (the researcher) and what can be known changes. For phase two I decided on the basic questions to be asked, but I could not be the hands-on researcher, nor could I decide what other questions would be asked and how the research would be carried out. Instead I would have to delegate the task to those with the funding, staff and training which meant that the methodological decisions have been made by others.25

The methodological questions for my research
My responses to the previous epistemological and epistemological questions led to a preferred methodology for most of phase one of my study that had a naturalistic, humanistic, descriptive and interpretive orientation. It was one that would allow me to explore the essence of experience of the phenomenon of informal caregiving with both


25 This separate inquiry was carried out in association with the South Australian Health Commission's Behavioural Epidemiology Unit and Harrison Marketing. They provide a well resourced and independent research group of trained investigators conducting annual Health Omnibus surveys. Occasionally, when funding is available they include the SF-36 as part of the survey as occurred in 1994 and again 1998 when I repeated my carer question 1998. This will be discussed in more detail in the next chapter.
carers and GPs. The addition of the GP survey to phase one would require that I employ other research suitable methods.

My research therefore took on a multifaceted methodological approach incorporating a variety of methods for collecting data and analysing answers to the many different research questions. Although this meant I incorporated both qualitative and quantitative methodologies, the dominant research strategy of my own study remained qualitative, phenomenological and inductive. It is qualitative because the nature of most of my data from informal caregivers and GPs was based on words, both textual and verbal. My aim was to obtain real ideas and concepts from information rich participants (utilizing focus groups and interview techniques) so as to acquire deep and valid empirical data from both carers and GPs. So as to clarify and show the differences between qualitative and quantitative research methodologies I prepared a comparative summary which I used as a guideline for working through my own project.

The Use of Triangulation
I deliberately sought data from several separate sources, namely carers, GPs, population studies, other statistical data and policy documents, so as to achieve data triangulation particularly about carer health status. I also utilized three other types of triangulation, as a means of 'increasing confidence in the validity and authenticity of the data and its

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26 The qualitative/quantitative approach that was becoming popular amongst staff conducting projects in Divisions General Practice and some Australian academic departments of General Practice by the mid 1990s.

27 Leedy provided a simple and succinct approach to data and methodology that I also found helpful. He wrote that "the nature of the data dictates the methodology. If the data is verbal, the methodology is qualitative. If it is numerical it is quantitative. A hybrid variation," he says, "is triangulation". Leedy added that qualitative methodology should consider words 'as the elements' of the data'. Leedy also wrote that qualitative research is field focused, dealing with ideas and concepts and converting those to verbal form. The researcher takes this potpourri of words (ie the data) and from them synthesizes the real problems underlying the condition.


28 See Appendix 6. for a synopsis of 'what is qualitative research?'

29 Triangulation, elaborated most extensively by Norman K Denzin is: "the use of at least 3 but preferably multiple studies, theoretical perspectives, investigators and data sets for research on one issue or theme. In particular the combined use of micro-level and macro-level studies, using each to complement and verify the other, in order to achieve robust research results.


30 Specifically I was keen to show that caregiving not only was associated with a perception of lowered health status at the individual level, but to ascertain if there was a difference between carers and non-carers across the wider population, the latter type of studies missing from the literature at the time of preparing my own inquiry.
interpretation’. The fourth type, investigator (or researcher) triangulation has been useful for comparing the health status of different populations in South Australia with national results from the Australian Bureau of Statistics. Most importantly it provides a good contrast to the findings of my own small study about local carers and increases the validity of my qualitative findings. That is why I included similar questions in my own carer questionnaire and in the Health Omnibus survey, on the perceptions of carers about their health.

Finally, it should be pointed out that my research is not a needs analysis, or a community study. Secondly, although my research acknowledges the importance of caring occurring within 'the caring relationship', this particular study is not inclusive of the person being cared for. Their presence is at all times implied but their voices were purposely excluded from part of the research questions or process. Including the 'patient' in such a study would have detracted from the focus of inquiry which was the carer's health and needs. Third, although it would have offered sharper methodological triangulation to have recruited the GPs of carer participants as GP subjects for this study, (instead of a separate group of GPs who were unrelated to the carers), the priority was to select information rich carers and GPs for this exploratory and descriptive study. Insisting on there being an association between the the carers and GPs might have enabled corroborate between GP and carer perspectives, but one could not presume that each subject was well informed. For this study, all the subjects who volunteered to participate indicated some prior knowledge of, and interest in, the topic and were therefore information rich.

Next I present in detail the study design and procedures I followed for my qualitative research in the field and afterwards for data analysis.

31 Willms and Johnson also state that: Triangulation is a strategy for ensuring a study's findings are not an artefact of a single research method or source. Willms, D. G. and Johnson, N. A. 1993, Essentials in Qualitative Research. A Notebook for the Field. Unpublished, p. 6.
33 There are two additional types of triangulation - Theory and Interdisciplinary which I did not use. In respect of the latter however, it could be argued I took a modified 'interdisciplinary' approach using information from both lay and professional participants [informal carers and GPs respectively] to compare the strength of the data on similar questions about the use of community services and carer health.
CHAPTER 8
STUDY DESIGN AND RESEARCH METHODS

My research design has three quite separate sets of activities and phases as briefly outlined below:

Phase I: A Qualitative descriptive study of carers and GPs [1994/5]

Carer Focus Groups/Interviews & Questionnaires
General Practitioner Focus Groups Interviews & Questionnaires
Survey of 200 GPs [using the same questionnaire]

Phase II: Population Health Survey. Carers vs non carers [1994 & 1998]

[Research in association with the SAHC Behavioural Epidemiology Unit]
1994 Health Omnibus Survey / SF36 of South Australian population
1998 Health Omnibus Survey / SF36 of South Australian population

Phase III: An overview of Carer-GP related Public Policy [1997-9]
The Policy context of meeting carer health needs.

Phase One involved my research endeavours in collecting, analysing and interpreting the qualitative data from 22 carers and a final total of 25 GPs from across Adelaide’s southern metropolitan and country areas. Phase Two involved the inclusion of my own questions about carer health in two state-wide population surveys. A quantitative approach\(^1\) was required when looking at the population health status of carers using the SF-36\(^2\), and was carried out in co-operation with the South Australian Health Commission Behavioural Epidemiology Branch\(^3\). The quantitative data was collected and analysed on my behalf by

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\(^1\) Quantitative data, was requested through the Health Omnibus /SF-36 Survey (and extracted from carer related ABS surveys).

\(^2\) The example of the picture and frame are a popular analogy for comparing qualitative and quantitative research methodology.

Guray, C., 1989, *Focus Group Methodology: An exploration of qualitative research*. New South Wales Medical Education Project on Alcohol and other Drugs, page 5. [A comparison of philosophies ...]. See also Leedy: Ch. 6 on Research Methodology-Qualitative and Quantitative.


\(^3\) Using Health Status measurement instruments like the SF-36 questionnaire is for individual research students, are prohibitive on such a large scale, mainly due to financial and organisational barriers. There are very sizable copyright fees payable to the developers/owners of the 'instrument' every time it is used in this way. Therefore it is mainly the larger government and research organisations which can afford to include and fund the SF-36 as part of their own surveys, in this instance as part of the SA Health Omnibus. However each external investigator, like myself, still incurred a cost of $600-$900 per question. I submitted two questions in 1994 and repeated them again in 1998. Secondly, the logistics of surveying a 3000 sample of the state's population and analysing the results requires a team of trained and paid staff, beyond the realms of any Masters student.
an independent organisation and used to compliment my research findings. The remaining section on policy takes a policy context approach.

Research Methods / Techniques: Focus Groups and Interviews
The preferred analytical tradition for parts of this study was phenomenological as I was exploring the essence of the experience of the phenomenon of informal caregiving in the context of general practice. For a different perspective I was also probing GPs, who in the long term, are usually closest to the carers and frail aged or chronically ill patients. Discussing phenomenological inquiry in more detail, Patton [1990: 68] presented phenomenology as multi-faceted and served as a paradigm, a philosophy, a perspective, a strategy, as well as a qualitative method. He describes it as "using qualitative and naturalistic approaches to inductively and holistically understand human experience in context specific settings". Some earlier authors like Bogden and Taylor took an even broader view, writing that all qualitative research was "based on phenomenological methodology, using naturalistic and descriptive methods to yield data.... " Patton places phenomenology as 'the most general of analytical frameworks' of the various theoretical orientations available. Phenomenologists, he says, "focus on how we put phenomena we experience in such a way as to make sense of the world and in so doing develop a world view". [Patton (1990) p. 68]. In my project the focus was on caregiving and the general practice domain. This latter approach best fits my research strategy.

RESEARCH METHODS & PROCEDURES

Data Collection
Data collection for this research project occurred in in two separate phases:

Phase I: Carers' & GPs' Project using qualitative research methods
Phase II: Population Health Survey using quantitative research methods

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4 The same cannot always be assumed about the relationship between GPs and family carers of the disabled in general. However, GPs remain an important source of support when parent carers are dealing with disabled children. Where the GP link appears less straight forward (or close) is where carers are caring for disabled adults—whether the the carers are parents or partners.


7 In this instance I need to make sense of both the carer and GP worlds and develop or contrast the world views for each of the two different groups.
Full details of the methodology for this second phase is presented separately as part of Section III on Carer Health at the Population Level. This work included two population surveys conducted in 1994 and 1998 on my behalf by organisations in association with South Australian Health Omnibus Survey. Both surveys included socio-demographic profile and health status of carers and the SF-36 questionnaire in tandem with one other health status measure.

PHASE I.

Overview of qualitative methods for data collection from GPs and carers

**Individual interviews versus group interviews (focus groups)**

Deciding on a general phenomenological approach as the qualitative method that best fitted Phase One of my research with carers and GPs, I was then faced with deciding what actual techniques to employ in collecting that qualitative data from participants. As Denzin said there is 'an embarrassment of choices', especially in the qualitative field. For example I had the option of conducting all individual interviews or all group interviews (focus groups) with the carers and GPs.

There was also a third qualitative technique available to researchers taking a phenomenological approach - that of participant observation. However this latter method was not going to be suitable for my particular study as it was not feasible for me to try to observe or participate in carer - GP interactions, either at the doctors' rooms or in the home environment of the carer and cared for person. Interviewing was the preferred technique for my own constraints as researcher and my options were individual or group interviews. I consulted many texts on interviewing and focus groups in the endeavour to make this

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8 Methodology relating to the focus groups and questionnaires as detailed in this section was based on lectures attended by the researcher at a 5-day course on 'Qualitative Methods in Health Services Research', conducted by the academic staff of La Trobe University in 1994.

Key references from that course used for Focus Group /qualitative methodology were from


decision, always returning to David Morgan's sound advice\textsuperscript{11}. Morgan clearly favoured focus groups but also provided an excellent review of the strengths and weaknesses of the group interview in comparison with the individual interview.\textsuperscript{12}

Initially I decided on three separate focus groups for 5-8 carers in each recruited from local carer support groups and other self-help groups across southern Adelaide. Another three focus groups were planned for 5-6 GPs in each, in three different geographical areas of the inner and outer Adelaide regions, plus in a country location on the south coast of the Fleurier Peninsula. [These locations were representative of the distribution of GP members of my local Division of General Practice and within the catchment area of the University Department of General Practice.

In summary, the carer focus groups went as planned, but only the first GP focus group [the pilot] took place - with four GPs, fewer participants than invited. Each doctor had been personally contacted by myself prior to the meeting and had willingly agreed to attend, however having worked with busy GPs over the past years, I was not surprised at the late apologies and disappointing attendance. Those who contributed on the evening however made up for the shortfall in numbers with the most excellent input. After some advice from my colleagues I decided on a slightly different strategy for gathering data from GPs. After a phone call to each of the remaining GP participants to ask for their preference between group of individual interview, the decision to have individual interviews was warmly welcomed. I would go to each of them separately to reduce the time they would be

\begin{itemize}
  \item Gurray, C. 1989, \textit{Focus Group Methodology: an exploration of qualitative research.} NSW Medical Education Project on Alcohol and Other Drugs.
  \item Miles M B. and Huberman , A. 1984, \textit{Qualitative Data Analysis: A Source Book of New Methods.} Sage, Newbury Park, California.
\end{itemize}

\begin{itemize}
  \item Morgan, D. 1988, 'Focus Groups as Qualitative Research'. \textit{Qualitative Research Methods.} vol. 16, Sage Publications, pp. 9-25.
\end{itemize}

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away from work and at the same time avoid asking them to give up an evening. I also re-contacted the GPs who did not attend the pilot focus group and interviewed them in their rooms.

This story of my own experiences in the early stages of the research process raises the question as to why Focus Groups worked with carers but were not so popular with GPs. Firstly it must be pointed out with the carer participants, they were very busy people with their own caring responsibilities. Time was just as valuable to the GPs' time, but there was not a monetary value attached to it. In reality many of the carers would probably have preferred me to visit them individually [as I offered to do for the GPs] in their own homes and not put them to the considerable inconvenience of attending an outside meeting. This inconvenience was compounded for more than half of the carers by the necessity to have 'sitters' come into the home to be with the cared for persons while they were away at my focus group. [Hence the necessity for recruiting carers in cooperation with carer support groups which are funded for providing sitters and for transport of the carer to the focus group location if required.]

Some ethical and practical time/cost considerations
With these considerations in mind I was keen to keep to the focus group method. As I was a student researcher, rather than health professional working from a clinical base, I had a few personal reservations about entering into the home of the carers and cared for persons [patient] where I was asking the carer to contribute to a project that could not offer any practical support in return. Caregiving is a very dynamic situation where the carers are shouldering considerable problems involving a sick individual in a complex relationship.

During the interviewing process in discussing their many problems there is often the expectation on their part that you might be able to help them. The correct procedure of

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13 Many students do conduct individual interviews in the home setting and there are no outstanding reasons for not pursuing such an approach so long as the appropriate ethical guidelines are followed and ensuring that the cooperation of the cared for person is obtained prior to any interviews in the home. [Whether the researcher needs the cared for person's consent is an ethical matter which I would have had to address had I proceeded with the home visits to carers. In the case of my own research using focus groups and in view of the fact each carer elected to attend a meeting independent of the home situation it was considered by those I consulted on this matter when developing my own strategy, that the initiative was up to the carer to decide if they provided extra details to the cared-for person or not.]

At the completion of the focus groups, I did actually have to conduct one interview at the home of a carer who could not attend the focus group but wanted to be part of the research project. This particular parent carer had a severely disabled and retarded adult daughter and it was difficult for her to make alternative arrangements so she could leave the house during the period I was running the focus groups. As it turned out her input was invaluable.
course is that they are referred back to the carer support group who have access to trained people to see to the carer's problems or needs and refer them on to other services for help. [This is another reason why it is so important for the student researcher to have a formal liaison with a carer support group.]

The great strength of the focus group is that each carer is able to participate as an individual, away from the cared for person. This engenders a more relaxed and frank contribution to the discussion, and being with other carers in similar situations often stimulates and prompts the carer to express him or herself beyond what would be possible at home. At the end of the focus group, I believe it is important that the carers should feel there have been some personal benefits for them, even if only the satisfaction of sharing some of their thoughts, fears and worries with others for a short time. Again from an ethical perspective as the researcher, I was aware that if any of the participants showed undue strain or distress as a direct result of talking about their circumstances, I could bring it to the attention of the group moderator (a person trained in counselling carers), so some form of follow up could be put in place. Fortunately this was not necessary in my group of carers.

There were other more practical and pressing reasons for preferring the focus group method for data collection from carers and for this I refer back to the work of David Morgan.\(^\text{14}\) He mentions the logistics of time and cost of multiple individual interviews. I had 22 carers in my study. From the time involved alone, it would have been difficult for me to arrange to do separate interviews for them all especially if they had extended over time and generated longer and more detailed transcripts than were really needed for my research. Without doubt using focus groups and an experienced moderator, it is possible to obtain more condensed information in a much shorter time frame.\(^\text{15}\) More significantly, the time and cost of transcribing twenty two separate interview tapes would have been prohibitive. I did my own transcribing of the focus groups, but I also paid a number of typists to transcribe the quite a few of the GP interviews and then rechecked every transcript. The sheer volume of data gathered from enthusiastic participants through only three focus groups was a testament in itself that twenty two separate interview transcripts


\(^{15}\) That raises the question if the researcher ends up with different data from a group interview in comparison to data gleaned the individual interview. Morgan (1988) and other authors in the past claim that it is. In the long run it depends on ... the research questions and depth of questioning that is required.
would have been a daunting task to handle and analyse and use. Morgan attests to this in his article.16

**CARERS: DATA COLLECTION**

**Carer Focus Groups**

*Identification and Selection of Carer Participants - Carer Focus Groups*

The process for selecting carers for the three Focus Groups was carried out on two different occasions. Selection of carers for the first (pilot) focus group occurred late 1994. The remaining two focus groups were organised March/April 1995. This phase of The Carers' Project identified a group of carers who were interviewed in three separate Focus Groups and asked to complete a self administered Questionnaire. The methods chosen were designed to draw on the experiences of a wide range of people who were involved, or had recently been in an informal caregiving role. For example those family members and other carers who were providing long term home care or support for a dependant person (or persons) were sought as participants. However no particular typology of carers were targeted or excluded for this preliminary exploratory research project. This was because the aim of the research was to gain an overview of a broad range of issues common to all carer groups, whilst examining areas where there were distinct contrasts. People who were "information rich" carers and willing to share their lived experiences were purposively selected for the study.

The primary purpose of the interviews were to discuss the peoples' own understandings of their roles and responsibilities as home based carers, issues relating to their health and well being, their special needs as carers, and in particular their needs and expectations in relation to the general practice setting. The questionnaires followed a similar format with some additional questions on the use of community support services and resources.

*Inclusion /Selection criteria for carers*

People accepted for this project were those principal carers who were providing long term home based care or support for dependant people with dementia, chronic mental and physical conditions, a debilitating or malignant illness, the frail aged or the physically and intellectually handicapped. This included dependants who had had a stroke, brain injury, and other neurological conditions, in both adults and children. All carers nominated were family members, (rather than non relatives such as friends or neighbours), and most of the

16 ibid
carers were resident in the same house with the dependent. In terms of the gender mix of participants, I was able to recruit a small number of male carers so that each focus group had at least one male representing this minority view.

Exclusion criteria for carers
Although children and adolescents are also known to be active as carers, it was acknowledged that their needs are very specialised and should be part of a separate research project designed specifically for them. In addition, due to the necessity for parental/guardian consent, and in view of the time and administrative limitations involved in acquiring that consent, carers under 21 years of age were excluded from this study. People who were unable to speak English were not sought or included from this study due to the lack of funding to provide interpreters for interviewing/transcribing or to recruit adequate numbers of carers to form homogeneous focus groups. It is again recognised that their specialised needs deserve a dedicated research project.

Pilot Focus Group-[October-December 1994]
Recruiting for the Carers
A range of Carer Support Groups and community service organisations associated with local government agencies throughout the southern suburbs of Adelaide were contacted by the researcher during the latter half of 1994. A letter had been forwarded mid year informing them of the research project and asking for their assistance to nominate two or three carers from their groups who might be interested in participating in this project about the needs of carers. Selection criteria were also discussed at the time. Five main agencies responded to the requests which eventually yielded over a dozen names. The Carer Support Network at Mitcham, Neurological Resource Centre, Stroke SA, the Parkinson’s Association’s southern group and the SA Carers Association were particularly helpful.

The Carer Support agencies were requested to contact their nominated carers, pass on a Carer Information Sheet already sent with the introductory letter, and seek their permission for the researcher to make contact with them. This was done so as to ensure that each carer could authorise the release of his or her name and telephone number before that information was passed on to the researcher. The researcher phoned each person nominated by the Carer Support Groups to introduce herself, explain the purpose of the research, provide extra information, and answer questions about The Carers’ project if required. The reason

17 See Appendix 4 for sample copy of letter sent to a number of community agencies.
of the phone contact at this stage was also to enable the researcher to assess the suitability of each person for participation in the project, based on the inclusion and exclusion criteria (as described above). After phoning this selection of people, two carers declined to proceed with the project, leaving twenty four people who were willing to be part of the pilot focus group process.

**Focus Group participants**

The carers who were nominated were surprisingly compatible and made up a more homogeneous group than originally anticipated. Therefore composition of the pilot focus group for carers was mainly determined by matching the times of the day and week at which the all carers could come together, at the Mitcham Community Centre. On the day, six family caregivers attended the Pilot Focus Group. They included two retired men, both over 75 years who were caring for their elderly wives with chronic neurological conditions, including dementia and Parkinson's Syndrome, three women who were looking after their dependent husbands with stroke, dementia, and multiple disabilities and one other woman who was the mother of a multiply disabled wheelchair bound adult son. Except for the mother who had only recently relinquished her son to formal care, all were resident in the same household as the dependent, and providing 24 hour care for that person.

**Focus Group Moderator: Identification and Briefing**

Prior to organising the Focus Groups, a person with facilitation skills and group work experience with carers was approached by the researcher and asked to be the Carer Focus Group Moderator. This person was given full details of The Carers' Project and later met with the researcher to discuss the study in detail. Once familiar with the research project the moderator was briefed with an outline of protocols for conducting the Focus Group including how to avoid moderator bias, discussed below, and consideration of ethical and privacy issues for the group based on the researcher's submission to an ethics committee. (see Appendix 5).

The three main sources of moderator bias that have the potential to affect the validity of a focus group data are firstly *personal bias*, where the moderator's own personal views can inadvertently direct how questions are put to the group. Personal bias could also be in relation to the participants if any of the carers were known to the moderator. Secondly there is sometimes an unconscious tendency on the part of a moderator to try to "please the client" or the researcher. This can influence the tone in which questions are asked, or has
the potential for comments of some participants to be overlooked. The third is a need for consistency in how questions are asked, particularly when the same questions are asked of different carers over several separate focus groups. As stated by Stewart and Shamdasani there can be a predisposition on the part of the moderator "to welcome and reinforce the expression of points of view which are internally consistent". Finally, the interview schedule was discussed in detail with the Moderator regarding the approximate timing required for multiple questions that had been divided into a four parts. Also the moderator was advised by the researcher about what emphasis to put on certain questions, and how deeply to probe into others.

This was a particularly helpful and reassuring aspect of the briefing process as strategies could be decided on in advance in how to deal with situations like premature stagnation of the discussion, problems with group dynamics, like anger, or disagreements amongst participants, and how to handle new or unexpected information by adapting the interview guide. As the researcher would be sitting in with the group as an observer it was decided that the Moderator could indicate if necessary, if the anything needed to be clarified during the actual. The final point decided on was how the moderator should wind up the two hour focus group on a positive note. This is very important if sensitive and personal issues have been discussed during the group interview. The Moderator suggested a most creative way of achieving closure by using "the magic wand" idea, which involves inviting each carer to state a wish list. This approach was received very well by the carers and provided an added dimension to the focus group data.

Development of An Interview Guide

Patton writes that the interview guide "...actually constitutes of a descriptive analytical framework for analysis...With an interview guide approach, answers from different people can be grouped by topics from the guide, but the relevant data won't be found in the same place in each interview. The Interview Guide / Discussion Schedule I developed [See Appendix 6 for a copy] was divided into four parts designed to explore the three main objectives relating to carers outlined in the original research proposal. These objectives were:

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To explore with carers, their experiences and understanding of the role of carer, the associated responsibilities of being a carer and their perception of the general effects caring might have on their health and well being. [Discussed in Section I: The role of carers and Section IV: The health and well being of carers]

To identify, from the perspectives of both carers and GPs, the major health and social needs of people who are providing informal care to a dependant individual. [Discussed in Section IV]

To explore, from the perspective's of both carers and GPs, how GPs can continue to support carers and better meet the future needs of carers in the general practice setting. [Discussed in Section III]

The same interview schedule was used unchanged for all the Carer Focus Groups as pre-testing during the pilot focus group. It worked well and proved to be a suitable instrument in terms of eliciting responses from carers. Although such an interview guide concentrates on and defines topics of interest to the researcher, with a well run focus group, there is more opportunity for the carers to volunteer data with very little direct input from that researcher. The advantage of group interviewing, in the words of David Morgan, is that:

"the participants' interaction among themselves replaces their interaction with the interviewer, leading to a greater emphasis on participants' points of view".

Group interaction can therefore provide access to forms of data that are not obtained easily with either of the other two qualitative methods. [ie individual interviews and participant observation].

Second and Third Carer Focus Groups- [February - April 1995]:

Recruitment and selection and of carer sample for remaining Carer Focus Groups

A more extensive recruiting process had been implemented for finding carers to participate in the other two carer focus groups. With the assistance of the SA Carers' Association and the Carer Support Network, fliers detailing the project and inviting participants (see Appendix 7) were circulated to one hundred and twenty one members of the Carers Association newsletter. Nineteen people responded to the notices, most of whom elected to attend focus groups. The same procedures for contacting each person by phone were followed as already described above. All people who returned the tear off slip from the fliers were first phoned and assessed by the researcher and if they fitted the selection criteria, were sent an information package which included a 12 page questionnaire for them to fill in and return on the day of the focus group. Six people proved to be unsuitable as they were not carers of dependent persons. Five other carers who nominated themselves as

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carers did not proceed in the study three indicating that on reflection they did not feel comfortable in discussion with other carers present.

Response rate and composition of the Carer Focus Groups
Of the nineteen people who responded to the flier in the newsletter, five carers attended the Noarlunga Focus Group which was held at Noarlunga Health Services with which all people from that area were familiar. The group comprised one husband caring for his wife who also had dementia, a middle aged son caring for his aged and disabled father, the mother of an adult son who had sustained severe brain damage from an accident, but who had responded to rehabilitation efforts, a retired school teacher who was caring for her frail aged mother, and had cared for her husband until his recent death, and a woman who was looking after her aged husband who was chronically ill and blind.

The six people who participated in the Mitcham Group were mostly wives of aged husbands who either suffered from dementia, stroke or a chronic disabling illness. One younger woman was caring for her elderly mother who had long term neurological damage and multiple chronic illnesses.

Individual Carer Interviews
One carer was interviewed in her home, because of restrictions caring for a severely disabled daughter. The same interview schedule, protocols and procedures were followed but without the moderator present. The questions were asked by the researcher and answers were audio-taped. Due to the more informal and conversational nature of the setting, less notes were taken and some extra issues were included during the one and half hour interview interviews.

DATA COLLECTION PROCEDURES
Carer Focus Groups
The focus groups were all planned for a maximum of two hours with a ten minute break at an mutually agreeable and opportune time. Only one of the three groups finished ahead of time due to the skills of the Moderator. On each occasion (of the pilot and two subsequent focus groups for carers), the same data collection procedures were followed. In terms of the optimum number of focus groups to conduct, the "ideal" stopping point is considered to be when there is some degree of repetition by respondents and no significant new data is emerging. Although the dictates of lack of funds and time were also key factors in limiting
the number of groups to three, by the third focus group it was noted that carers were making very similar comments to those in previous interviews.

Recording procedures
As well as the session being audio-taped, and conducted by an independent moderator, I as the researcher sat in on the group and recorded written notes about the conversations. This provided cross referencing of data should there be any uncertainties or discrepancies during transcribing caused by people not speaking clearly, unexpected background noises or technical problems with recording. This was a useful backup procedure as all these events occurred and the notes were required as an alternative source of information. If there were other problems for example with the tape, the proceedings were halted until the matter was resolved. There was also the option of clarifying specific points with individual participants after the focus group to ensure accuracy of reporting.

DATA COLLECTION PROCEDURES
Carer Questionnaire
Carer Sample
The Carer Questionnaire was designed as an supplementary instrument for gathering demographic and additional background data from those carers who attended Focus Groups I also used the same questionnaire with the carer who was interviewed. This provided a final sample size of 22 subjects. Two people who returned their questionnaires did not attend the focus group.

Development of the Questionnaire
The questionnaire was developed after examining a number of major project reports on carers' needs which were carried out in both the United Kingdom and Australia one which related to carers and general practice. (Southern Community Health Services, 1989; Carers National Association, 1992; Brodaty et al, 1994). The questionnaire was then re-drafted after consultation with a number of researchers who had experience in surveying carers and lay groups locally in Adelaide. This was the draft that was handed to carers at the conclusion of the pilot focus group for carers who were asked to post it back to the researcher within two weeks.

The responses to each question in the Questionnaire were then assessed by the researcher to identify any questions that indicated the respondents might have had problems in
understanding what was meant by the question. For example if the question should be worded differently or if it needed to be split into separate smaller questions. The researcher then contacted a number of the carers to ask for verbal feedback about the questionnaire in terms of ease or difficulty in understanding the questions and length of time taken to complete the task.

Following this assessment stage many of the questions were further refined and reworded, and some other questions were added. Its format was also altered to facilitate a better flow of questioning. With this re-working of the questionnaire, about a dozen were handed to carers at a number of support group meetings to trial and comment upon. No other changes were necessary and a final version was ready for distribution to participants of the remaining two Focus Groups. The actual questionnaire comprised four sections, that provided demographic data on each person.

*Carer Questionnaire: Data Collection Procedures*

The questionnaire was self administered by the participant carers in their own homes at a time that suited them. Some indicated they completed it in one sitting, others tackled it piecemeal over a period of seven to ten days. Other than those carers who attended the pilot focus group or the one person interviewed separately, most handed back the completed questionnaire personally on the day of their focus group.

**DATA COLLECTION: GENERAL PRACTITIONERS**

*GP Focus Group / Interviews and Use of GP Questionnaire*

*Recruitment and sample of GPs*

Achieving the cooperation of GPs for my project was a challenging exercise. Advance notice about this research and an invitation to participate was provided through two newsletters (from a local Division of General Practice) for GPs in the southern region of Adelaide and Fleurieu Peninsula. Additional fliers with background information about my research (referred to initially as 'the Carers Project') and a return form for expressions of interest, were also posted to the GP members of a local Division of General Practice, which comprised about three hundred doctors. Only three GPs responded expressing interest in being part of the project.
Ch. 8: Study Design And Research Methods

As I had originally planned to recruit a minimum of 10 GPs, with the possibility of 15-20 if available, I then purposively selected the remainder from a list of GPs in the southern region of Adelaide who were known to be interested in community issues associated with the local Division of General Practice. Of those original 15 General Practitioners contacted, 13 remained as part of the qualitative study. Five initially agreed to pilot the GP Questionnaire with me.21 4 GPs participated in the one hour focus group interview, including one who had piloted the questionnaire, but had not been interviewed. The remaining three GPs from the focus group and an additional 5 participants (8 GPs) then completed the modified questionnaire. Five other GPs opted to be interviewed at their surgeries rather than attend another group interview. Each of the GPs interviewed were asked to complete and return the questionnaire to the researcher within seven to ten days - which they did.

STAGES FOR PUBLICITY & RECRUITMENT OF GPS

<table>
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<tr>
<th>TIME LINE</th>
<th>N'letters with Flier</th>
<th>Flier Posted</th>
<th>Purposive selection</th>
<th>Survey</th>
<th>FINAL TOTAL GP RESPONSES</th>
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<td>= 25 GPs (who completed Questionnaires)</td>
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3 GPs responded to fliers
10 GPs contacted /agreed
12 'Survey' GPs returned a completed Questionnaire

1ST GROUP OF 13 GPs----- 2ND GROUP OF 12 GPs
(Original 13 GPs recruited & interviewed) (None of survey GPs interviewed)

The process of recruiting the GPs, arranging and conducting both interviews and the focus group was carried out over a period of four weeks. It was interesting to note that focus groups were not popular amongst the doctors but when interviewed the GPs were very generous with their time without financial reimbursement.

Data Collection Procedures

GP Focus Group

As well as generating data, the one hour pilot focus group was used to test the suitability and appropriateness of questions on the interview schedule which was also going to be used for one-to-one interviews. The GP moderator was already well briefed on the project, including the line of questioning and timing required for the meeting. Exactly the

21 After the GP questionnaire was piloted, few modifications were subsequently made to the GP questionnaire to clarify some of the questions.
same data collection procedures as used for the carer focus groups and interviews were repeated with the GPs. This involved recording on quality equipment and transcribing answers and comments ready for analysis and comparison with data gathered from the GP questionnaires.

**GP Face-to-face Interviews**
Other than the focus group, personal interviews with GPs were carried out in their consulting rooms. Most GPs scheduled their interviews mid afternoon before commencing with their final list of patients for the day, and remained attentive and keen to talk about carer and community issues in general practice. Duration of the interview varied from forty five minutes to one hour, some GPs willing to go over time to cover all important subject areas.

**GP Questionnaire and the Survey**
As described, the GP Questionnaire was used by each of the GPs who participated in the group and individual interviews so as to provide background information as well as comparable information to that explored in the focus group and interview. As the questionnaire was well received by the GPs, but the number of participants was low, I extended my study to gauge carer awareness amongst a much wider group of GPs aiming to gain a clearer idea of the use of carer and community services by GPs. I subsequently posted out the questionnaire to a randomised sample of 200 GPs from the local Division of General Practice. This yielded only 12 responses. With such low response rate it was clear that I could not use this as survey data requiring any statistical calculations. Statistical rigor meant that there was insufficient data to provide any valid or reliable numerical results. For an earlier interim report on my research in 1995, I excluded all the survey results, including responses to the open ended questions of the questionnaire.

Nonetheless, the 12 GPs who filled in their questionnaires as part of the 'survey' had provided very valuable comments in the open ended questions. Their responses were reasonably consistent and complementary to the qualitative data collected in questionnaires from the initial group of 13 GPs. Therefore, after I had analysed both groups of GP comments separately, I included responses of the survey GPs in my GP data sets. This makes an overall total of 25 GPs from the southern region of Adelaide who have provided qualitative input to this descriptive study. The final thematic analysis of GP responses in

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22 I prepared this randomised survey according to:
Section II of this thesis represents comments from all 25 GPs but it is possible to differentiate between which group a GP comes. In the Appendix, I list Questionnaire results from both groups of GPs, in such a way that the original group of GPs, (GP-1 to GP-13) are easily differentiated from the survey respondents (GP-14 to GP-25). Comparing characteristics of the two groups of GPs in this way, in contrast to the initial group of GPs who were purposively selected GPs (plus the few who responded to the flier), the majority of GPs who responded to the survey were female, in the 30-40 age range. In comparison to the original group of 13 GPs, nearly twice as many GP respondents from the survey worked part time and had been in practice 10 years or less.

**DATA ANALYSIS: Carer and GP Data**

*Description of all text data and thematic analysis*

For the purposes of achieving a comparable data analysis between both carers and GP participants, the carer focus groups and carer questionnaires, GP interview schedules and GP questionnaires were purposely designed so they had four similar main parts. These explored the role and experiences of the carer, needs of the carer, carers and GPs and the health and well being of carers. After verbatim transcriptions, all data from focus groups, interviews and questionnaires were initially collated using these headings and emergent themes also identified under those topic headings.

*Data Analysis - GP Questionnaires*

A total of thirteen Questionnaires were collected from the first group of GPs (who had also been interviewed). As most of the questions from the draft version of the Questionnaire were relatively similar in their meaning, the pilot results were combined with the two later samples. As with the Carer Questionnaires, an initial analysis was carried out in two stages. Socio-demographic data and responses to closed and short answer questions in the questionnaires were keyed into Epi Info and a data base on GPs' responses created. This program was particularly useful for those questions which listed GPs' observations of the health of carers and the use of community based services for carers.

**DATA ANALYSIS: Carer Questionnaires**

*Thematic Analysis - GP Questionnaires*

A separate analysis of GPs' responses to all the open ended questions were categorised by the researcher according to the four separate parts of the questionnaire: i.e,
Section I: Identifying carers and their needs in general practice;
Section II: Effects of caring on carers' health and well being;
Section III: Support for Carers by GPs; and
Section IV: Future Support for Carers in General Practice.

Within each of these sections of the questionnaire, emergent GP related themes were identified and additional topic headings and sub-headings created under those themes. After an initial thematic analysis of GP comments gathered from group and individual interviews and the questionnaires, the researcher attended a meeting with a group of about ten GPs from the local Division of General Practice. Two had been part of the study and provided the researcher with the opportunity to present a structured presentation of her analysis to the GPs for their critical assessment and comments on her own interpretation. The report was well received and not challenged as had been anticipated.

Data from all the carer questionnaires were analysed on two ways. Socio-demographic data and responses to closed and short answer questions in the questionnaires were keyed into Epi Info 6.02, a word processing computer program for public health information. This data base provided a statistical tool used for setting out and calculating the frequency of responses to the questionnaires that could also provide a variety of variables to describe the sample, eg. Age, Gender, Financial, Educational and Employment status, as well as length of time caring. For the purposes of analysis, as the overall sample numbers were small, data from carers involved in the pilot focus group was included with data from subsequent focus groups, interviews and questionnaires.23

*Thematic Analysis - Carer Questionnaires*

A separate analysis of carers' responses to all the open ended questions were initially categorised by the researcher according to the four separate parts of the questionnaire: Part I: Background information on the caring relationship (role and experiences); Part II: Carers and General Practice; Part III: Effects of caring on carers' health and well being; Part IV: Carers' needs. Within each of these sections of the questionnaire emergent carer related themes were identified and additional topic headings and sub-headings created under those themes.

23 These frequency results of the carer responses were presented in my 1995 interim report, and are still available, but have not been included in this final report because for the final analysis I did not use Epi Info to analyse my GP data.
Reporting back to a carers group
After an initial thematic analysis of carer comments gathered from both the focus groups and the questionnaires, an additional meeting was arranged with a group of about twenty carers. Many had also attended the focus groups, so this enabled the researcher to provide a structured presentation of her analysis to the carers for their critical assessment and comments on her own interpretation. This provided an opportunity for carer feedback.

DATA ANALYSIS
GP Focus Group

Initial Data Analysis - GP data from focus group
The GP focus group and subsequent interviews with eight GPs resulted in verbal data being collected from a total of 13 GPs from both urban and rural areas of the southern region of Fleurieu Peninsula. This data was combined and collated for thematic analysis using the same procedure as for carer comments. It was initially subdivided into the major subject areas as outlined in the focus group and questionnaire. Key issues and themes raised by the participating GPs were then highlighted, coded and collated.

After an initial analysis of the GP focus group data, interview data and open ended responses in questionnaires from those GPs, had been carried out, an interpretive summary of the data was presented at a Divisional meeting to a third group of GPs for their comments. Several of the GPs in that group had also participated in the study.

DATA INTERPRETATION

Qualitative phase (one): Carers and GPs
Data analysis and interpretation for both carer and GP responses was a lengthy and complex process. The interpretation slowly evolved by choosing and blending the most compatible ideas and approaches as described by qualitative commentators. I also found that I reviewed my data frequently, often preparing overviews of my research data and findings for presentation to conferences, meetings of other public/professional venues. Each time I did this, often for a different audience [ eg GPs, palliative care audience,

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government bureaucrats, nurses, dementia and carers support staff etc.] Thus data analysis and interpretation for me was an ongoing process which I repeated several times over a period of years. It was not until I attended a one day workshop\(^{25}\) however, that I found the approach which best suited my data and research questions. Then I was able to prepare my final version of the data.

My task may have been made more difficult by the fact that I chose not to use any dedicated computer software for this process (eg the two most popular of the decade have been N.U.D.I.S.T and Ethnograph). My considered decision was that ethnography was unsuitable since my research orientation was not really ethnographic. However N.U.D.I.S.T seemed a possibility so I spent some time reviewing it. After trying N.U.D.I.S.T having attended workshops and talked to staff about its usefulness, I concluded it was most suited to studies that had fewer questions requiring deep and meaningful answers. After considering its strengths and weaknesses, I favoured a hands-on approach to analysis and persevered by using the word processing functions of my computer including the very useful 'search', 'find' and other other tracking options of Microsoft WORD programme.

**OTHER ETHICAL, LEGAL AND CONFIDENTIALITY ISSUES**

Ethical aspects of my research project have already been included throughout this methods chapter as part of the ongoing process of designing and conducting a study with carers who are often in a vulnerable situation themselves. Initially I prepared a submission for the ethics committee when I first proposed this study. [See Appendix for part of that submission on ethical matters.]

*Questionnaires, Group and individual interviews*

Written consent was obtained from all carer and GP participants after assuring that each person was provided with adequate information about the study. I personally spoke with each person prior to their receiving and signing their consent form to ensure each participant understood what was being asked of them - particularly the carers. For the Focus Groups all carer participants were reminded by the moderator on the day, that the recording was part of a research project and therefore would be transcribed for coding purposes.

\(^{25}\) University of Adelaide Department of Clinical Nursing. *Data Analysis.* (Seminar Manual).

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Confidentiality of data

It was restated to carers that the information gathered from the interviews would be stored so as to protect the privacy of the participants. It would be used in such a way that did not identify them, the person they were caring for, their family or any health professionals or service providers involved. This included the use of experienced and well briefed typists for the transcribing of audio tapes from the focus groups and interview. The same principle applied to the content of questionnaires. All participants were identified by predetermined codes. The Moderator was fully briefed to explain confidentiality at each focus group so that everything discussed during that session was to be treated as strictly confidential. Carers were told that nothing they heard about another person was to be repeated outside the focus group. These measures were instigated to protect each person's and patient's privacy and that of their family.
SECTION II
SECTION II

INFORMAL CAREGIVING AND GENERAL PRACTICE
Findings of a Qualitative Study of Carers and GPs in General Practice

CARERS: Data and Findings
Part 1: Role and Responsibilities of Carers
Part 2: Needs of Carers.
Part 3: Carers and their GPs
Part 4: Health of Carers.

GENERAL PRACTITIONERS: Data and Findings
Part 1: Identifying Carers in General Practice
Part 2: Needs of Carers - (GP observations)
Part 3: Health of Carers - (GP observations)
Part 4: GP Needs - (GP suggestions)
SECTION II: INTRODUCTION
CARERS AND GENERAL PRACTICE

A Qualitative Study of Carers and GPs in the General Practice Domain

Introduction
This section presents a compilation of all the textual data collected from carers and General Practitionerers. It was obtained through questionnaires and group interviews (Focus Groups) for the qualitative part of my research project. The format I use for describing the findings follows the sequence of the Carer and GP Discussion Schedules /Interview Guides (Parts I-IV). As I work through each part I also incorporate responses from Carer and GP Questionnaires which ask similar questions to the interview guide. I will not be presenting all the findings of the Questionnaires separately in the body of the thesis, but all relevant carer and GP written responses are included separately in the Appendix.

Carer Responses
I start this section with a demographic profile of carer participants, which was asked in the Carer Questionnaire. After that follow carer responses to Part I: Exploring the Role and Experiences of Carers, which raises the issue of choice in becoming a carer and people's feelings about being a carer. Part II questions are on the general needs of the carer; Part III discusses carers and their GPs, with specific references to carer support in the General Practice domain. Finally in Part IV, I collate carer comments on their own health and well being. So as to give the health component some structure, I group the carer responses under headings that are similar to those used in the population health survey. This is very helpful when later comparing the qualitative data with results from the SF-36 questionnaire of the 1994 and 1998 Health Omnibus surveys. I use the same approach for GP comments about carer health later in this section. This yields surprisingly consistent results from the three sources of information (ie from carers themselves, GPs' observations and population survey results.)

GP Responses
I use a similar format when reporting what GP participants of this study contributed. This includes responses of those GPs who were interviewed and attended the focus group, and

1 It is here I am also looking for examples of carer perceptions of their roles which might match the elements of informal caregivers which I presented in Section I.
completed a questionnaire. It also includes written responses of those few GPs who returned a GP questionnaire as part of the later larger postal survey.

Following the four-part format of the GP Interview Guide I present my data according to the questions within each part. Part I is on identifying the carer in general practice and focuses on how GPs perceive and recognise the roles and responsibilities of carers. Part II draws on GPs' own experiences and interpretations of carer needs, describing what GPs are already doing to help carers. GPs are asked about their own needs in accessing carer support and community services, (but I include this data with that of Part IV). Next in Part III on the health of carers I draw again on GP observations of carers they have known in their practices. This introduces a clinical perspective to the discussion with some interesting thoughts from the GPs. Finally Part IV teases out what GPs feel they need to assist them in their daily work to support carers.
CARER DATA

FINDINGS FROM
CARER FOCUS GROUPS, INTERVIEWS & QUESTIONNAIRES

CARER OBSERVATIONS

PART 1: ROLE OF THE CARER
PART 2: NEEDS OF THE CARER
PART 3: CARERS AND THEIR GPs
PART 4: HEALTH OF THE CARER
CHAPTER 9
Part I (I): DEMOGRAPHIC PROFILE OF CARER PARTICIPANTS

Introduction
The following profiles of carers and details of the persons they care for, are built up from data taken from both the carer questionnaires and the carer focus groups / interview. For accuracy where carer responses appeared confusing or contradictory, it was necessary in some instances to compare information provided by the carer between the questionnaire with what was said and recorded in the focus group. This proved a most useful way of cross checking the and validating what the participants said compared with what they wrote.

Gender and age: Twenty two carers returned their Questionnaires, most attended the Focus Groups and one was interviewed due to her inability to attend the Focus Group. Seventeen carers were female, and five were male carers, while carer ages ranged from the 35-83 years, with just over half in the later years aged 65-84. Four carers were in the middle age range, 45-55 years, and a further four were in the early retirement years aged 55-65.

Marital, educational and financial status: More than half of the carers [13 of the 22] were married, 4 of the 22 were separated or divorced, two were widowed and only one had never married. Almost half [11] were retired, 7 stated they had home duties and only one carer worked part time in paid employment. No one worked full time and no one marked themselves as being unemployed. The educational status of the carers indicated that 9 of the 22 had Certificate/Diploma or Trade/Business qualifications, 8 of the 22 had attended secondary school and 3 of the 22 had left school before they were 15 years. With the optional question on gross annual household income, more than half [13] of the 22 carers answered. Of those, only one carer earned more than $30,000 in the previous financial year, two had an annual income of between $20,000-$30,000 and more than a third, [4 out of the 13 respondents] only earned $12,000-$20,000. Almost half of the carers [6] were living on gross annual incomes of $12,000 or less.

The relationship of the carer to the dependent person being cared for was 'wife' for 10 out of the 22 carer participants, four carers were husbands, five carers were mothers of a dependent young person, three were daughters of an older parent, and one was the son of
the cared for person. No one was looking after a sibling, friend or neighbour. Three carers identified themselves as having multiple caring responsibilities for more than one sick or frail dependent person.

**How long had the carer been in the caring role?**
The 22 carer participants for this study represent the differences in time spent by carers in the caregiving role which ranged from 2 years to 29 years. Not all carers answered every question, but of those carers who did respond, most (13 out of 15) indicated they were carers involved with their caregiving role 7 days a week or ‘full time’. Only 2 carers were caring ‘part’-time, 1-2 days a week and 3-5 days per week respectively.

**Illness or disability of person they are caring for + co-morbidity**
More than half [13 out of 22] of the sick or disabled dependent persons being cared for at home were listed as having multiple disabilities. The next predominant groups were those with dementia/Alzheimer’s disease [8 people of the 22 persons] and problems associated frail aged-[8 persons], of whom almost half were listed in both categories. Brain damaged or intellectually disabled persons represented a small proportion of those cared for [6 of the 22 persons], while 4 of the 22 had physical disability, two of whom were both physically and intellectually disabled.

The remainder of cared for persons had heart and or respiratory conditions [4 people] or a stroke [3 people], and two persons had a severe visual impairment. Another two had Parkinson’s disease, one had cancer and one was reported as suffering kidney/urinary related problems. In some patients these conditions were compounded by additional medical problems of epilepsy, incontinence, cerebral palsy, Pagets disease, lymphoedema, colitis, diverticulitis and blood pressure.

**Age of Cared For Person:**
The age groups of the cared for persons ranged from teenage to the very old, although a half [12 out of the 22] were aged 65 -84 years. 4 of the 22 persons were aged over 85 years. Of the remaining over 50s age group, 2 persons were aged between 55-64 yrs. In the youngest category one was in his mid teens, while the remainder of cared for persons were in the 25-44 age group. One of this ‘adult’ group was a severely and multiply

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1 She is described as having severe and multiple disabilities, ranging from cerebral retinal damage, epilepsy, chest infections. Her developmental age is five months old, C-22 Int. p.2 L.29.
disabled girl who although aged 30 by calendar years, had the actual age of a 6 month old baby. One other person was aged in the 35-44 year age group.

These profiles are not representative of carers in the wider population as can be demonstrated when compared with the Health Omnibus Surveys carried out in 1994 and 1998. For example from a total sample size of 3010 people across South Australia in 1994, 104 were identified as carers.

**Gender:**
In the Health Omnibus Survey, the male to female ratio of carers is less pronounced than the higher percentage (77%) of females in my qualitative study.

**Age:**
The population age distribution was roughly a third for each of the age groups of the Health Omnibus Survey, whereas of the group of carers who nominated for my smaller study more than half were over 65. A third were aged 45-64. Only two carers aged in the 20-44 group were part of my own small research project.

**Marital:**
Comparing marital status of the small group of carers in my study with results of the Health Omnibus Survey, there were similar trends between the other three categories, but in my own study there was also a higher percentage of separated or divorced carers.

More details of the Health Omnibus Survey are provided in Section III.
FOCUS GROUP DISCUSSION SCHEDULE & INTERVIEW GUIDE  
FOR CARERS

Part I  Exploring the role and experiences of the carer

(1) How long have you been a caregiver? [See Questionnaire results: Appendix]  
What is the illness/disability of person you are caring for? [See Appendix]

(2) What do you understand as the ROLE of a carer? - describe role
(3) Did you feel you had (or wanted) a CHOICE in becoming a carer?
(4) How do you feel about being the carer?

Part II  Needs of the carer

(1) What are your needs as a carer?

(2) Where do you go for help with these needs?
   - You very own personal needs
   - Need for assistance with the dependent person,
     Information needs / community resources
     Practical assistance in the home
   - Other needs?

Part III  Carers and their GPs

(1) Do you think your local doctor sees you as the carer?
(2) Has your role and needs been discussed with your local doctor
(3) What support has been given by your GP? - how has it helped you
(4) How could your local doctor provide more help?
(5) What support do carers expect from their GPs?
(6) How often do you see your GP in a year/month?

Part IV  The health and well being of the carer

(1) Does the carer feel his/her health or well being has been affected by that caregiving experience?

(2) In what ways has the carer been affected by that caregiving role
   - Physical health, Emotional health
   - Ability to go out during the day/ evening
   - Ability to live an independent life
   - Employment - recreation and relaxation, holidays
PART I (2): EXPLORING THE ROLE & EXPERIENCES OF THE CARER

WHAT DO CARERS UNDERSTAND AS THE ROLE OF A CARER?

In the Focus Groups and interview, carers were encouraged to describe their informal caring role and how they felt about it. Also in the Carer Questionnaire, two questions further teased out the meaning of being a carer.

Q. 3.9: What are some positive and enjoyable aspects of your caring role for you?
Q.3.10: What does 'being a carer' mean to you?

Question 3.9 was included so as to achieve balanced responses from carers. More importantly it was done purposely to avoid too much emphasis on the hardships endured by participants. As the majority of these carers were still very active, it would have been inappropriate on the day of the focus group to dwell on the negative aspects of caring without recognition of the motivating factors and rewards carers derived from their role.¹

Five themes motivating the caring role

Five main themes motivating the caring role emerged from carer responses. These were of the notions of responsibility, protection, love, the relationship and maintaining the cared for person's comfort and quality of life. All these concepts of caregiving were interconnected and used interchangably by carers as reasons why they kept on caring. The dominant theme expressed by participants however was one of the carers feeling responsible for someone who could not look after his or herself. A carer summed it up by saying she felt overwhelmingly responsible for another person's life. [C-20].

"I just felt responsible for everything when he [husband] got sick ... I was the strong one then and that's how it's gone on and it's very tiring really". C-20 [fg2-comb] p.27. L.3

"When a person can't look after themselves you've got the responsibility of the whole 24 hours of the day, every day ..." C-6[fg1-comb] p.3. L.20.

"As far as I'm concerned it means looking after somebody and maintaining their independence as long as I can possibly can". C-12 [fg2-comb] p.16. L.30

¹ Since experiencing being a carer myself I am pleased I made this earlier decision to include positive aspects of caring. The negative side of caregiving becomes quite overwhelming at times and the longer the caring continues, and the person's condition deteriorates, the harder it gets to look on the bright side. Carers cling to the few positive philosophical beliefs and values that drive them to keep going. It does not take much to tip the delicate balance between hope and hopelessness.
"I count it as my wifely duty, from our marriage, you know, "in sickness and in health". ...I feel I'm responsible for him." C-14 [fg2-comb] p.26. L.30

"Being responsible for another person's health and well being, but to try and look after your own at the same time." C-17[fg2-comb] p.26. L.21.

In the questionnaire, carers were asked to give examples of their responsibilities. Their written answers are listed in the box below. This is only a glimpse of their 'job' or the 'duties' which continue and often intensify year after year. As one carer wrote, "After 2 years I feel so tired of it all." C-15

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**Carer Questionnaire: Q. 3.11 What are your responsibilities as the carer? [What the carer does]**

<table>
<thead>
<tr>
<th>Personal care [Tasks and Tending]</th>
</tr>
</thead>
<tbody>
<tr>
<td>A job where I felt overwhelmingly responsible for another person's life, I had to try to get the best help and advice available. I had to organise our finances, make all decisions. I tried to keep our friends by explaining quite openly what was happening to my husband (with dementia), welcoming their visits and trying to stay bright and happy with them. I wanted my husband to feel safe and much loved. Also to give him some quality of life. C-20</td>
</tr>
<tr>
<td>To do my job as a carer and see that the person I am caring for revives every attention C-10</td>
</tr>
<tr>
<td>Overseeing /Giving personal cleanliness C-8</td>
</tr>
<tr>
<td>Reminding about hair cuts C-8</td>
</tr>
<tr>
<td>I have the absolute responsibility for my son's life and well-being. Trying to find and co-ordinate help and services, his lifestyle, his behavioural problems, his medical problems and health - working hard to give him as much independence as possible - mostly with an angry lack of co-operation, I can't give up on him though, even though I have been advised to at various times. C-11</td>
</tr>
<tr>
<td>24 hour constant care C-19</td>
</tr>
<tr>
<td>To provide shelter, food, love, warmth, education, exercise, different experiences of life and living - spiritual, physical, artistic etc. C-23</td>
</tr>
<tr>
<td>Supervising the life of my Father in his basic needs of life</td>
</tr>
<tr>
<td>To make sure Mum lives comfortably in her own home surrounded by her own things and her memories C-16</td>
</tr>
<tr>
<td>To nurture self-esteem and confidence, to accept and love someone for what they are and help them along their way, offering as much independence as they can manage. C-23</td>
</tr>
<tr>
<td>Overall health care of the sick/disabled or frail dependent person</td>
</tr>
<tr>
<td>To make sure that your patient is always happy, comfortable and contented and that he/she has no wants. Medication should be given in correct quantities and at the right time to ensure the patients as free from pain as possible and getting all the aid and rest that is needed. C-21</td>
</tr>
<tr>
<td>Visits to specialists. Medication supervision; C-8</td>
</tr>
<tr>
<td>Check at nursing home to see medications are given as ordered by specialist's C-15</td>
</tr>
</tbody>
</table>

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Carer Questionnaire: Q. 3.11 [continued]

Domestic
To clean, shop, wash, handle accounts, be a cook etc - The bonus - I am my own boss C-18
Doing Laundry C-8

Everything, such as seeing bills are paid. All household chores, garden, C-15

To maintain my own health so that I can maintain a reasonable lifestyle for both of us C-17

Administrative / Coordination / Service needs
Checking on appointments C-8

Help my son to re-build his life using his present abilities; See that he (son) receives as much assistance from 'service providers' of all sorts as I can. C-9

24 hour, 7 day, 52 weeks each year. Manage our HACC (and other support) funds. Involvement on various Board and Committees to ensure that things get done properly. But am rapidly becoming disenchanted by the attitudes of people in the various bureaucracies that are responsible for providing services to daughter and myself. C-22

A carer’s sense of responsibility was often linked with the desire to protect a vulnerable / sick loved one (either disabled children or very ill adults) from an inferior quality of life, especially if at risk of being placed in formal residential care. Several carers made very similar comments on the importance of maintaining their loved one’s comfort and lifestyle.

"I just wanted to make my mother’s life safe and secure." C-19[fg2-comb] p.27. L.15
"Just to be here when my husband needs me and to make his life as comfortable as possible" C-8

"...because he was ill I wanted to look after him, make his life as comfortable as possible." C-20[fg2-comb] p.27. L.10

In her questionnaire this carer also wrote: "Of course if I hadn’t loved my husband I imagine it would have been different". C-20

"...it’s because you want to do the best for that person while you can, rather than have them go into a hostel or a nursing home where you know that life would be very different for them." C-11[fg2-comb] p.17. L.5-11

One carer described that her blind husband could not go into a hostel or a residential facility because he it was disoriented:

"My main object is that I can keep fit enough, long enough to look after my husband because he could not possibly cope on his own ....because being blind he needs help with his medication and some dressing and he cannot see whether his clothes are clean, or dirty ..."

"...he is so familiar with the area he’s living in and can find his way around, that’s he quite disoriented if we go anywhere else ...and that’s one reason why we want to stay in our own home and we will accept all the help that we can get." C-8[fg2-comb] p.16. L.4
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In almost all instances, the motivation for caregiving was for the carers to stay with the person they loved, and the overall driving ambition to care appeared to be a moral responsibility to keep the family member safe and happy in their own home. This involved supporting them and attending to their needs so as to make up that person's deficit to afford them the best kind and quality of life for as long as possible. In many cases, the carer felt he or she was the only one available to do it and had no choice.

"...as soon as the wife came out of hospital I realised there's only me." C-10[fg2-comb] p.15. L.14

"...I had a choice of either putting my mother in a nursing home or keeping her home, but I didn't have a choice in as much as I was the only one who could look after her, so I have a brother but he was not able to do it." C-19[fg2-comb] p.27. L.34

Description of the Caring Role

Respondents described carrying out their caring role as a battle and a self sacrifice involving personal loss of freedom, isolation with major impacts on social life, lifestyle as well as their own physical and mental health. It is particularly hard for the ageing carer as one described:

"I think one of the problems with the caring, it is the ageing process going on. I turned 78 last week and it's starting to slow down a bit.... What I mean is the caring chore does become hard and as the Parkinsons progresses so you're going the other way." C-3[fg1-comb] p.7. L.23-25

'Well it means that you've got somebody in your care that needs to be cared for, and I've got one that needs to be cared for and I want to keep caring for her, but it's a battle because you're battling to try to get some help'. C-10[fg2-comb] p.15. L.26-30

Over-riding these challenges was the genuine satisfaction of carers achieving their personal goal to keep the person home. This enabled them to retain their marital or familial relationships, with quite a few seeing it as their duty to a spouse or reciprocation to a parent as commented by a son below.

"Being able to give back to my father some of the love and care that he gave me as a child. To extend his enjoyment in life as long as I can." C-12

Parent carers

Similar attitudes and perceptions of the caring role for spouse respondents were found amongst the offspring carers of elderly parents in the study group. Spouse carers' attitudes and feelings contrasted however with the responsibility felt by the three parent carers of disabled children included in this study. For example one parent's comments about having to continually fight for her disabled child's right to live were very poignant.2 This problem

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2 One should bear in mind that this carer was referring to her earlier experiences when her son was very young, probably in the 1960s.
was raised by each of the parent carers which shows that those much earlier experiences continued to colour how they saw their caring role. Their priorities were to protect the child from the formal care system that threatened the disabled youngster with serious neglect - or worse.

"I think the thing that I find hard apart from all the care and being up through the night [is the] continual fight against society and doctors for [my child's] right to live.... I don't see why it's a continual question... even when you walk into a doctor's room, they just take one look and think well, you know, why is he here? ...that's the hard part." C-7[fg1-comb] p.4. L.18-24

The mother of the severely disabled girl told a similar story where she saw her role as protecting her daughter from neglect when in the formal care sector. Because of the profoundness of the disability her caring role involved total care. She described herself as her daughter's care manager which involved:

"All areas of activities of daily living, ... personal care, every single activity of any person, of a human being I have to assist [my daughter] with - she's unable to do anything for herself, ... [I am] organising her workers; organising her support scheme funding; organising her day activities; purchasing her clothing, all of her health requirements, doctor's appointments" and in addition... "Giving medication, [dealing with] bowel movement, everything - ... absolutely." C-22 [Int.] p.3 L.24

This is certainly not the routine of a mother of healthy child in society and serves as a good example to differentiate between the meaning of the 'caring' role of an informal caregiver, from that of the nurture type of caring involved in every day family life activities. The description above perhaps portrays an extreme case, but many carers of both sick adults and severely disabled children are providing hands-on personal care to a family member in the home which can be intensive and total.

There are other levels of informal caring of course, which require more emotional support and supervision for those individuals with mental illness, dementia, or intellectual disability. Sometimes persons are born with an intellectual disability, other times the deficit is as a result of brain injury. One mother described her caring role as her son moved through childhood, as "enabling my son to regain some of his life skills". She saw her role as carer was to be there "as a sort of protector", qualifying this by saying, "well it was a protector at first, but now it's as a companion and someone there to give him supervision and prompting." This carer therefore has seen some progress in her disabled son's condition, but despite him developing some limited independence, her responsibility for his well being remains. C-9 [fg2-comb] p.16. L.33-36 The carer made the point later during a focus group that an intellectually disabled child often needs even more time and effort from the parent carer than a physically disabled child.
Chapter 10: Exploring The Role & Experiences Of The Carer

Despite these demands on carers for whatever the level of care they are giving, they felt their role was often not recognised by many trained personnel in the health profession. As one carer commented,

"I've been surprised at the fact that the people you expect to understand [the caring role] is the medical profession...because they are supposed to know, they are the ones that show the least understanding, ... I can cope with Mrs J down the street or whatever because you can say, well that is ignorant, but if it's a doctor or a nurse or somebody who is in a position of authority, that's when it never ceases to amaze me."  C-7[fg1-comb] p.6. L.17-22

The Caring Context / Situation of the Caring Role: Tasks and Tending

In Focus Groups and interview, carers were encouraged to describe their caring role and daily responsibilities. In the Questionnaire they were asked: "What are your responsibilities as the carer?". In other words, what does the caring role involve and what do carers actually do in terms of caring tasks and tending the cared for person? [Refer to Appendix for Carer Questionnaire in full which lists the main personal care activities undertaken with additional tasks indicated below by the respondents].

The bulk of activities involve personal care that is in essence 'tending' to a person similar to a nursing /care worker role. For example hands-on physical and health care involved dressing/undressing the dependent person, co-ordinating or giving medications and treatments, helping with mobility, bathing, showering and toileting. Separate comments from carers in the questionnaire described additional tasks which included "providing nursing care during and after [epileptic] seizures" [C-11], while another carer wrote 'absolutely every aid to daily living [C-22]. Several carers were responsible for supporting persons who could not sit unaided, could not stand, walk, talk, write or think independently. In addition to physical tending of their personal needs at home, the carer needed to provide emotional support, twenty four hour supervision and prompting actions or conversation if necessary. For some carers this can feel very demanding.

"Supporting them emotionally. That's probably one of the hardest parts that is really difficult."
C-X[fg1-comb] p.4. L.2-3

"I find it very hard to keep him amused all day long when he's not at the Day Care centre ..."
C-6 [fg1-comb] p.7. L.15-21

Co-ordinating, accompanying and transporting the sick or disabled person to medical and other appointments as well as arranging additional home based services are all part of the role. All the personal tending described above is in addition to the domestic chores and tasks that are involved with maintaining a family home [such as the cooking], cleaning and

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3 The importance of cooking for a sick or disabled person is often glossed over, and the skills and effort to provide special foods underestimated. Cooking is an issue that has not been explored in the
shopping], as well as a garden, and associated equipment and vehicles. As these carers sum it up:

"A carer is someone who gives 24 hour care to somebody either family or friend and that includes everything... Cooking, washing, ironing, cleaning, feeding, medication, entertainment, bathing, dressing..." All those things...C-11[fg2-comb] p.17. L.5-11

"Well the main thing I think is going to the toilet. [ie toileting the cared for person] You have got to look after them in that respect, bathe them, dress them, shave them do their hair, practically everything, help them with their food...you're there 24 hours...you don’t let them go on their own." C-6 [fg1-comb] p.3. L.28-31

"It's bloody tiring...it's frustrating, it's isolating, it's...inadequately supported by all levels of government - local, state, federal." C-22 Int. p.2 L.41-42

Changes experienced by carer in the caring role - an overview

Sifting through the responses of this small number of carers about what caring involves highlighted a few additional issues for consideration. For example several carers mentioned how they had to cope with changes inherent to role reversal and attitude reversal. As well as having to give personal hands-on care, the spouse usually has to take over other domestic, financial or maintenance tasks previously managed by the other partner. One gentleman laughingly referred to his new role as that of the housewife-maid. More significantly though he found that it restricted his lifestyle.

"I guess the day in the life of a carer starts when you get out of bed in the morning until when you go to bed at night. ...You are a housewife or maid... It does restrict you.... you see your mates going off to play bowls or golf or these sort of things." C-3[fg1-comb] p.4. L.7-14

A female carer’s response to the experience of role reversal and the surprises it brings with it was quite different, more in terms of the impact it might have in her health.

"The reversal of roles is one of the challenges but also I think as carers we have to take into consideration our own physical, mental and emotional position because once that deteriorates we then become inadequate carers." C-4[fg1-comb] p.5. L.17-20

Another participant, a wife caring for her husband, reinforced the challenges of a caring relationship when there is an attitude reversal of one partner to the other due to the illness.

"I think the surprise I had, but it’s only because of the illness... is the reversal of his attitude towards me .... the constant thing is... [her husband was saying to her] ‘you aren’t the girl I married ’... You sometimes get very angry and say, ‘what have I done that you hate me so much?’ Really in my case it's a complete turn around....to be honest..." C-Z[fg1-comb] p.6. L.11

thesis, but has implications for carer support in the future. It will be referred to again in the discussion chapter and recommendations.

4 This comment was made in 1995 which predates most of the current government carer respite initiatives, Care Link and a general expansion of HACC services introduced during the late 1990s and year 2000. It would be most interesting to ascertain if these programs have significantly changed carers perception and access to government support.
Several carers indicated they understood that these changes can be very difficult to deal with, especially if the attitude reversal is due to dementia or mental illness, and when caring is thrust upon them without warning. The carer needs additional knowledge and some form of training on how to manage. It helps make their responsibility more effective. For example:

"...I've just recently completed a course with the Alzheimers Association on the carers' education training course. ... I think is essential is the carers is to be informed somewhere, somehow as to what is available..." C-4{fg1-comb} p.7 L.28-36

"One of the important things that I have learnt is to appreciate what is available and to know ...what is out in the community by way of respite and support which is essential if the carer is going to maintain a sense of balance. It makes the responsibility effective. That is the part that you learn. There is so much out there, so few people realise" C-4{fg1-comb} p.7 L.28-36

"It [caring] just came out of the blue...I had a nursing background so for me...what would have been trauma maybe for someone else hasn't been for me in that respect. [C-6{fg1-comb} p.6 L.1-3] ...I know how to shower and how to watch the safety angle and how he is medically and reactions to tablets - so that has helped. " C-6{fg1-comb} p.6 L.8

Part 1 (3): CHOICE OF BECOMING A CARER

The third question in Part One of the Discussion Schedule explores whether the carer felt they had a choice in taking on the caring role. It was asked of carers at the Focus Groups and was also included in the Questionnaire to ascertain the proportion of carers who made a conscious decision to care or whether the role had been imposed on them by circumstances or people around them at the time. As to why they chose to become a carer is only touched on since this opens up many complex ethical, philosophical, psychological and social avenues for discussion which would require a separate and different research project. I felt it important however within the context of my own study to avoid making any assumptions as to the reasons for carers taking on the role and motivation for caring. To that end I present an overview of the carer comments, keeping in mind how a caring relationship evolves and the conceptual framework\(^5\) of caring I developed for this research - described in Section One.

The moral imperative

Of the eighteen respondents to Q.1.11 in the Questionnaire, three quarters [13 people] indicated they felt they did not have a choice. Less than a quarter of the carers [4 of the 18] stated they did have a choice. One type of response, already touched on in the

\(^5\) Elements of my conceptual framework include Relationship, Responsibility, Moral decision making, Tasks/Tending, Accountability, Consequences and Recovery
previous chapter illustrates the ambiguity of some situations for parent carers but moreso highlights the difficult moral decisions faced by family members. These parent carers recall their experiences from many years ago.

"Yes I had a choice of leaving my daughter in ....formal care. No, I couldn't morally leave her there because ....the organisation failed in their care to support her in a way that kept her well, safe and out of danger!!" C-22

During interview, the mother again mentioned this situation adding, "...I believe she would have died had she been left at that house." C-22 Int. p.4 L.43.

A second carer with a similar dilemma over a disabled son felt just as definite.

"... I was given a choice with ...[my son] but the alternative was that he was going to be kept in the ... hospital and starved to death. So that to me it was no choice. I took him home and got on with it..." C-7[fg1-comb] p.10. L.7-

Other carers who were, adult daughters, also decided in the end there was no acceptable alternative for the carer of a sick or frail aged parent and therefore they felt they had no choice at all:

"The choice would be for mother to be in a nursing home and there is no other option... " C-18 [fg2-comb] p.27. L.30

For other carers it is perceived as their duty as spouse, offspring or other relative, responding to being needed, wanted by another person. Therefore the challenge of having to make a decision of whether to care for a loved one at home can be more straightforward. For some carers there is never any doubt, it is automatic, the right thing to do, a natural thing to do, especially within loving marital or familial relationships.

"No choice, just automatic." C-8 [fg2-comb] p.17. L.29

"I think the choice that most people take ..., is an automatic choice. The only way you'll find a carer is somebody who is going to look after them and not going to take the decision to put them straight into a home." C-12[fg2-comb] p.17. L.34

Another daughter carer also saw it in simple terms:

I ... lived with mum ... ever since since my marriage broke up so I just naturally thought that was the way to go. Also my brothers' and sisters' lives don't correspond with that sort of thing. They probably would want to put her in a nursing home, but I like to see her home and happy. " C-16[fg2-comb] p.28. L.9

Choosing to become a carer of a sick, frail or disabled relative is not necessarily a one-off situation however, especially for married women who can have multiple caring roles at the same time. People may also take on a caring role for a second (or even third) time around

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6 These experiences were probably 25-30 years ago...
for different members of the family. This was mentioned by one carer commenting in the second focus group. She describes two different situations in her life.

I didn’t have any choice about looking after my husband, that was just wifely duties, but with my mother I had a choice... I felt that was the right thing to do, to help her as much as possible, and she didn’t want to go into a home, so that’s why I’m doing that. C-11[fg2-comb] p.17. L.22-25.

Another carer of her husband was told to find a nursing home, but vigorously resisted this pressure to be separated from her spouse.

...the doctors' at the hospital told me to find a nice nursing home for him, but I just couldn’t do that, it’s been very difficult, but I couldn’t do it without help with the nurse coming in and that. I struggle along and I’ve got him home and that makes both of us happy, to be together,...”
C-14[fg2-comb] p.28. L.12-15

One older male married carer gave a more pragmatic response, focusing on his long time relationship with his wife.

"After 50 years of marriage, ...one could hardly back out of the responsibility ... in a sense because of the relationship that has been developed over those years ...” C-4[fg1-comb] p.8. L.33-35

Several other spouse carers, both male and female, said they didn’t even want a choice.

"I didn't want a choice because I wanted to look after her." [C-10] and,
"I didn't even consider, I just did it..." C-9[fg2-comb] p.18 L.7

Again a reasonably common comment from older female carers was:

"...it’s just something I’ve grown into. We’ve been married fifty five years, and it’s been something I’ve just take for granted. " C-8[fg2-comb] p.16. L.4

Of those who felt they had no choice to carers how they feel about not having a choice], the majority were accepting of the caring role, but for some the going got very tough and community or support services didn’t measure up [C-7]. [Refer Carer Questionnaire Q 1.11 in Appendix].

"It was a stifling feeling I felt I would not and could not cope, but I knew it was my duty to at least try.” C-21
"I wanted to care for him, but knew I would need help." C-20

WHEN DID THEY REALISE THEY WERE 'A CARER'? 

Lastly, one of the questions asked at what stage of taking on the caregiving role did each person realise they were 'the carer'? As can be seen in the responses on the next page, this realisation came at all stages of the caring cycle. [Refer Q. 1.12 in the box on the next page.]
Chapter 10: Exploring The Role & Experiences Of The Carer

Carer Questionnaire: Q. 1.12
At what stage of taking on a caregiving role did you realise you were "the carer"?

About 3 years ago. C-8
Whilst my son was still in hospital. C-9
At the start. C-10
When my son was 8 months old and I found he had brain damage-then became a severe epileptic at 2 1/2 [years old], C-11
From when my daughter became of school age (1970) and there were no options for her. C-22
When my son was 15 years old. C-23
When he came home after being in hospital 3 months. C-14
Early stage when I knew my husband had multi infarct dementia. C-15
About 12 months ago when the 'Year of the Family' placed slight emphasis on that role. C-16
2 1/2 years ago when I received a carer's pension. C-17
Since mother lost her ability to perform simple tasks (the last six years). C-18
15 years ago when I cared for my late husband. C-19
Possibly at the stage when after a month of trying unsuccessfully to find a nursing home which would accept my wife as a fulltime patient. All had waiting lists. C-21

Part I (4): HOW DO CARERS FEEL ABOUT BEING THE CARER?

Completing this first part of the Discussion Schedule is the question, How do carers feel about being the carer? overlaps a little with the previous questions on the caring role, and choice. This question drew some surprising responses, again illustrating some differences between the parent carers of their disabled children, and the experiences of carer participants looking after older persons. I first focus on the negative responses of the carers, and end the chapter with a description of some positive feelings expressed in the focus groups and questionnaire.

Parent carers
Some strong negative feelings of two of the parent carers again emerged during focus groups and interview. Although what is said can only be seen in the context of these persons unique circumstances, their comments highlight the emotional demands of parent and other carers in similar situations. The feeling of being taken for granted is certainly not restricted to parent carers but is obviously more intense for them. One parent also said she felt personally devalued, even abused (by successive governments) and constantly under pressure as a parent to care ad infinitum. The attitude and expectations imposed on this carer was that, "She's your child - that's what you should expect." 7. She felt that she was-

7 C-22 Int. p.6 L.29-32
"Taken for granted. By everyone, you know, the whole of society. People will say "Oh well but she's your child." [C-22 Int. p.6 L.20] My answer is, 'Excuse me, I didn't go into hospital and say I'll have one of those children over there with a disability'. And I didn't say that I would do it until she was 30 or 40 or 60 or 70 like some of them out there are doing it." C-22 Int. p.6 L. 29-32

This comment uncovers the overwhelming feelings of burden these parents carry as they face a lifetime ahead as carer of a disabled child who will remain disabled into adulthood. It also highlights the underlying anger associated with many carers not being able to trust other people to provide alternative care for the child. As the carer explains:

"...the fallacy is that people choose to support their children at home until they die and the reality is that people can't trust other people to do the job. So they will support their children but they don't really CHOOSE to do it, they don't have a choice." C-22 Int. p.6 L.36-39

When questioned further as to why the carer felt devalued, it was clear that a lack of recognition of the special needs of the parents of disabled children resulted in a lowering of their self esteem. It gave them no self respect to be in this role or position - something that contrasts with the attitude of older carers of spouses who often express a pride in their caring 'work'. The point of contention for one parent carer seems to be they are working hard caring twenty four hours a day providing intensive support for children (who remain fully dependent and child-like into adulthood) which is different to what is expected of parents of normal and usually healthy children. Where the child's disability is profound, parents are denied seeing this happen, as is the case for the caregivers of sick or frail adult persons who will not see them improve. Rather it is until an imminent death. All they can concentrate on is maintaining the quality of that life while both parties are alive.

Although receiving government benefits, they remain poor and feel on the same level as those on the dole or pensions.

"...puts us in the same place as the people on the dole, people on sickness benefits, aged care pensioners, and we are working 24 hours a day for the same amount of benefit. And it's that lack of recognition financially - you know they can stand up and say what a good person we are - we know that, we know we're good, but we know we're poor". C-22 Int.p.6 L.46-51

Compounding these negative feelings for some parent carers is the reaction they get from members of the public, making them feel that they are should not be taking government handouts.

"I find that a lot of people when you turn around and say, you're a carer. "Um, what's that?"... I mean when you tell them, some come across with the attitude that you're only bludging on the social system. C-12 [fg2-comb] p.24. L.32
The surprising aspect of the responses, from parent carers in particular, is that despite the provision of funding to carers in this country, making support services available to them has not proved to be the salve to their distress as one might expect. For example the carer explains how she felt resentful at the way she was always left with the less enjoyable aspects of caring for her son.8

"...I had resentment for caring for ... [my son] but the resentment ...was the fact that we get help through ... Services, but ... Services only wanted to do the good part. I get left to do the crappy part and I want some of the fun times ...because he is an enjoyable scallywag..." C-7[fg1-comb] p.11. L.14-

This pressure all takes its toll on the carer, resulting in another instance, with the mother rejecting help and going it alone in a vulnerable state. This occurred in the early 1990s.

"...Last year because of everything that he had built up, I got so that I never wanted to speak to another person who would ask me a question, I didn’t want to have any new person coming into the house... I just pulled up the draw-bridge and shut myself in. I felt, no, I don’t want anything, I’d rather manage on my own just for a bit. Because I just felt that I was so vulnerable to everything. It’s passing now, so. C-9[fg2-comb] p.23. L.23-28

Again it is unlikely that these responses were only felt by parent carers at the time, as there are many parallels with what was said by carers in general in my study. The parents though, seem to have been more affected emotionally by their experiences. We are also discussing of course, a younger age group of carers who feel the restrictions and unfairness inherent in the caring role much more acutely than many older carers in this study. There is a greater sense of acceptance amongst older or married carers as the next comment attests. Perhaps in some instances there is an associated aspect of grieving that accompanies and mollifies the care of older spouses.

"You accept it as you wouldn’t have [it] another way but you accept it and you keep on the positives... I went through a period where... I kept sort of looking back on what it was like as a couple and you’ve got to stop that. You can’t do that, but I think that’s just a part of the grieving process of what’s happening." C-X[fg1-comb] p.11. L.7-12

Nevertheless, the stories told by carers involved in demanding hands-on personal care showed they felt they were being punished in some strange way as evident in the next comment. It may have been said in jest, but the sentiment remains.

"I sometimes get fed up when I get wet beds, wet clothes ...I said, to mutual friend of mine...“ I must have been a lavatory attendant in the past life”... something you did before you are caring and you are working off a bit of your kama and next time you will do that much better... Why and I doing this? I’m doing good ... I must have done something rotten before..ha ha, and next time it will be that much better..." C-7[fg1-comb] p.11. L.20-27

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8 This was probably 2 decades ago and may not reflect current circumstances.
Chapter 10: Exploring The Role & Experiences Of The Carer

Four recurring themes:
Isolation, Loss of Friends, Loss of Freedom, Lack of Understanding

Four important themes emerged as carers expressed their feelings. That of isolation associated with loss of their friends and the lack of understanding shown to them by family members, friends and professionals. These feelings were tinged with fear of an unknown future, dealing on their own with medical emergencies, and feelings of sadness and loss not only for the demise of a loved one but also for the life they themselves can no longer live - because of their commitment to caring for a sick, demented, even suicidal person at home who needs constant supervision.

"I think the hard thing about being a carer is when the person you are caring for isn’t very happy and doesn’t want to live. That’s my situation." C-17 [fg2-comb] p.29. L.5

"The hardest part is when the person you care for will never be better again... decline." C-18 [fg2-comb] p.29. L.8

The aspect of loss of personal freedom and self sacrifice is crucially important to appreciate as we are considering persons who first and foremost are restricted by someone else’s illness, disability or frailty - not initially by their own. If they were not in the caring role, most would be living quite different lifestyles - they certainly crave more outgoing and spontaneous options.

"I do find that you do become slightly isolated. Your previous friends, don’t really forget you, but they don’t remember you quite as often as they used to.... we’ve always been very sociable people, and very active outgoing people, that I think I miss a little bit of the social life. ...C-8[fg2-comb] p.24. L.23-28

Carers cannot live their own lives

In other words, carers do not live their own lives - they are tied to another individual 24 hours a day - often feeling they are working a ‘36 hour day’ with no relief in sight. Several commented how they felt they worked even harder than paid care workers and felt that they provided better care for their loved ones at home than given in formal care.

"I think that’s what caring is to me and I feel like I am a carer, because the girls in the nursing home, they’re carers, and I feel like I do more than they do in the nursing home for him." C-15 [fg2-comb] p.28. L.33-35

One carer summed up caring describing it as a 'different world' where they cannot join in with the usual activities of their friends, and hence lose them because they are constantly refusing invitations; they cannot join the paid workforce and mix with their work mates; they cannot take holidays. Many cannot even go out socially, day or night (without a great deal of effort to arrange respite for the cared for person). Carers find other people simply
do not understand their predicament or experiences, nor their feelings, except other carers of course.

"I think actually you get used to those sort of comments from people who don’t know and aren’t in this world..." C-17 [fg2-comb] p.30. L.24

For those carers who do join support groups and reach out to others they appreciate their new friendships.

"I guess the only positive thing, as far as I’m concerned is ... like meeting the various groups that are supporting our problems because we’re in a different world now." C-17 [fg2-comb] p.29. L.29

"I’ve made some wonderful friends through the groups I go to and I tried to help other people because you understand what you’re going through...you can talk to them." C-15 [fg2-comb] p.29 L.33 and p.30. L.3


**The Positives of Caring**

This last part of the chapter features the positives of caring which according to the carers, are often simple things which help to offset the hard times and keep them going.

"...I find that there’s a lot of good things...you’ve come to the end of your tether and you get a smile and you think it’s all worthwhile, it’s all worth it." C-19 [fg2-comb] p.29. L.22

The most enduring comments by carers from this study emphasised the importance of a sense of humour to keep going and the inner strength they find to keep caring, sometimes against ... odds.

"It is important we retain a sense of humour if you lose that you’ve lost the battle. " C-4 [fg1-comb] p.11. L.20-27

"... it makes you stronger looking after somebody. I think it does. You seem to get an inner strength." C-15 [fg2-comb] p.30. L.7

The most common comment is the feeling of satisfaction they are doing a good job.

"...we’ve been married for fifty five years in November..... and we’ve been together since school days. Well, caring for D..... although it’s hard work- its exhausting, because you’ve got to do everything and you’re tired out every day. ... You do it and you get a lot of satisfaction out of it, because you think you’re doing a good job. C-10 [fg2-comb] p.23. L.6

Again there are noticeable differences between the parent carers whose efforts are often directed towards helping the young person develop life skills so as to live as independent a life as possible.

"...I get a lot of satisfaction and perhaps again because my son is a young man. I hoping he’ll go out into a world on his own. All these little successes when he has learned a new skill, we are all excited about it and we know that’s another thing done, now we’ll start something else. Yes, I get a lot of satisfaction." C-9 [fg2-comb] p.23. L.18-28

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The final data presented in Part I of the role and experiences of carers come from the responses to question 3.9 in the carer questionnaire which focuses on the positive and enjoyable aspects of caring. [Refer Box below and on the next page]. The responses were remarkably consistent, fitting under four main headings relating to the satisfaction that comes from providing a better quality of life for the dependent person, the knowledge that the carer is doing their best for that person, the love that sustains their efforts within the caring relationship and some personal growth benefits for the carers as individuals in their own right. These are all very powerful motivating forces indeed.

### Carer Questionnaire: Q. 3.9 Carer Responses

**What are some POSITIVE and enjoyable aspects of your caring role for you?**

<table>
<thead>
<tr>
<th>Better QOL for dependent person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Just to be here when my husband needs me and to make his life as comfortable as possible C-8</td>
</tr>
<tr>
<td>Shared achievements - goals realised; Shared enjoyment - knowing that I am good at my job; Working together to create a 'good life' for both of us. C-9</td>
</tr>
<tr>
<td>I am caring for someone I love and do not wish to be separated from C-10</td>
</tr>
<tr>
<td>My son is fairly unrewarding, being non-appreciative mostly. However thanks to my personal commitment to his care he has exceeded all expectations of his specialist, and has a good quality of life. It is important to me to be able to feel I've done the best I can for him, even though his is considered very difficult. C-11</td>
</tr>
<tr>
<td>Have made new and interesting friends C-17</td>
</tr>
<tr>
<td>I am giving my mother home life in a family (instead of an Institution) for as long as I can manage to do this C-19</td>
</tr>
<tr>
<td>I felt at peace within myself having him at home C-20</td>
</tr>
<tr>
<td>My daughter is safe and well and wakes up in her own room each day. That I am in total control of her support and people do things the way that I know is best for her. C-22</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Love</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being able to give back to my father some of the love and care that he gave me as a child. To extend his enjoyment in life as long as I can. C-12</td>
</tr>
<tr>
<td>I love my mother and I do not want her to end up in a nursing home</td>
</tr>
<tr>
<td>I love my son, we get on really well. Through him I have gained much insight into myself I have been led to some wonderful people and experiences and have learnt to really know human worth. Also ignorance and fear. It's nice to reassure people C-23</td>
</tr>
</tbody>
</table>

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Carer Questionnaire: Q. 3.9 Carer Responses [continued]

Doing my best

It's important to me to be able to feel I've done the best I can for him, even though he is considered very difficult. C-11

My desire to help my wife seemed to grow stronger as I progressed with my caring. I devoted all to help her. Now that my total caring is our home is finished, I look back with pride and happiness on what I did to help my wife. I feel I could not have done more for her. C-21

Benefits for self

The people I have met at the various courses I have done; The wonderful friends I have met and knowing I am a much stronger person now than I was when I was not a carer; The courses I have done with carers club have given me the extra strength to carry on C-15

Have learnt new skills. C-17

Have become more positive person C-17

Have learnt to enjoy whatever activity or outing I participate in C-17

Am more patient and understanding with people in a similar situation C-17

Being able to handle new situations and having time to enjoy my house, pet dog and garden C-18
FOCUS GROUP DISCUSSION SCHEDULE & INTERVIEW GUIDE FOR CARERS

**Part I** Exploring the role and experiences of the carer

1. How long the carer has been a caregiver?  
   What is the illness/disability of person they are caring for?

2. What do you understand as the ROLE of a carer? - describe role

3. Did you feel you had (or wanted) a CHOICE in becoming a carer?

4. How do you feel about being the carer?

**Part II** Needs of the carer

1. What are your needs as a carer?

2. Where do you go for help with these needs?
   * Your very own personal needs
   * Need for assistance with the dependent person,
     Information needs / community resources
     Practical assistance in the home
   * Other needs?

**Part III** Carers and their GPs

1. Do you think your local doctor sees you as the carer?

2. Has your role and needs been discussed with your local doctor

3. What support has been given by your GP? - how has it helped you

4. How could your local doctor provide more help?

5. What support do carers expect from their GPs?

6. How often do you see your GP in a year/month?

**Part IV** The health and well being of the carer

1. Does the carer feel his/her health or well being has been affected by that caregiving experience?

2. In what ways has the carer been affected by that caregiving role
   - Physical health, Emotional health
   - Ability to go out during the day / evening
   - Ability to live an independent life
   - Employment - recreation and relaxation, holidays
CHAPTER 11
PART 2. CARERS' NEEDS

Carer Perspectives of their needs
Exploring carer needs with Focus Groups and through Carer Questionnaires generated a great deal of comment from carers. Wherever possible I have tried to reduce that data, incorporating it into visual representations using lists and diagrams which are based on established models of carer need. With so many quotes from carers, I have condensed them and included others in the Appendix.

At the time of preparing for this research project in 1994, very little groundwork had been carried out in Australia to delineate carer needs in general practice. Most academic and organisational research activity at that time was directed at community and consumer needs, neither of which provided an adequate template for my study. After extensive searching for an appropriate model for examining carer needs, the only suitable framework I was able to find to use in my research was from the publication: "Carers' Needs. A 10 point Plan" prepared by the Carers Unit of the Kings Fund Centre in London UK. I had found this during a previous study trip to Britain in 1993. For part of the analytical framework for my initial data collection, and when designing my carer questionnaire I used 8 of the 10 statements of the Kings Fund 10 Point Plan listed overleaf.

Although the 10 Point Plan made some references to the personal needs of carers as individuals in their own right, it was not as the focus of the Kings Fund plan which was clearly focused on service provision to carers. Thus for my research the framework was incomplete. My study extended to the health needs of carers specifically to their needs in the context of general practice, so I incorporated my own relevant questions throughout the

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1 I used the carer 10 point plan from Kings Fund Centre and Maslows hierarchy of human needs
2 In relation to carers, there were a number minor surveys conducted through the relatively new South Australian carer association in the early 1990s, a publication on Counselling Carers through the Noarlunga City Council [The Carers Counselling Kit] and a limited selection of reports from the carers' national body, the Carers Association in Australia.
3 Two points from the Kings Fund List not used were on carers being involved in income and employment to cover caring costs, and on service design and policy planning through consultation with carers. I did not include them in my own study at the time as is would have extended the questionnaire too far beyond health needs and made it too long.
4 Additional publications discussing carer needs were available at the time through the National Carers Association of Britain which provided me with useful information when preparing my own carer Questionnaire and Discussion Schedule for the Focus Groups for this study.
carer questionnaire and Discussion Schedules. Statements chosen from the 10 Point Plan and used for my research are listed in the box below:

<table>
<thead>
<tr>
<th>Statement 4.1: Recognition</th>
<th>I would like recognition of my contribution as a carer and recognition of my own needs as an individual in my own right.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statement 4.2: Services-Suitable to Me</td>
<td>I would like services tailored to my individual circumstances, needs and views, through discussions at the time help is being planned.</td>
</tr>
<tr>
<td>Statement 4.3: Sensitive Services</td>
<td>I would like services which reflect an awareness of differing family, racial, cultural and religious backgrounds/values.</td>
</tr>
<tr>
<td>Statement 4.4: A Break</td>
<td>I need opportunities for a break, both for short spells (e.g. during day or night) and for longer periods (a week or more), to relax and have time to myself.</td>
</tr>
<tr>
<td>Statement 4.5: Alternatives to Family Care at Home</td>
<td>I would like to explore alternatives to family care, both for the immediate and long term-future.</td>
</tr>
<tr>
<td>Statement 4.6: More Practical Help</td>
<td>I need more practical help to lighten the tasks of caring, e.g. domestic help, home adaptations, incontinence services and help with transport.</td>
</tr>
<tr>
<td>Statement 4.7: Someone to Talk To</td>
<td>I need someone to talk to about my emotional needs, at the start of caring, during and after my caring task is over.</td>
</tr>
<tr>
<td>Statement 4.8: Information</td>
<td>I need information about available benefits and services for carers as well as how to cope with the condition of the person I care for.</td>
</tr>
</tbody>
</table>

See Appendix: Carer Questionnaire results for all carer responses under each Statement of need.

A holistic approach to carer needs
Carers' needs were different for each individual because of the culture of the family and the caring relationship involved. They were also time bound and dependent on the caring situation, the cared for person's illness/condition, the home environment and geographical location and other relationship(s). The issues are many and complex. Therefore carers participating in the focus groups of my own study were encouraged to talk broadly about their needs.

To avoid any prompting, statements from the Kings Fund list were purposely not mentioned during the focus groups, while for the carer questionnaire, the statements were placed at the end of the document and carers invited to consider them and add additional
comments of their own. After completion of my data collection and its conversion into progressive data sets for analysis, I looked for an additional analytical framework within which I could structure all elements of carer needs and critically examine their comments according to their role needs and needs as an individual in their own right.

What the carer responses revealed from an initial thematic analysis of the data from both focus groups and questionnaires, was that their needs adapted very neatly to Maslow's hierarchy of human needs. I subsequently conducted a further analysis of my data on carer needs within a slightly modified Maslow framework. My final diagramatic interpretation of carer needs is presented in Figure over. I shall be referring to it as "the A.B.C. Model of carer needs". I emphasise that this should not be seen as a comprehensive list of carer needs. It is my visual representation (data display) of the main issues raised by the twenty two carers in this own study.

Describing the A.B.C. Model of Carer Needs
I arranged carer needs from my qualitative data into two main categories for my diagram.

• ROLE NEEDS: Needs relating to the carer's role [home help and respite services, and information for the physical and/or emotional work of providing support for dependent persons]

• PERSONAL NEEDS Needs relating to carers as individuals in their own right. This includes the health of the carer [psycho-social and clinical needs] which I also adapted to Maslow's triangle.

5 Maslow's hierarchy of human needs, proposed in 1970, is an enduring theory of self-actualization in well functioning people. He proposed that human desires exist in an ascending hierarchy, each level of needs having to be met before a person can achieve his or her full potential. It is a reasonable assumption that most carers start out as well functioning people - otherwise they would not cope as carers in the first place. As I examined what the carers said about their needs in comparison to their lifestyle 'losses', restrictions and sacrifices, it was clear that with the caring experiences, carers were losing aspects of their personal life at each level of the Maslow triangle. Significantly, they appeared to give up their personal interests and life plans, lost control over their lives, lost their network of friends and work acquaintances, lost their self confidence and were financially disadvantaged. Some felt they were losing order and security in their lives, and at home. In parallel to this, carers were deprived of sleep, lacked rest and their own health needs were often not met. With this downward cascade of losses, it was very hard for carers to achieve successive gains at each of the Maslow levels. Once deprived of so many of their basic human needs, whilst tied to the caring role, carers' social, emotional and physical functioning is reduced (as also shown by the SF-36 survey results in this study). Carers then had difficulty regaining their health, friends, self esteem and particularly opportunities for individual creativity - in that order.
CARER'S NEEDS

ROLE Needs of Carer's
[A] GENERAL needs of caring role
[B] SERVICE needs of caring role

INDIVIDUAL Needs of Carer
[C] INDIVIDUAL Needs of Carer in own right

A GENERAL needs of carer ROLE

"I need as the carer" -

RECOGNITION / REASSURANCE of my role as carer and to be told that I am doing it well

MORAL SUPPORT & UNDERSTANDING
about my role by family and carer aware doctors [GP]

EXPLANATIONS / REASONS for changes in the condition of the cared for person. What to expect.

ACCESS TO INFORMATION ON RESOURCES / BENEFITS, when I need it!
- from Health Providers, GPs, Support Groups etc.

SOMEONE TO TALK TO

EDUCATION & TRAINING
for the caring role

ALTERNATIVES TO CARING AT HOME

RELIEF FROM MY RESPONSIBILITY

CHOICE TO STOP BEING THE CARER

C CARER'S CREATIVITY NEEDS

Aesthetic Needs:
I need to listen to music
I need to paint, play the organ
I need to study / take hobbies
I need to walk along beach at sunset

Self Actualization
I need to pursue retirement plans
I need to use own ability

B SERVICE needs of carer ROLE

"I need as the carer" -

SERVICES that are Personalised, Co-ordinated and Flexible (Options, choice, alternatives)

INFORMATION AND REFERRAL - ON TO SUPPORT SERVICES

PRACTICAL HELP IN THE HOME
Personal care of the sick/frail or disabled child/adult, Sitter Service, Domestic and Home Maintenance

Someone to take an interest in the dependent person - a "buddy"

SAFETY NET for my caring role / responsibilities if I am ill, injured.

REHABILITATION services for the dependent person - Ongoing

RESPITE CARE/SERVICES
EMERGENCY SHORT TERM
LONG TERM

FINANCIAL SUPPORT
Allowances
Pension Benefits [Ongoing]

SOCIAL NEEDS

I need friendships
I need reassurance and moral support
I need the support of the family
I need to be valued by others
I need someone to talk to - general conversation [unrelated to being a carer]
I need Rest and Relaxation, Recreation and holidays (fun) to do my own thing

SAFETY NEEDS

I need a safe and secure environment suitable to care for a sick or disabled person
I need financial support to maintain the safety needs for myself and the person I am caring for

PHYSIOLOGICAL (HEALTH & CLINICAL) NEEDS

I need adequate rest, sleep and a break
I need someone to look after my health especially when I am sick and vulnerable
My health and physical needs may also be compromised by poverty

[C] INDIVIDUAL Needs of The Carer

[Needs in the triangle identified from qualitative data - Adapted to Maslow's hierarchy of human needs]
Carers' Personal / Individual Needs

The first group of needs identified include those which relate specifically to caring ROLE, which I have separated into [A] general and [B] service needs to support that caring responsibilities. In the diagram I have listed these outside Maslow's triangle. [A] General needs relating to the caring role are listed and arranged on the left hand side. [B] Service needs are listed and arranged on the right hand side of the triangle.

The second main category of carer needs identified from my research lie inside the triangle, representing PERSONAL needs of carers as individuals in their own right. Carer participant responses about their personal needs are grouped within the five levels of the triangle, in keeping with those featured in Maslow's triangle of human needs. Starting from the base and working upwards, I have labelled each successive level of need in the triangle as: Physiological and therefore health and clinical needs; Security and safety needs; Social needs; Self-esteem; and finally at the apex, the Creativity and Esthetic needs that contribute to the self-actualization of each person.

Together, these five levels enable me to describe carer needs holistically, which takes into account each individual's own environment, lifestyle, quality of life, health and well being. These represent the often hidden needs of carers which clinicians, GPs, health care professionals, policy makers and service planners should be particularly aware of when considering the impact of home based care of complex and chronically ill persons on family caregivers.

Carer "role" needs

Carer needs listed outside the triangle are unique to the caring role, relationship, and responsibilities. The left hand side list of their general needs, [A] are based on the overall experiences of caregivers where as the providers of the informal care they want recognition, reassurance, moral support, understanding explanations and information about their roles and responsibilities. I have included in this list, needs relating to alternatives to caring at home and the choice to stop caring. The last two issues are concerned with ethical decision making about their caring role.

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6 Headings in Maslow's triangle have been slightly modified according to the data returned through carer questionnaires and focus groups.
On the right hand side I feature carer needs specific to the services they require as carers. Services may be directed at the person being cared for, or to the carer him or herself. At the time of the first part of my study [1994/5], the emphasis was still on the person being cared for with services dedicated to the carers poorly funded in comparison. That has since improved and it should be acknowledged that over the past six to seven years, carer service needs have been identified and dealt with quite robustly in countries like Australia and Britain. One cannot assume however that carer needs are well known among health or social service providers, health care professionals or the public.

In reality the service needs of carers have taken precedence over the more salient and silent personal needs of carers - those I have featured inside Maslow's triangle. Therefore in 2002 we still see deficiencies in the provision of preventive health care for carers, counselling for carers, education and training for carers to avoid home based injuries from over lifting etc - to name a few. Teaching carers coping and survival skills is not widely catered for. At the moment formal carer education and training programs are mainly confined to organisations associated with dementia, while some local carer support groups offer informal teaching sessions and workshops for carers.

Due to the large volume of all relevant data from carers, this chapter is mainly presented as a summarised overview and lists of findings of carer needs. I have displayed carer responses about their the needs using the "A B C" model just described. Carer comments generated by their responses to the Kings Fund statements from the 10 point plan for carers (from the Questionnaire) are included in full in the Appendix. Health needs are treated separately and presented later on in this section. On the following pages I present a simplified version of carer needs in an alphabetical listing of Carers' perspectives of their needs under the headings of "Role related needs of carers" and "Personal needs of carers as individuals in their own right".

The second part of this question "Where do you go for help with these needs?" is incorporated into the next chapter with answers from Part III on Carers and GPs as this was also asked as part of the carer questionnaire. (For more details refer to Carer Questionnaire results in Appendix ).

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# Chapter 11: Carers' Needs

## AN ALPHABETICAL LIST OF NEEDS OF CARERS RELATED TO THEIR 'ROLE'

### ALTERNATIVES TO FAMILY CARE
- the choice to STOP caring
  - A BUDDY for the cared for person
    - someone to take an interest in the dependent person

### COMPANY & CONVERSATION
- someone to talk about one's problems, fears, share ideas, have a cup of tea
- moral support and understanding about the caring role from family, friends and health professionals

### DOCTORS [GPs and Specialists]
- to be more understanding
- to listen and believe what the carer is telling them
- to communicate more

### EDUCATION & TRAINING
#### For the carer
- Condition specific courses: eg Coping with Dementia, Palliative Care, Mental illness, Disability, Brain injured persons [children & adults]
- Care of stroke, M/S, Parkinson patients
- Lifting [techniques] Home nursing
- How to get carer entitlements & other carer support
- Personal Courses on Assertiveness training; Self development; Confidence building; Looking after own health

#### For the carer's family
- so family members can understand the carers' problems and assist
- so family members can appreciate the carer

### EMERGENCY ARRANGEMENTS
- What alternatives available for care of the dependent person

### EMPOWERMENT- to manage care of the dependent person [ in constrast to relying on a case manager ]

### HOME FOLLOW UP
- By phone: Ask if carer feeling OK. Ring during the difficult times

### HOME VISITS
- Specialists (like Geriatricians) - Talk to me / Help me through problems

### FINANCIAL HELP
- Access to early information on Carer on Financial benefits for carers and community resources
- decent living wage [income support / pension ]
- permanency of funding [ eg not needing to re-negotiate every 6-12 months if dependent person is profoundly / permanently brain damaged etc]
- assistance with low interest, subsidised loans for suitable vehicle,
- extra funding to cover extra costs of disability - separate from income support for water, electricity...
Chapter 11: Carers' Needs

PRACTICAL HELP
- experienced help caring for the dependent person [showering, incontinence problems etc]
- proper domestic help with house and garden chores
- provision of home care aids when needed

RECOGNITION
- of carer's role, responsibilities, knowledge
- that carer's role may change over time
- as an individual with personal needs

REASSURANCE
- from carer's family and professionals, like family doctor

RECREATION
- guilt free FUN and HOLIDAYS

REFERRAL-ON
- to services for both self and recipient

RELIEF- from stress, anxiety, pressures [associated with caring for a sick/disabled/frail dependent person]

RELAXATION
- Quality time out to relax

RESPITE
- It is not enough to have respite - it needs to be done in a way that carer approves, feel comfortable with and are able to trust
- Obtaining respite without having to constantly justify it and fight for it
- Respite Options;
  - Home based; day time or over night,
  - Separate facility:
  - Emergency
  - Holiday respite
  - More varied / flexible respite: For a few hours / daily / Day care,
  - Short term, [ W/E or a week] longer term [month at a time]

REST: Uninterrupted sleep at night [and a sleep in]

SAFETY NET
- For emergencies or unexpected events
- Somebody to take over responsibility of TCFP if carer ill, injured, away unexpectedly

CO-ORDINATED / INTEGRATED SERVICES
- Avoid overlapping or many different government departments

PERSONALISED SERVICES
- Services tailored to my circumstances and suitable for me
- Involving carer as partner in liaison and decision-making

SUPPORT
- Moral, Emotional, Family, Friends, Health providers, GPs and Specialists

TIME
- Time for oneself to do one's own thing
  [and to have reliable sitter services so carer can leave TCFP for a few hours]
- Time for normal time with family [just to be mother, wife etc]
Chapter 11: Carers' Needs

PERSONAL NEEDS OF CARERS

[Identified by carers - adapted to Maslows' Hierarchy of human needs pyramid]

At Apex of pyramid

LEVEL V:  CREATIVE NEEDS (SELF FULFILLMENT)

Aesthetic needs:
- Walk along the beach at sunset / go to art exhibition [Enjoy beautiful things]
- Education for self e.g. University studies that I always wanted to do
- Hobbies and courses in art, crafts, photography
  - Opportunity to paint, play the organ, listen to music

Self Actualization: (reach full potential, set personal targets,
Pursue dreams for holiday or retirement
Use own abilities - join a political party
Ability to cope with changes in self (eg as person ages) and
those associated with life changes

LEVEL IV:  NEEDS FOR SELF-ESTEEM / SELF WORTH / SELF RESPECT

Make decisions
Have control over one's own life
Be an individual - "be my own self"
Have confidence
Recognition
Respect
  - *useful and productive
  - *able to make contribution in life

LEVEL III:  SOCIAL NEEDS

Be included: Feeling of belonging and acceptance by others -
Reassurance
Giving and receiving love and affection
Being cared about
Be valued by others
Support of Family
Friendships
Conversation - someone to talk to
Recreation, rest and relaxation - i.e. fun!
Holidays

LEVEL II:  SAFETY NEEDS

Safe surroundings of the social group, a safe environment (and maintenance of environment)
Privacy
Financial support
Protection against danger or threat
Access to transport
Lack of finances (no longer earning), poverty + impact of ageing
like poor mobility can compromise some of these basic needs
[eg less money available means difficulty in paying for or collecting food supplies,
shopping for clothes
Poor dental care/ dental pain or need for new dentures reduces intake of food.
In poverty, may not use heating appliances to reduce costs

LEVEL I:  PHYSIOLOGICAL [HEALTH / CLINICAL NEEDS]

Includes basic needs of: Shelter, warmth, food, drink, clothing
See Separate List in Part IV on Carer Health for Health and Clinical needs

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**FOCUS GROUP DISCUSSION SCHEDULE & INTERVIEW GUIDE FOR CARERS**

**Part I**  Exploring the role and experiences of the carer

1. How long have you been a caregiver?
   What is the illness/disability of person you are caring for?

2. What do you understand as the ROLE of a carer? - describe role

3. Did you feel you had (or wanted) a CHOICE in becoming a carer?

4. How do you feel about being the carer?

**Part II**  Needs of the carer

1. What are your needs as a carer?

2. Where do you go for help with these needs?
   - Your very own **personal** needs
   - Need for **assistance** with the dependent person,
   - **Other** needs?

**Part III**  Carers and their GPs

1. Do you think your local doctor sees you as the carer?

2. Has your role and needs been discussed with your local doctor?

3. What support has been given by your GP? - how has it helped **you**

4. How could your local doctor provide more help?

5. What support do carers expect from their GPs?

6. How often do you see your GP in a year/month?

**Part IV**  The health and well being of the carer

1. Does the carer feel his/her health or well being has been affected by that caregiving experience?

2. In what ways has the carer been affected by that caregiving role
   - Physical health, Emotional health
   - Ability to go out during the day/ evening
   - Ability to live an independent life
   - Employment - recreation and relaxation, holidays
CHAPTER 12

PART 3: CARERS AND THEIR GPS

Five questions were put to carers for in Part 3 on their relationships with GPs:

(1) Do they think their local doctor sees them as the carer?
(2) Has their role and needs been discussed with their local doctor?
(3) What support has been given by their GP? - how has it helped them?
(4) How could their local doctor provide more help?
(5) What support do carers expect from their GPs?
(6) How often do you see your GP in a year/month?

The last question has been placed first in this chapter. Question 6 (also included in the carer questionnaire) asked carers how often do they visited their GP in a year/month? This was to gain some idea of their familiarity with the local doctor, and if they had been seeing the same doctor for an extended period or if this was a new doctor they had changed to. In this particular cohort, the majority of carers saw their doctors mostly for coordinating care of the sick, frail or disabled 'patient'.

Q. 2.1
It is acknowledged that the local GP is the most frequently consulted health care professional in the community.

How often did you see a GP in the last year?

<table>
<thead>
<tr>
<th>Number of times consulted GP in last year</th>
<th>For self</th>
<th>For the person being cared for</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=18</td>
<td></td>
</tr>
<tr>
<td>0-5 times/yr</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>6-10 times/yr</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11-15 times/yr</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>16-20 times/yr</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>21-25 times/yr</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>26-30 times/yr</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>30-40 times/yr</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>40-50 times/yr</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

As can be seen in the table above, the six of the 18 carer respondents who answered this questions, saw a GP for themselves at least 6 times a year, and another six carers saw a GP between 11-15 times a year, which was reasonably frequent if one takes the average
consultations for males and females as between 5 and 7 times a year respectively\(^1\). Added to that though are the times the carer takes the person being cared for to the GP (who might not necessarily be the same doctor as the carer consults for him/herself). 4 out of the 18 carers took the 'patient' to the GP up to 5 times a year, 2 of the carers visited the GP between 6 and 10 times a year with the cared for person, and 5 carers said they accompanied the cared for person to the GP between 11 and 15 times a year. Therefore 11 out of the 18 carers attended their GPs up to 15 times a year with their 'patient' and 13 out of the 18 carers consulted a GP for themselves.\(^2\) No equivalent statistical information was available on carer consultations at the time of my research in the mid 1990s. To my knowledge even recent Australian Institute of Health and Welfare ["Australia's Health"] and BEACH\(^3\) statistics do not specify this type of carer consultation.

**Part 3 (1): DOES YOUR LOCAL DOCTOR SEE YOU AS A CARER?**

In 1995, of the eighteen carers who answered question 2.3: "Has your local doctor (GP) recognised and supported you as the carer with special needs?", fifteen reported in their questionnaire that their GPs did perceive them in this way, while five of the eighteen carers felt the GPs did not. The latter group felt that the doctor saw them as just the parent, [C-9] the spouse, [C-14] someone to solve the problems [C-7] or merely as an object. [C-18]. The fifth carer commented that the doctor had no real idea of what 'caring' entailed. [C-11].

An overview of similar remarks from carers from the focus groups reinforces this. For example one carer felt the doctor was a bit condescending - "...he just saw me as the wife".\(^4\) Another did not think that the doctor realised what was involved, not seeing her as

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1 I have provided a very simplistic interpretation of frequency of GP consultations, compared with that described in 'Australia's Health [2000: 300] which gives 1998/99 rates for people consulting a general practitioner or specialist as being 4.3 times per year (males) and 6.3 times / year (females).

2 This information on carer-GP consultation rates was purposely kept simple so as to establish if there might be grounds for developing it as a question for inclusion in statistical surveys of general practice consultation. [eg ABS, AIHW and BEACH]. In the AIHW Australia's Health 2000 [p.293] it referred to encounters 'with a patient' to GPs for different age groups, but the presence of 'carers' was not identified. I suggest that informal caregivers are a legitimate category in their own right and should be considered for inclusion in statistics - otherwise they will remain hidden and the efforts of GPs on their behalf will continue to be overlooked. This is the subject for discussion an debate.

3 BEACH, Bettering the Evaluation And Care of Health, is a national survey of the clinical activities 1000 GPs per year which began in April 1998. The study is conducted by the General Practice Statistics and Classification Unit - an AIHC collaborating unit within the Family Medicine Research Centre, University of Sydney. [Australia's Health 2000: 293].

4 C-11[fg2-comb] p.10 L.14-19
her son's carer.\textsuperscript{5} Two wives believed their husbands (as the patients) were seen by the doctor as more important than the spouse carer who were there to 'look after' the husband.\textsuperscript{6} The second carer reported that her husbands needs were dealt with by the doctor, more than hers.\textsuperscript{7} For some carers it took a long time to find a doctor who the carer could relate to, eventually she found one who told her she was doing "a damn good job" at caring for her severely disabled daughter.\textsuperscript{8}

Carers were asked to specify if they saw the same GP as the person they were caring for or if they consulted a doctor separate to the other person. The majority, 13 out of 18, consulted the same GP. There clearly were valid pros and cons for each arrangement, whether using the same GP or one specifically for the carer.

\textbf{Questionnaire}
Q. 2.2 \textit{Do you and the person you are caring, both consult the same GP?}

\begin{tabular}{|l|l|}
\hline
\textit{YES}: Carer consults the same GP as dependent person & 13 \\
\hline
\textit{NO}: I have a different GP to the person I am caring for & 5 \\
\hline
\end{tabular}

Some carers mentioned having to change their GP and how the doctors differed in their approach to the person who was the carer. One said she 'shopped' around for a doctor who listens.\textsuperscript{9} Another changed their first doctor to someone who "lets me talk,"\textsuperscript{10} while another made the change so that the doctor "only had to look after me."\textsuperscript{11} One carer reported she was looking for a younger more flexible doctor who was not set in his/her ways.\textsuperscript{12}

\textsuperscript{5} C-9[fg2-comb] p.10 L.21-29
\textsuperscript{6} C-14[fg-3 comb] p.24 L.4-9
\textsuperscript{7} C-17[fg-3 comb] p.24 L.16
\textsuperscript{8} C-22 Int. p.8 L.34
\textsuperscript{9} C-18[fg-3 comb] p.23 L.7-11
\textsuperscript{10} C-2 [fg1-comb] p.3 L.26
\textsuperscript{11} C-17[fg-3 comb] p.22 L.22
\textsuperscript{12} C-17[fg-3 comb] p.23 L.13
Chapter 12: Carers and their GPs

For the carers who saw the same GP as the person they were caring for, there were some benefits like the doctor "being aware of all the things going on". A carer said she felt it, "... important for the GP to be well up with what's wrong with both of us". Below are written comments from Q. 2.2 of the carer questionnaire about using the same GP: Do both you and the person you are caring for, consult the same GP?

### Carer Questionnaire Q. 2.2
Do both you and the person you are caring for, consult the same GP?

I have known him for 23 years and am very comfortable talking over problems for us both. C-8

GP has known the family since 1967. Continuity has been helpful. C-9

The doctor is a caring person and is interested in us both. C-10

Yes because he knows both of our positions in life. C-12

It helps because the GP knows my husband and myself and I can discuss the problems I have with my husband with GP. (But) He does not understand dementia. C-15

I was hoping for it to be beneficial but was wrong. This GP is only interested in some physical symptoms. C-18

Can combine visits to the doctor's surgery. The doctor can see the problems of the carer. C-19

Most beneficial as he understood the situation at home. Appointments at the same place and time. C-20

Yes it gave me more opportunity to discuss with the GP my wife's health and how I could best help her and how I could cope with various situations myself. His advice and assistance proved very valuable. C-21

I have been with my present GP since Dec 1994. I feel confident that she gets a better understanding of both of us when she knows us both. C-23

Some carers who saw a different GP as the person they were caring for, could see added benefits for themselves especially having their needs attended to apart from the cared for person. The first comment is an important observation and points to the issue of carers' medical problems being overshadowed by the patient's needs when consulting the GP.

"My son's GP seemed to see me as 'stress related' with problems that were quite separate medically. My own GP doesn't 'assume' that." C-11

"We did have the same GP until 18 months ago and my husband changed to another. It did have benefits but I think I am happier separate. ... I feel my GP can concentrate on my problems only." C-17

"It gives me my value as a separate person but my mother's GP is understanding and supportive of me too. " C-16

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13 C-12[fg2-comb] p.13 L.25
14 C-8[fg2-comb] p.13 L.21
15 C-16[fg-3 comb] p.24 L.16
Chapter 12: Carers and their GPs

The majority of carers who felt they were recognised, appreciated their doctors asking and checking if they were coping with the demands of caring. The kindness and responsiveness of their doctor was appreciated. Carer statements below provide good examples of how they feel their doctors were doing right and what helped them.

"Our doctor always concludes the consultation with, "... now is there anything else?..."
C-2[fg1-comb] p.3 L.30

"...he hasn't got time to really give you a lot of time, but he is kind to me when I need him."
C-15[fg-3 comb] p.23 L.32

For one carer it was not until she was hitting the bottom that things changed with her GP.

"... I just let him have it all and from that day on he was a different person and often, yes, if things were really bad I knew I could go and have a little cry."
C-17[fg-2-comb] p.22 L.9-13

"...our doctor, he is really good. He is very interested. If you go to see him he always asks how you are doing, how are things going. Is it getting too much for you? ... He does get interested in yourself .... He is good that way."
C-10[fg2-comb] p.11 L.20

Carers not always honest with GP

An unexpected issue that emerged out of the Focus Groups concerned those carers who were not always honest or up front with their doctors. This group of carers revealed that even if the GPs did ask after the carer, they denied being anything but 'fine', or they can keep going a bit longer "no worries". In reality some mentioned at the focus group that they had not been well at that time, but would not admit it at the time for fear of showing that they were not coping or not well enough to continue caring for the dependent person at home. As one carer said, it is easy to be critical of GPs, but is hard for the doctor to be supportive if the carer is not co-operating. So there is another side of that question for the GP.

"I try and pull the wool over her eyes quite a bit because if she is coming out to see Mum she will say to me, "How are you J?", and I will say, "I am fine! ....I don't in a way I don't want her to think that I am not coping."

A carer warned from her experience,

"You have got to be careful because last year I was sick for quite a while and then she realised. But up until then she thought I was coping quite well. So you have got to be honest, but you can not let them know that you are not coping very well." C-19[fg-3 comb] p.23 L.19-28

16 C-3 [fg1-comb] p.2
17 C-2[fg1-comb] p.3 L.32
Part 3 (2): CARING ROLE AND NEEDS DISCUSSED WITH GP?

This question, *Has the caring role and needs been discussed with their local doctor?* has been touched on in the previous pages but it also highlights important communication issues inherent in carer recognition by GPs. Sometimes there is a reluctance on the carer's part to raise the issue of their caring role with a GP. Fewer carers appear pro-active with their doctors and the onus is usually on the GP to be perceptive to the carer's situation. More so I see it as a form of negotiation and joint decision-making that has to go on between carer and GP.

"In the early days I did my discuss my role which he [Dr] didn't think I would be able to cope with. I tried to explain to him, that to put [husband] somewhere would be more stressful to me. I said at least I have got him home and with me, whereas putting him somewhere at this stage he would get very worked up and wouldn't cope and I would just be there most of the time with him, and it would have been an absolute mess" C-20 [fg-3 comb] p.25 L.5-11

"... I 've spoken to my doctor quite a few times. Especially when I got ill and I couldn't care for my husband and he said he had to go into a nursing home, or I did - one of us had to. So he went and I stayed home, and rested - which was fine. It was good advice because I was just cracking up as there was too much to do. ... I think they try to help you "...C-15 [fg-3 comb] p.26 L.16-19

Part 3 (3): CARER SUPPORT FROM GPs

The next questions put to carers for this part of the focus groups were about their relationships with GPs:

(3) *What support has been given by your GP? - how has it helped you*
(4) *How could your local doctor provide more help?*
(5) *What support do carers expect from their GPs?*

In the Carer Questionnaire, Q. 2.5 provided examples of what support has given and how it had helped the carers. It dove tails with carer comments to the previous questions but provides practical details of what was happening at the carer-GP interface. I include a series of quotations and short stories by carers as Vignettes while additional data has been para-phrased and listed. [All responses to the Carer Questionnaire are provided in full in the Appendix.] Some findings from the questionnaire on how GPs have helped carers, are summarised and integrated with verbal data in this chapter where appropriate.

Carer appreciation of their GPs was palpable during the focus groups although there were a sprinkling or stories where past experiences with less well informed doctors had caused problems for the carers. What is interesting when one compares verbal reporting by carers with the more in-depth questioning about GP support obtained through the carer
questionnaire, is that there are some serious gaps and deficiencies around GP referral to community and carer services.\textsuperscript{18}

**HOW HAS YOUR LOCAL DOCTOR HELPED YOU?**

In Question 2.5 of the questionnaire, carers were asked: *In what ways has your local doctor been able help you as the carer, either recently or in the past?* A summary of the carers’ responses indicates that most fall within three or four main categories. Being available, including for home visits, for advice and for help and encouragement to access services (referral).

<table>
<thead>
<tr>
<th>Carer Questionnaire, Q. 2.5</th>
</tr>
</thead>
</table>
| *In what ways has your local doctor been able help you as the carer, either recently or in the past?*

**Advice**
- He has advised me as well as helped me to seek help from various local helpers, eg. domiciliary care; District Nurse, referred my wife to specialists at the hospital. Placed my wife in a private hospital to receive special care and to give me some respite from the constant pressure. C-21
- Directing us to persons who are able to help us C-1
- Recommending appropriate support facilities C-4
- Home visits, referral to hospital, encourage me to go out more C-5
- By helping me to get our entitlements. C-10

**Available / Home visits**
- Always at end of telephone and will make a house-call if required. C-3
- Doctor calls to house to examine husband, instead of us going to the clinic. C-6
- He has gone out of his way to be available to talk to when needed. C-12
- Has always been available for support and very understanding and listens to me. C-17
- I think just by allowing me to pour out my worries and concerns. Sometimes he does suggest things that are helpful. C-16
- By being very kind when I have needed him and being able to talk to him about husband. C-15

**Help/encouragement to access Services**
- If I know what I want will refer me on. C-7
- He helped me to receive the service of Community Options. C-8
- Helpful in enabling us to use local community transport service. C-9
- Told me to have a week’s respite when my blood pressure was up high. C-14
- ...my son was acknowledged, accepted, not threatened. The GP has been quick to act when asked for help and is not judgmental. She is empathetic, helpful and approachable. C-23
- In the past they used to come out to my son quickly during the night—now those services are not available. C-11

\textsuperscript{18} As this information was collected in 1995, the data is now well out of date. There have been major changes with Divisions General Practice, improved provision of carer respite and carer resource centres, care planning initiatives through the Enhanced Primary Care Program and most recently the national telephone CareLink service for the public, carers and health professionals like GPs.
Although the data is dated and services have changed, I believe that what the carers had to say tells a story that has not changed with time. Anecdotal evidence collected by state based and national carer organisations, even to the year 2001, attest that we have only just started in bridging the carer-GP interface. What the carers say in this small study provides a useful point of comparison for future efforts to bring carers and GPs to the planning table. I now present a summary of how the carers felt local doctors had helped them, describing their experiences and expectations.

Carers reported that doctors (GPs) were:
- available to the carer when needed,
- always there for emergencies, including after hours
- very kind and understanding
- quick to act: phone back to carer, provide home visits
- available for talk,

GPs also:
- arranged back up from other partners in his practice
- listened to the carer’s worries and problems
- provided reassurance
- provided emotional support and counselling
- provided advice - where to get help, respite, some home based services

Probably the most important issues for carers was firstly that the GP provides reassurance and for the carer to know that the doctor was there as a back up. Secondly for the doctor to show kindness, that he cared about the carer and the patient, be understanding and listened. The carers felt they could "pour out their worries and concerns".

The issue of the GP (or his/her partner from the surgery) being available when needed by the carer for house calls especially in an emergency and after hours was so important to the carer. For some carers it would be impossible to move a very sick, or difficult patient to the clinic to see the doctor. Some carers reported feeling distressed by the effort involved in taking frail aged or disabled persons to the doctor’s rooms. The home visit is an important and simple solution.

"I’ve only got to ring him up and he comes straight up, you know. He’s always on call. He has even given me his home number that I can ring in the morning before he starts his rounds if I need him. So I suppose he is pretty marvellous." C-15[fg-3 comb] p.28 L.29

"I’m very happy with my doctor / our doctor. He has several other doctors to back him up. We are never left without attention." C-18[fg-2 original] p.37 L.10-11
"He or one of his partners has always been available" C-8
"Doctor calls to house to examine husband, instead of us going to the clinic." C-6

"... I could ring him [GP] up and if he wasn’t available to talk to me then he would ring me back later and ask me what the problem was. If I really wanted him to come to the house he would, but usually we could solve the problems over the phone. But, it took a while to get to that stage. It was worthwhile in the end". C-20[fg-3 comb] p.21 L.33
Chapter 12: Carers and their GPs

It was mentioned that more practices used locums at night which for some carers was a problem because the temporary doctor was not familiar with the patient, the carer or the support networks sustaining that relationship. Here is one carer's story.

Vignette 1

"My doctor did give me his after hours number, but the trouble is, the one night when I really needed him, my husband was having convulsions... the number, - someone had switched it off at home, so I got onto the agency and it was an answering machine... In the meantime I rang a friend around the corner who was a nurse - this was as half past two in the morning and she was around in a flash and she helped me through it.

But he [doctor] would have come... if the phone had rung through... I got that way that if I was capable, I would ring for help first to get someone in with my husband before the doctor came, otherwise he would have said, we have got to send him off. Which is understandable isn’t it because one night when I was passing out, my husband was screaming around the house, “She’s dead, she’s dead”... Well someone walks in and comes across that, they would..."

Another episode gives an example where well meaning assistance may not be helpful if the carer is not consulted.

Vignette 2

"... Doctor rang for a nursing agency to come to look after L, [husband] that night because I was sick. But that in itself was a boo boo. He should have rang my usual helpers, because all it did was throw the house into chaos because L’s frightened of a stranger coming in, and it just upset everything. So the doctor learnt from that. I explained to him how it happened, and he had no idea that I could get so much help. He was amazed that I’d organised so much help on my own.

One carer described a different after hours arrangement, not with the GP but with a support person to provide after hours support if needed. It has great potential to provide an much needed safety net for the carer if after hours support from the GP is a problem.

Vignette 3

"I think that J [the support person] has put my mind at ease now because she has said, she has given me her after hours number and that never to feel that my husband was left on his own and she sends the same people to the house all the time - like to help. One particular lass is very helpful, and doesn’t live very far away, and I feel sure that, with the network that J is building up that I feel a lot more relaxed than I did before..."

INFORMATION AND SUPPORT TO CARERS BY THEIR GPS

Question 2.7 (A) asked what general information and support was offered to the carers by their GPs, for example with information on the dependent person's illness, what to do in a medical emergency, contact for after hours care and more carer specific examples such as respite services, adaptations for the house, carer benefits and the Carers' Kit.
Chapter 12: Carers and their GPs

<table>
<thead>
<tr>
<th>Carer Questionnaire Q. 2.7</th>
<th>What general information and support has your GP offered you in your caring role?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A. Information</strong></td>
<td><strong>Never</strong></td>
</tr>
<tr>
<td>• the dependent person's illness/disability</td>
<td>2</td>
</tr>
<tr>
<td>• what to do in a medical emergency (concerning the person you are caring for)</td>
<td>6</td>
</tr>
<tr>
<td>• contact for after hours medical care (for you or the person you are caring for)</td>
<td>5</td>
</tr>
<tr>
<td>• respite services available for you</td>
<td>9</td>
</tr>
<tr>
<td>• other services available for you or the dependent person</td>
<td>7</td>
</tr>
<tr>
<td>• government benefits or special allowances and where to go to apply</td>
<td>11</td>
</tr>
<tr>
<td>• where to obtain a Carer's Kit</td>
<td>12</td>
</tr>
<tr>
<td>• special adaptations for the home including where to go to find out where to get them</td>
<td>10</td>
</tr>
</tbody>
</table>

The list above highlights that GPs were reasonable at providing information of medical conditions and details about after hour medical care, but less likely to know about or pass on carer specific details. Information about practical aspects of caring, services and benefits were hardly ever offered to this group of carers. One can't help but wonder how much this might have changed over the intervening years. However in 1995:

- The majority of GPs (12 out of 14) sometimes/always provided information to carers on the dependent person's illness or disability;
- More than half of the GPs had discussed with the carer sometimes/always, what to do in a medical emergency. Less than a half had never provided carers with this information;
- Two thirds of GPs (10 out of 15) had sometimes/always provided the carer with information on who to contact for after hours medical care. A third had never passed on that information to carers;
- Less than a half of carers (6 out of 15) had sometimes/always been told by the GP about respite services. More than a half carers reported that their GPs had (9 out of 15) never given them information on respite services;
- Approx. a half of carers (8 out of 15) had sometimes/always been told by the GP about other support services to help them. About a half had never had that information on other services available to the carer of dependent person;
- The majority of carers (11 out of 14), had never had information from GPs on government benefits or special allowances for carers.
The majority of carers (12 out of 14), had never had information from GPs on where to obtain the Carers' Kit.

Most carers (10 out of 14) had never had information given to them from GPs on special adaptations for the home, and where to get them.

Other comments by carers included:

"My first GP gave me no information. The lady who help me with house cleaning gave me a lot of information, she had nursed her mother." C-20.

"...[you] virtually you've gotta know the answer yourself before he does, I mean he's happy to do it, I've got to know who I want to go to." C-4 (fg1-comb) p.4 L.20

"I was in possession of this information before I met my GP, a lot of it from the ...agency". C-23

"I had found out about most services that we could use whilst my son was still at the ...Centre" C-9

"I have received the information from hospital, domiciliary care and mum's". GP. C-16

"Medical advice only". C-22

"I have just discovered a great doctor. Signs documents for carers pension, mobility allowance & DNBC [Domiciliary Nursing Care Benefit]". C-22

Question. 2.7 (B) was on Referrals by GPs: :- Carers were asked if they had been referred to a range of other agencies and services by their GP? The table below illustrates that in 1995, most carers had not been referred on to community and carer support services. Only a third of carers had been referred on to the well known established agencies such as Domiciliary Care, day care services and Community Health Centres.

<table>
<thead>
<tr>
<th>Q. 2.7 (B) Referrals</th>
<th>Yes [referred]</th>
<th>No. [Not referred]</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Support Group</td>
<td>2</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Community Health Centre services</td>
<td>3</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Day Care Services</td>
<td>3</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>District Nursing Services</td>
<td>2</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Domiciliary Care Services</td>
<td>4</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Financial /Legal Advice or Services</td>
<td>0</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Meals on Wheels Services</td>
<td>0</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Professional counselling services</td>
<td>3</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Respite Care</td>
<td>2</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Local Council Community Services</td>
<td>1</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Other Community services</td>
<td>1</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>(eg for practical home/domestic help or assistance with transport)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Q. 2.7 (B) Referrals

Carer comments

I have told the doctors what help I have found out about and used. C-14
Not by my GP but by my mother's GP. C-16
He [Doctor] has advised me as well as helped me to seek help from various local helpers.
eg. domiciliary care; district nurse, referred my wife to specialists at the hospital.
If I know what I want [Doctor] will refer me on. C-7
He [Doctor] helped me to receive the service of Community Options. C-8
[Doctor] Helpful in enabling us to use local community transport service. C-9

Within the focus groups, carers discussed issues surrounding respite in more detail. The following story illustrates the importance of carers getting the respite when they need it.

Vignette 4

"Last year, I remember I had a cold on my birthday, which is mid August and I still had it in November. So the doctor, in November put my mother into hospital so that I could try and get rid of it. But it took her [the GP] from August to November to do it. Because by November... I was a mess... I was trying to get away for a few days... and she said, 'Oh, no it is harder to put people into hospital now', " C-19[fg-3 comb] p.28 L.17-24

What information from the GP was most important / helpful for the carer?

Question. 2.7.1 (C) asked carers what information from their GP did they consider to be the most important and helpful?

• How to care for myself C-17
• To watch diet and exercise if able; to take prescribed medication as instructed. C-3
• Availability of counselling services; C-23
• Providing contacts to the caring network. C-4
• Medical information
• What symptoms to look for [in the cared for person] and his referral to hospital or specialist when necessary. C-8
• He explains the illness and tells me of any side effects from the medication. C-5
• His decision to refer my wife to specialists at hospital. They were able to seek government approval for my wife to enter a nursing home to receive far better care there than I could give her. C-21
• I really think the specialists at Daws Rd hospital have given me most information about my husband. C-15

It was interesting to see who carers felt had given them the most useful information in question 2.7.2 [overleaf]. Top of the list was the social worker closely followed by hospital doctors and specialists, carer support groups, and then the General Practitioner.
Surprisingly, not many carers included nurses (whether hospital, district or community based), as being providing useful information. This grouping suggests that perhaps carers valued medical information and any suggestions for practical assistance. It would be interesting to know now who carers found the most helpful.

Carer Questionnaire: 2.7.2

Who has provided you with the most helpful information in the past?

<table>
<thead>
<tr>
<th>Who has provided you</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>11</td>
</tr>
<tr>
<td>Carer Support Group</td>
<td>10</td>
</tr>
<tr>
<td>Hospital doctors/specialists</td>
<td>10</td>
</tr>
<tr>
<td>GP</td>
<td>9</td>
</tr>
<tr>
<td>Community Health Nurse/worker</td>
<td>4</td>
</tr>
<tr>
<td>Local Council</td>
<td>4</td>
</tr>
<tr>
<td>Friend</td>
<td>3</td>
</tr>
<tr>
<td>ADARADS [Dementia support]</td>
<td>3</td>
</tr>
<tr>
<td>District Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Hospital Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Relative [daughter]</td>
<td>2</td>
</tr>
</tbody>
</table>

Other comments
- GP - hospital, Doctors/specialists C-1
- GP & specialist, also family support C-2
- GP & specialist, district nurse C-3
- GP, social worker C-4
- GP, hospital doctors, hospital sister, carers support group C-5
- HACC program C-7
- Hospital social worker informed both carer support network and Alzheimers Assoc. C-6
- Day Centre staff C-10
- Daughter C-15
- Day Care centre, Dom Care C-17
- ADARADS Carer education C-19
- My own network C-22
- Women's resource centre, Telephone book C-23

Specific comments:
- My own networks, which consist of other carers, public servants at state & federal levels.
- Carer Support Group: Too group oriented. Too aged care focused. C-22

Emotional Support for carers from GPs

Question 2.8 (C) asked specifically about emotional support and coordination of services by GPs for the carers. Results indicate more than half the GPs gave emotional support but at the time, only a third coordinated any of the services for carers. Less than half reviewed the carer's situation regularly. It is to be hoped that with the introduction of the Enhanced Primary Care Initiative, this support for carers through general practice will improve.
Chapter 12: Carers and their GPs

Q. 2.7 C . Support:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your GP ?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offered you emotional support?</td>
<td>9</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Provided co-ordination of any of the services above?</td>
<td>4</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Reviewed your situation regularly?</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

Other comments by carers of helpful support by GPs

Keeping a check on my blood pressure. C-14
Routine health checks. She has made herself available for discussion. C-23
Always asks how I am coping first without me bringing the subject up; asks about problems. C-17
Is understanding and supportive would give counselling if I asked. C-19
In these last years whilst my husband was home my GP was very supportive. I could ring him any time to discuss a medical problem. C-20
Emotional support by recognizing my (at times) frailty (emotional). C-22
Home visits, referral to hospital, encourage me to go out more C-5
Told me to have a week's respite when my blood pressure was up high. C-14
Placed my wife in a private hospital to receive special care and to give me some respite from the constant pressure. C-21

Vignette 5:

Doctor suggested home nursing help but not respite.
"When Mum has been in hospital -(she was in hospital, 9 times I think last year,) and it was on the third visit when she had her third or fourth stroke, that the doctor said there were home nurses. Well I didn’t know that she was eligible for home nursing, and I am pretty knowledgeable. So the doctor initiated that. I could get someone in to give her a bath because I’ve got dom care and they said you are on the books but it could be 2 months - it could be 3 months. So in the mean time, I could use those ...but as far as [the GP suggesting] I dom care and home nurses, yes, and district nurses, Yes - that is for nursing, but not emotional or anything else. So in other words, for the nursing side yes, but not, um, ... she never suggested respite."
C-19 [fg-3 comb] p.27 L.28-36

Other home based help

Carers shared some of their experiences about other home based services which helped them. For example delivery of medication from the chemist, and having the pathology nurse call at the house.

"I believe some of the chemists will deliver if you are familiar with that particular chemist."
C-8[fg-2 original] p.38 L.17

Vignette 6:

"... my hubby always has to have a blood count done at [pathology labs], 3 - 4 months ago ... I said to the doctor, ‘oh no not again’ and he said ‘You don’t have to go there... the pathology nurse can come to you. Well I didn’t know that before that the ...[pathology] nurse comes to us!... Don’t let them put you off. They tried put me off, so I said ‘you ring up the doctor and have it out with him”
...C-6[fg1-comb] p.5 L.26
Chapter 12: Carers and their GPs

Vignette 7:
"...My mother has always had UTI so the doctor will ..., (if I can get somebody to drop a specimen down), always examine it and then if I need medication straight away, the chemist will generally deliver it. So that is good. She [the doctor] will always send [pathology services] out, so I don’t have to get my mother down for a blood test. Some doctors won’t do that, or won’t even think about it. She [the doctor] will always take a phone call from me... they will put me through, so she will always do that..." C-19 [fg-3 comb] p.28 L34

Vignette 8:
"I had a surprising situation. I had severe heartburn...pains in shoulder - worried... it could be heart trouble. Rang night doctor... checked me over... said he would give me a tablet for heartburn. Said tomorrow morning at 10.30 there will be a courier come with some more tablets for your. There won’t be any need for you to go to the Chemist.... At 10.40 they called- there was the courier at the door with some tablets. I was amazed. And that was just the locum!" C-10 [fg-2 original] p.38 L.19-24. Also-
":... when I was sick this last time ....The doctor realised that I had an infection and he brought some tablets with him and said just take this course of tablets... He did help. He did have to give me a prescription to get some tablets- and I thought that was fantastic." C-10 [fg-2 original] p.38 L.32-34

HOW COULD THEIR LOCAL DOCTOR PROVIDE MORE HELP?

The fifth question in Part 3 was to explore with carers what GPs might do to provide more help. In summary carers repeated some messages suggesting:

- Listen - understand
- Show empathy, non-judgmental attitudes
- Recognise the carer's stress
- Arrange respite /temporary care for the dependent person - but be careful to check with carer what services are already being used, and advise them help is needed.
- Provide house calls
- Be more supportive when the carer is ill

"I’d like to just talk to the doctor confidentially who is not going to remind you next time about what you said. ...Talk to you without the prescription pad in the hand." C-7 [fg1-comb] p.9 L.20

Helping the carer if sick / injured or during an emergency

In relation to specific issues like helping the carer if injured, sick or in an emergency, there were few direct answers. Most carers shared more stories on what they had endured, what had gone wrong and what worries them should they fall ill - or fall off a ladder and get concussion. Very often they just have to muddle through on their own without help or proper rest. 19

One carer asked: "I wonder, if I’m in bed with the flu - and need tablets, would the GP provide the prescription? How would you get your medicine?" C-7 [fg1-comb] p.9 L.24

19 C-7 [fg1-comb] p.9 L.32
Another carer answered: "... ring the Doctor and ask someone from the surgery to take the prescription to the chemist for you." C-X[fg1-comb] p.9 L.27

"I sometimes think about that if I am out in the car. What if I had an accident... what is going to happen. You need to know that there is someone who can come into the home in an emergency if anything does go wrong... somebody reliable." C-11[fg2-comb] p.17 L.1-4

"That’s it, it is the emergency side of it. Something that happens suddenly that you have got no control over. So then you are wondering. What could have happened to my girl." C-10[fg2-comb] p.16 L.33

Vignette 9

"...it is when something happens suddenly, that there’s an emergency. Now a thing happened to me that really made me sweat, because I went to the ... Hospital Day Surgery for exploratory surgery. I had to be there at 7 o’clock in the morning and so I made arrangements for somebody to look after my wife for the day. I would be home at 3 o’clock." C-10[fg2-comb] p.15 L.132

"Well, I went into this surgery. They put me under anaesthetic and they did what they wanted to do - they tried to find where this blood was coming from and they put me in bed ... I had a bit of trouble. So they said, you can’t go home. As I said, I just made arrangements for someone to look after my wife until 3, so I had to get on the phone then to domiciliary care to try to make arrangements for someone to look after my wife for the night. But that night turned up to be 5 days, so they had to get somebody from an agency (Domiciliary Care arranged it) to arrange in-home respite to look after ... [my wife]. And it worried me to death as I hardly knew what were going on."
C-10[fg2-comb] p.15 L.32

"...It really worried me. So the next time I went into hospital for day surgery, I made arrangements that if anything happened, ... [my wife] went to the nursing home. And she went into hospital for 3 weeks ‘cause this same thing happened again. I couldn’t go home."
C-10[fg2-comb] p.16 L.19

Vignette 10

"My husband has been so ill for the past 3 years, I felt that if I went down as well, what would happen to my son? There is a respite house for people with brain injury, and it is certainly beautiful and it has recreation facilities and it has people there to look after them, but it doesn’t provide all the things that my son does day by day. ... what I would really need is someone that would come in and keep his routine going exactly as it is, because once his routine goes, he goes with it, and it could take me months then to get him back into a stable condition to carry on working well."
C-9[fg2-comb] p.15 L.15

What do carers expect of GPs?

Carers expect support from their General Practitioner through early diagnosis and proper management of conditions like dementia. Carers place a great deal on their GPs knowledge for example about local or state based carer support and community services. Unfortunately some carers found that knowledge lacking on those issues. For example on GP knowledge carers made the following comments:

GPs HAVE LIMITED KNOWLEDGE OF DEMENTIA

"I have heard from friends is that when they go to the doctor in the early stages of Alzheimers, with dementia and what-have-you, make the comment; you’ve got to expect it - its just the ageing experience, where it need not necessarily be that and the sooner you know the reason for the confusion and the loss of memory, the better you are able to handle it." C-4[fg1-comb] p.5 L.12-17

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DOCTORS ' LIMITED KNOWLEDGE OF COMMUNITY SERVICES
"Doctors are only really aware of dom.care, RDNS and meals on wheels. They don't have anything on any other bits and pieces that are available. " C-X[fg-2 original] p.37 L.1-2

CARER HAS TO HAVE THE INITIATIVE - FIND OUT FOR SELF
"Yes, being in a Support group has helped me, but with my husband blind I had to find out everything for myself.. is a better situation now.. after 8 years struggling, we have the RSB down here in Noarlunga House- an achievement. " C-8 [fg-2 original] p.37 L.45-50

IT IS UP TO THE CARER ANYWAY
"A lot of it is up to the carer anyway. The doctor can only sign the papers for you. Perhaps if the doctor had a list it would be for the carer to follow up. Have you done this/that? " C-11[fg-2 original] p.37 L.33-34
**FOCUS GROUP DISCUSSION SCHEDULE & INTERVIEW GUIDE FOR CARERS**

**Part I**  Exploring the role and experiences of the carer

(1) How long have you been a caregiver?  
What is the illness/disability of person you are caring for?

(2) What do you understand as the ROLE of a carer? - Describe the role

(3) Did you feel you had (or wanted) a CHOICE in becoming a carer?

(4) How do you feel about being the carer?

**Part II**  Needs of the carer

(1) What are your needs as a carer?

(2) Where do you go for help with these needs?  
- Your very own personal needs
- Need for assistance with the dependent person,  
  Information needs / community resources  
  Practical assistance in the home
- Other needs?

**Part III**  Carers and their GPs

(1) Do you think your local doctor sees you as the carer?
(2) Has your role and needs been discussed with your local doctor
(3) What support has been given by your GP? - how has it helped you
(4) How could your local doctor provide more help?
(5) What support do carers expect from their GPs?
(6) How often do you see your GP in a year/month?

**Part IV**  The health and well being of the carer

(1) Does the carer feel his/her health or well being has been affected by that caregiving experience?

(2) In what ways has the carer been affected by that caregiving role  
   - Physical health, Emotional health
   - Ability to go out during the day / evening
   - Ability to live an independent life
   - Employment - recreation and relaxation, holidays
CHAPTER 13
PART 4. CARER HEALTH

Introduction
To examine the findings of this aspect of the study on carer health, which also generated a
great deal of data, I first grouped responses to each main question of the Discussion
Schedule and Questionnaire into common themes to establish the main topics. The next
stage involved matching these topics to broad categories similar to those of the SF-36
health status measure. The final breakdown of carer responses are represented by the
following headings in this chapter:

Current Clinical Status of Carer
Physical Functioning  [includes Role-Physical where appropriate - eg ability to lift, move around etc]
Vitality [includes levels of energy and tiredness]
General Health
Social Functioning  [includes Lifestyle / Quality of Life issues]
Role Emotional
Mental Health

Carer responses had been sought mainly through open-ended questions within focus
groups, to purposely avoid too tightly structured prompting. Additional lifestyle issues
which emerged, needed to be grouped under their own heading. I also asked about
existing health problems identified by the carers under an extra heading - clinical status. An
initial overview of findings, generated as textual data from all focus groups, highlighted the
following health problems experienced by carers as part of their caring role. Of particular
note were the physical problems of back and other musculo-skeletal conditions, emotional
problems, lack of sleep, tiredness, stress, depression, and frustration. Social and personal
issues that impacted on their quality of life and well being were loss or friends, feelings of
loneliness and isolation, loss of confidence, a loss of freedom to pursue their own lives
and interests and a loss of privacy. These occurring in addition to or concurrently with ill
health /disability all impacted on their ability to cope from time to time.

Responses from the carer questionnaires yielded similar strong trends showing nearly half
[11 out of the 22] of the carers complaining of serious tiredness (associated with weariness
and debilitating exhaustion). 13 of the 22 carers also indicated that the tiredness was due to
the sleep interruptions as part of their caring role. Depression was mentioned by almost a
quarter of the carers [6 of the 22] while back, neck and muscle problems were highlighted
by 9 of the 22 participants. Several of these carers mentioned difficulties manouvreng cumbersome or heavy wheelchairs, including injury and strains from doing so.

**How carers rated their own health in the Questionnaire**

In answer to Question 3.1 asking carers to rate their own health, there was a 50:50 split

<table>
<thead>
<tr>
<th>Q. 3.1 How would you rate your own health?</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>0</td>
</tr>
<tr>
<td>Very Good</td>
<td>5</td>
</tr>
<tr>
<td>Good</td>
<td>6</td>
</tr>
<tr>
<td>Fair</td>
<td>8</td>
</tr>
<tr>
<td>Poor</td>
<td>3</td>
</tr>
<tr>
<td>Very good/Good</td>
<td>11</td>
</tr>
<tr>
<td>Poor/Fair</td>
<td>11</td>
</tr>
</tbody>
</table>

11 of the 22 carers reporting *fair* [8] to *poor* [3] health, while the same number [11] reported their health as *good* [6] or *very good* [5]. Not all carers answered the second part of Question 3.1 about the existence of chronic illnesses or disabilities of their own, however three quarters, answered 'yes'. Only a quarter answered they did not have any chronic illnesses or disabilities.

Next in Q. 3.2 carers were asked if they felt that their caring role had health and well being

<table>
<thead>
<tr>
<th>Q. 3.2 Do you feel your caring role has affected your physical or emotional health or well being recently, or at any time in the past?</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>My caring role has not affected my health</td>
<td>3</td>
</tr>
<tr>
<td>My caring role has contributed to my health problems i.e. Has had a minor effect on my health</td>
<td>12</td>
</tr>
<tr>
<td>Has had a moderate effect on my health</td>
<td>8</td>
</tr>
<tr>
<td>Has had a major effect on my health</td>
<td>10</td>
</tr>
<tr>
<td>Has had a major effect on my health</td>
<td>4</td>
</tr>
<tr>
<td>Moderate / Major effect combined</td>
<td>14</td>
</tr>
</tbody>
</table>
Chapter 13: Carer Health (The Carer Perspective)

Approximately three quarters [14 of the 22] carers answered they had experienced a moderate [10] or major [4] effect. 8 of the 22 carers felt caring had only a minor effect on their health, while only 3 of the 22 carers indicated caring role had NOT affected their health.

Question 3.3 focused specifically on whether carers' sleep had been interrupted by their caring role and 13 of the 22 respondents answered 'yes'. 6 answered 'no'. When asked in the second part of question 3.3 and in question 3.4 to describe how they felt the lack of sleep had affected their health and well being, 14 and 18 carers respectively indicated it had had a noticeable an impact on them. [Mentioned later in this chapter.]

<table>
<thead>
<tr>
<th>Q. 3.3 Has your sleep often been interrupted because of the caring role and responsibilities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=22</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>C-1, C-7 [always], C-10, C-11, C-12, C-14, C-15, C-16, C-17, C-19, C-20, C-22, C-23</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>C-2, C-3, C-4, C-5 [occasionally], C-6, C-18</td>
</tr>
</tbody>
</table>

Ability of carers to go out during the day, evening or take holidays
The remainder of questions in the questionnaire 3.5 were lifestyle related, asking carers to describe what effect the caring role had had on their ability to go out during the day, evening or take holidays. 1 16 of the 22 carers reported they could not go out during the day unless help was arranged to care for the sick or dependent person, or they had to take that person with them.

<table>
<thead>
<tr>
<th>Q. 3.5 What is the main effect your caring role has had on your ability to do each of the following?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) To go out during the day n=22 [Some respondents answered more than once]</td>
</tr>
<tr>
<td>No change</td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>Minor change</td>
</tr>
<tr>
<td>5 C-1, C-8, C-15, C-16, C-17</td>
</tr>
<tr>
<td>You can only go out when help is arranged</td>
</tr>
<tr>
<td>14 C-2, C-3, C-4, C-5, C-6, C-7, C-9, C-10, C-12, C-14, C-18, C-19, C-22, C-23</td>
</tr>
<tr>
<td>You can only go out with the person you care for</td>
</tr>
<tr>
<td>5 C-3, C-10, C-14, C-15, C-23</td>
</tr>
<tr>
<td>You are not usually able to go out in the day</td>
</tr>
<tr>
<td>1 C-10</td>
</tr>
</tbody>
</table>

1 This is the question based on similar ABS questions included in the Disability, Aging and Carers: Australian Bureau of Statistics, 1993, Disability, Aging and Carers, Australia 1993, ABS Cat. No. 4433.0, Australian Bureau of Statistics, Canberra.
Similarly 12 of the 22 carers could not go out at night without the above restrictions, while 10 of the 22 carers reported they could not usually go out in the evening at all because of their caring role.

Q. 3.5
What is the main effect your caring role has had on your ability to do each of the following?

(b) To go out during the evening

<table>
<thead>
<tr>
<th>Effect</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>2</td>
</tr>
<tr>
<td>Minor change</td>
<td>4</td>
</tr>
<tr>
<td>You can only go out when help is arranged</td>
<td>9</td>
</tr>
<tr>
<td>You can only go out with the person you care for</td>
<td>2</td>
</tr>
<tr>
<td>You are not usually able to go out in the evening</td>
<td>10</td>
</tr>
</tbody>
</table>

[Many respondent answered more than once]

C-16, C-18
C-1, C-5, C-9, C-17
C-2, C-4, C-11, C-12, C-17, C-18, C-19, C-20 C-23
C-3, C-23
C-6, C-8, C-10, C-11, C-14, C-15, C-19 C-20, C-21, C-23

It was the last part of the question of taking holidays which provided the most telling results. 15 of the 22 carers indicated they could either not take as many holidays or could not take holidays at all. 8 of the carers 15 carers who answered had not taken holidays for at least 18 months, meaning that many had been caring non stop, day and night without a proper holiday, for periods of two years, some six years and even nine years.

Q. 3.5
What is the main effect your caring role has had on your ability to do each of the following?

(c) To go on holidays

<table>
<thead>
<tr>
<th>Effect</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>1</td>
</tr>
<tr>
<td>Minor change</td>
<td>2</td>
</tr>
<tr>
<td>You could take more holidays</td>
<td>2</td>
</tr>
<tr>
<td>You cannot take as many holidays</td>
<td>5</td>
</tr>
<tr>
<td>You cannot take holidays</td>
<td>10</td>
</tr>
</tbody>
</table>

C-22
C-1, C-17
C-8, C-19
C-4, C-9, C-10, C-17 C-19
C-3, C-5, C-11, C-12, C-14, C-15, C-16, C-18, C-20, C-21

CARERS - GENERAL HEALTH

This next part of the chapter now presents carer comments from the focus group interviews about their health using the headings listed earlier. Comments from relevant open ended questions in the carer questionnaire are included where relevant.

Talking of the caring role and their health in general terms, carers acknowledged that there was an effect and for some their health suffered greatly. Carers reported that the themselves
had disabilities, chronic or serious conditions such as blood pressure, asthma, diabetes, cancer and had suffered a stroke.

"Well it affects your life, it affects your health really, because you get that fed up, the best thing you can do is to go and take it out on the garden." .....C-10[fg2-comb] p.14 L.16-21

"Well I've had a blood pressure problem ever since the first stroke. ... So that has to be kept in check and I guess that was stress and what have you. I am always tired because although if you do go to sleep for a night you are still laying with one ear open, waiting for the fall, ...sometimes you know you can go out and do things but you are too tired to make the effort to do it. I find if I have a commitment like today, I'll do it. If it is not written in the diary, I think, Oh, I won't do that today. So I make myself have commitments that I will keep that are necessary. But yes my health has suffered greatly. "C-17 [fg3-comb] p.12 L.13-22

One carer described how her own health in fact was worse than that of her husband, with a dementia related illness. She as the carer was trying to cope with the demanding caring role as well as her own multiple chronic conditions.

"... as I said to him the other day, 'You've had an A1 bill of health!' - In hospital he had every test known to man and even his eyes hadn't changed since 1985. He can see better than I can and I said to him... I've been pushing you down the street ... you've got an A1 bill of health and I've got glaucoma, diabetes and not only that, I've got a lump on my leg I'm supposed to have taken out... its ludicrous isn't it?" C-6[fg1-comb] p.8 L.8-15

Another carer's comment is perhaps the most significant when she pointed out that for her, (and it seems for most other carers), their personal health needs are relegated to the bottom of the list for things they must attend to. She had said earlier in the focus group that if she had had more knowledge when she started as carer, she may have survived better.

"If you're ill yourself and you go along to the Doctor and the first thing they say is your neglecting your own health. You are not neglecting it, it's just got it on the bottom of the list..." C-7[fg1-comb] p.13. L.11

"I'd like to have known, what I know now, when I started being a carer and I would have survived a lot better I think." C-7[fg1-comb] p.3 L.31-32

Of most concern is the tendency for carers to reject proper care and neglect their own health so they can be at home to look after the dependent person, even to the point of discharging themselves from hospital as described below. Throughout the focus group interviews it was quite evident that carers feared what would happen to both themselves and the person they were caring for should they as the carers became ill. "If you got sick, that's what used to worry me."²

² C-20 [fg3-comb] p.30 L.34
and ... that is a big worry - What is going to happen to the person when I do take ill? Cla-8fg2-comb
p.14 L.28

Current Clinical Status of Carer Participants
Carers were encouraged to list or mention any current medical problems, chronic illnesses or disabilities. This produced a wide range of conditions in some ways consistent with the population health profile. This list is compared with the main health conditions featured in Australia's Health 1995 ? in which the most prevalent conditions affecting people were musculo-skeletal, cardiovascular and respiratory as well as emotional and mental health related problems. The prolonged periods of daily stresses and frustrations are seen to impact on their physical health, with references to stomach 'ulcers', heart conditions and 'weakened' immune systems.

Health Problems reported by carers themselves

<table>
<thead>
<tr>
<th>Always tired</th>
<th>Anxiety</th>
<th>Arthritis</th>
<th>Back problems</th>
<th>Cancers</th>
<th>Constant frustration</th>
<th>Daily Stress</th>
<th>Depression</th>
<th>Exhaustion</th>
<th>Heart conditions</th>
<th>Hiatus hernia</th>
<th>Hypertension</th>
<th>Lack of sleep</th>
<th>Physical injuries</th>
<th>Sleep disturbances</th>
<th>Mentally tired</th>
<th>Stress</th>
<th>Worsening existing health problems- negative effect on general health of carer</th>
</tr>
</thead>
</table>

Of most concern are the number of carers who had serious health conditions requiring surgery but who refused to have anything done. They were not wanting to risk being parted from the person they are responsible for at home, and were determined to put their caring role first, many refusing more complex treatment. In some instances this could be life saving involving cancer or pre-malignant conditions that need prompt attention.

Carers also indicated what made their health worse [see list below]

**Carers' health problems can be made worse by**:-

- Ageing combined with caring
- Denying neglecting or not seeking treatment
- Delaying/refusing surgery
- Declining health/strength/mobility due to ageing process whilst being a carer
- Denial of intimacy
- Guilt feelings and anger about caring role
- Having to live with "a changed person"
- Inability to go out without difficulty
- Inability to live an independent life
- Lack of freedom
- Lack of holidays
- Lack of accessibility to respite
- Lack or loss of friends and relationships
- Little/no recreation
- Loneliness
- Loss of employment and earnings + personal contacts
- Not being able to relax (on 24 hour call)
- Not being able to be spontaneous to do things or take time to have a chat
- Reduced convalescence after illness/hospitalisation
- Social isolation

**Health Needs of carers**
- Relief from anxiety and stress of responsibility
- Rest
- Sleep

Refer also to next section on GPs: Part 3: Carer Health Problems observed and reported by GPs

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**CARER PHYSICAL CONDITIONS / FUNCTIONING**

I next present details of carer health problems according to the broad headings used for the SF-36 questionnaire.

**Musculo-skeletal Conditions**

This particular carer cohort of whom more than half were aged over 65, reported many musculo-skeletal health problems ranging from osteoarthritis/arthritis/rheumatic pain [C-21], oesteoporosis [C-9]. Many carers mentioned back problems, many who also suffered from additional muscle strains. As will be noted, some carers associated these physical health

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4 C-1, C-2, C-20, C-23],
5 C-1, C-5, C-11, C-19, C-21, C-Z] 
6 C-1, C-5 C-19, C-22].
problems directly with the negative effects of the caring role particularly involving lifting heavy patients and wheelchairs. Some of their disabilities, arthritic or osteoporitic conditions are perceived as making the caring role harder, or alternatively were exacerbated by the caring role.

"After my surgery, caring for my son’s physical needs during seizures, hurt my back more. I had a disc removed from my spine 5 years ago and have been in constant pain ever since. Getting more frequent migraines through my back problems. I am limited to what I can do." C-11

"I’ve got a hatchback [car] - difficult to get my mother’s wheelchair in." C-2[fg1-comb] p.3 L. 26

"Putting his wheelchair into the back of the car, I’ve starting getting lower back pain ..." C-Z[fg1-comb] p.1 L.13-19 ...so we invested in a lightweight wheelchair which is easy to put in and out of the car. C-Z[fg1-comb] p.1 L. 31-33

"You do knock yourself about more....- You walk into the wheelchair." C-6[fg1-comb] p.3 L. 18-19

"... one of the things that broke me was her heaviness and my ability to lift her.... We had no wheelchair, we had not way of mobilizing her at all. " C-22 Int. p.14 L.5-8

Husband "...he fell off [the toilet] - because of having one leg... It took about quarter of an hour to get him off the floor, I know there’s not much of him, but it still took us a long time to get him up." C-6[fg1-comb] p.4 L. 1-5

Cardiovascular System / Hypertension

A number of carers identified blood pressure problems while a few others had heart / vascular conditions that either were not being fully treated because of their giving priority to their caring role or were cause for concern to the carer should they suddenly need urgent medical attention themselves.

"I’ve got heart problems. I had an operation eleven years ago, a triple by-pass, and the angina has come back again." C-8 [fg2-comb] p.18. L.35-

"My problem is that I could get an angina attack at any time and if I do I’ve got to get to the hospital, and it’s leaving my husband on his own. But now that I’m with Community Options, I’ve got that back-up and I’m much more relaxed since that has happened..." C-8 [fg2-comb] p.19. L.7-11

"I have a carotid body tumour which I’m told should be removed. Because of my husband’s needs and the fact that such an operation could cause one to have a stroke and I wouldn’t be able to care for him if I did, I’m very very reluctant to have the op. " C-5

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7 C-6, C-5, C-16, C-17,
8 C-7, C-8, C-5

146
Gastrointestinal Tract

For those carers with GIT problems, many mentioned stomach and other digestive ulcers\(^9\) - some directly stress related\(\text{C-7}\). The other notable problem was associated with hiatus hernia \(\text{C-1, C-6}\) which was worsened by all the continuous bending associated with caring and gardening activities.

"I have to do, as well as all the housework, the gardening and everything... I find now bending down doing a lot of weeding at a time I'm getting a hiatus hernia,... bending down putting [husband's] socks and shoes on its coming back a little bit more than I think it should. So I am going to be aware of that so much bending." \(\text{C-1 [fg1-comb] p.1 L.13-19}\)

Other health conditions of carers

Other health conditions described by carers included respiratory conditions of asthma\(^10\) endocrine related, eg Diabetes\(^11\) thyroid and 'nerves'[C-15]. Several referred to allergies\(^12\) and their immune system\(^13\). It was particularly hard for the older carers who had been used to being cared for by their husbands, prior to that person's current dependency, meaning that the wives now had to look after themselves and a sick, ageing spouse.

"Well I have had bronchial asthma and been on cortisone for over 40 years so that sort of put me back a bit because my husband used to do a lot for me and look after me...\(\text{C-20 [FG3-comb] p.12 L.24}\)

"Born with bronchial asthma, have been on cortisone daily for over 41 years, bones and immune system affected." \(\text{C-20}\)

Several of the male carers were being investigated for haematuria and prostate problems\(^14\) and some female carers had bladder trouble [C-15]. One carer mentions breast cancer and had a partial mastectomy [C-7]. Her comment below is of concern, and it should be noted that she in fact is aged under 65 years. She is responding to a question about whether carers felt their health had been affected by a demanding caring role.

"Definitely, particularly seeing as when you do have a health issue. One that still hasn't resolved itself is breast cancer. 10 years ongoing. Its only since [my son] moved into his cottage that I've got a little bit of time. I realise that I just put those sort of things behind me. And now I've got to deal with it. ... I feel as fit as I was five years ago I think. I'm just normal ageing process, just slower, a lot slower at doing things,..." \(\text{C-7[fg1-comb] p.2 L. 6-13}\)
The remaining health problems experienced by the carers include headaches [C-5] and benign essential tumour [C-4]. Several carers had sensory loss due to hearing [C-21] or eye problems due to glaucoma [C-5, C-6].

**CARER VITALITY**

*Carer Tiredness and Exhaustion*

It is perhaps not surprising knowing the constant demands on carers, that the majority complain of severe tiredness and weariness, both male and female carers complaining of exhaustion. Occasionally they will say they are near collapse. Carers in general are too tired to make an effort to do things for themselves, often not following up their own health needs, and especially are too tired to tackle anything new or go out for recreational activities. Several reported being so tired that they felt it caused them loss of memory from time to time. [C-6, C-21]. For one carer, it felt to her as though 'tiredness takes over your life'[C-15].

Tiredness, C-1, C-3, C-6, C-15, severe tiredness C-7, terribly tired, C-23
When very tired - loss of memory, C-7
With my wife needing total care it is very tiring, at times I feel exhausted. C-10
Too tired to make the effort C-17 [fg3-comb] p.12 L.13-22
I was just so weary, I couldn't tackle something else... C-9 [fg2-comb] p.15 L.30
I was just so exhausted. C-22 Int. p.15 L.44
I'm exhausted C-19 [fg3-comb] p.11 L.34-
Tiredness takes over your life... C-15 [fg3-comb] p.16 L.30-32

One carer in the 65-74 early retirement age group, who had been caring on several occasions since her mid twenties, made the following observation of her own circumstances. She compares how she was now with her earlier caring experiences as a younger woman.

**Vignette-1**

"I am finding that now by 8 o'clock I am exhausted whereas before at 8 o'clock I'd just be starting. I would be saying, where could I go? Yes... I'm tired. I...was 24 when mum had her accident, so therefore I was quite young" [when she became her mother's carer]. "What gets me is that there is a lady who lives in the units and she is in her mid 60's, still quite young and she has got boundless energy and I think, 'where does she get it from?'. And that is the thing that is getting at me is that I am 20 years younger than her and don't seem to have her energy."... C-19 [fg3-comb] p.13 L.24-34

Ironically for many carers, even their own immediate family do not see how desperately weary they are feeling, and hence do not give the extra support that is needed.

"It's my own family that is hardest to get through. Family don't think - as you 've got Dad there, you don't need to be taken out... By the time night time comes I am too tired." C-14 [fg3-comb] p.16 L.3-5
Lack of sleep and vitality

One factor that contributes to this profound tiredness and debility in carers is sleep disturbance (and this type of sleep deprivation associated with the caring role can continue for years). This problem is important not only in terms of its consequences on the ability of the carers to function, but its direct effect on their health. Carers were asked in the questionnaire how they felt lack of sleep had impacted on their health and well being.

What effect [has interrupted sleep had] on your health and vitality?

Sleep interruptions for carers in this study affected more than three quarters of the participants. The pattern can be ongoing if caring for severely disabled, mentally unstable individuals or dementing persons who wander at night. Not surprisingly, carers who had recurrent broken sleep did complain of severe tiredness,[C-8], sheer exhaustion [C-21], and listlessness [C-21]. They felt irritable [C-19] and some had longer term problems with insomnia. For example:

"Broken sleep due to the caring has created listlessness as well as sheer exhaustion which have influenced my health". C-21

"I sleep lightly as my son’s seizures are nocturnal and necessitate jumping up when I first hear him convulsing. Sleep is constantly interrupted." C-11

"When my husband was home full time I could not sleep and got quite ill. Now he spends 4 days in nursing and still have trouble sleeping because of worry all the time." C-15

"Before his tablets were adjusted, he was having hallucinations - up sometimes 5 times between midnight and 5.30am. [Now he sleeps right through the night.] On bad nights I get no sleep - but he needs constant supervision next day." C-6

One carer felt near collapse, eventually needing medication to help her to sleep, while others reported that the tiredness caused depression and a feeling they were not coping.

"Am never sure how I really am until near collapse - need the help of pills to sleep. C-7

Tiredness causes depression and the feeling of never quite coping with everything." C-19

Vignette-2

"She [daughter] was sick the first 12 months she was home. I reckon I was lucky if I got 2 hours sleep a night. She used to vomit - she used to cough and vomit. I would be washing sheets and blankets once, twice, three times a night in the washing machine. That year would have had to be the worst initiation anyone could have had into caring. I was just beside myself in the end." C-22 Int. p.11 L.43-47

When asked if sleep interruptions had interfered with their normal daily activities, 16 out of 20 respondents answered yes. Only 2 of all the carers replied no. Carers again highlighted the problems of ongoing or chronic tiredness from lack of sleep [C-11, C-15] which produced effects on the next day(s) of draining their energy levels, causing them
confused thinking and reduced alertness. They found it hard to stick to a set routine, too tired to plan irritable and accident prone. This carer commented that she had little joy in life at the time [C-23].

Tiredness in the morning which makes arising and taking part in the remainder of the day a depressing objective. C-22
Broken sleep leaves me tired next day C-1
I find my energy level becomes effected. C-16
I don’t seem to have the energy to do anything. C-10
Being too tired to do as much as I would like to do. C-8
Has tended to slow down my activities and created confused thinking. My alertness is badly dulled. C-21
I suppose I had little joy in life at that time, tending (to be) irritable and accident prone. C-23

CARER EMOTIONAL FUNCTIONING

It is clear from the carers who participated in this study that the role and experiences of informal caregiving can have a major impact on their emotional health. The sheer volume and depth of carer responses is testament to that. As described there is a noticeable link between carers' emotional and social functioning that ultimately interacts on their overall well being. For example lack of sleep, tiredness, stress, loss of friends, feelings of isolation and lack of freedom, all associated with their caring role, can result in an altered lifestyle and a loss of confidence which in turn may impact on their ability or inability to function in life. As one carer said, 'you can just be engulfed by the caring role'. This will be discussed further in the chapter on social functioning.

For the purposes of analysis most of the emotional type feelings expressed by the carers, including stress and anxiety have been grouped under a heading, separate to depression which is dealt as a mental health issue. There is much overlap between all these areas and it is hard to differentiate as one carer's comment attests.

"Well it [caring] certainly has affected my emotional and mental health. I'm sure. My physical, other than the tension myalgia, is good. ..." C-22 Int. p.17 L.16

Carer participants when asked how caring had affected them described general feelings of irritability, frustration, guilt feelings C-5, and anxiety C-16 to name a few. Another said she felt frustration more than burden16, while one gentleman said he felt suffocated in the sense that his wife (who had dementia) was always following him around. She 'competed with

15 C-11[fg2-comb] p.16 L.1-21
16 C-X[fg2-Noarlunga] p.39 L.1-2
his shadow). This was not an isolated experience as several other carers made similar references during the focus groups. Here a wife refers to her husband.

... He’s my shadow. Although he’s slow, his mobility is slow, he can still be there, you know.”

C-1[fg1-comb] p.6 L. 29-30

Speaking specifically about emotional needs, the carer with a severely disabled child suggested what she had needed was: "... a counsellor - so some sort of counselling agent - a specialty in counselling. We...need somebody who has got counselling skills who is a parent or carer whose got to have those skills to be able to talk to other parents and carers. One of the main fears of carers is that they might die before the cared for person. In the case of a parent carer the worry is - "what's going to happen to the kid?"

CARER STRESS

Without doubt stress, along with tiredness, were the dominant and recurring mantras of the carers in this study and is consistent with the published literature of the past fifteen to twenty years. 13 of the 22 participants talked in my study about the stress of their caring role as affecting them directly, while many others made passing references to their having felt seriously stressed and debilitated.

"I found it very confining. Also stress got to me very severely on several occasions. But I have a very supportive family. They will take dad, leaving me with 2-3 days to myself, but freedom is a big issue for me and accessibility- it is not easy to get into respite."  C-12 [fg2-Noarlunga] p.38 L54-56
Stress is a major contributor. C-12;
Stress and anxiety are 2 major concerns. C-8
Sometimes stress causes problems. C-2

What is significant is the ability of the carer to deal with that stress within the constraints of the caring relationship. Another carer, the mother of an intellectually disabled child, explains as many other carers experienced, the usual de-stressing strategies people may have used, to help themselves, often can’t be used because of the restrictions of their role and needing to constantly be with the cared for person. It cannot be presumed that carers can have access to enough in-home support, nor would they use it for these sorts of activities, when there are more pressing uses of their free time.

"Makes life more difficult because I can’t do the physical things I used to-to alleviate the stress of caring for my son -ie. hiking, riding, gardening, driving, classes, etc. C-11

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17 C-4[fg1-comb] p.5 L. 10-11
18 C-22 Int. p.19 L.22-26
19 C-22 Int. p.19 L.41
20 Stress mentioned by carers: C-2, C-3, C-4, C-7, C-8, C-12, C-23, C-17

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Identifying exactly who or what are the provocateurs of that stress is difficult. For example just 'coping' with the caring role was in itself was a source of stress. Coping for the ageing carer is an additional element that adds stress to caring. Even seemingly simple activities like having to transfer frail, sick or dependent and disabled persons into the car for an outing or an appointment can be difficult as one daughter wrote: "Taking Mum out is very stressful for me." Another found her stress was mainly due to having to run backwards and forwards to hospitals.

Having to leave the cared for person at home on their own for short periods while the carer slips out for essential shopping, (or even with a sitter to keep an eye on them) generates fear in the carer for the safety of that person should something go wrong. This puts the carer under pressure to complete their errands as soon as possible so they can quickly return home.

"I think it’s just a little bit stressful sometimes, cos you’ve always got that, I suppose, while you’re away..." C-2[fg1-comb] p.2 L. 17-18

Coping with behaviour change in the cared for person

Carers in my study, as in the published literature felt great emotional strain trying to cope with and accept behaviour change in those they were caring for, especially those with dementia related conditions in adults or brain damaged induced intellectual disabilities in children. It also had the potential to dramatically alter their relationship either with the spouse, the parent or a child, adding that extra pressure to an already stressed environment.

A male carer looking after a very dependent wife with dementia describes his reaction to his caring role which in the example he gives below shows that even the seemingly simple tasks may become insurmountable.

[Caring] "It worries me. It puts me under stress...You see on top of that, taking her to the toilet, lifting her up holding her up and putting her clothes on... it's physical and that gets you down. C-10-[fg2-Nourunga] p.39 L. 36-41

Secondly many carers may not properly understand their spouse’s medical condition and feel stressed and a bit out of their depth. Whatever their attitude to the caring role, the stress can build up and in several instances the carers reported as loss of confidence.[See also later in chapter in social functioning section].

"I find that I’ve lost confidence. I go in spurts. When the pressure gets a lot of caring my confidence goes down and I think hang-on, we’ll do something about this. So, I work at it for days. As the stress builds up again you just sort of get exhausted as that exhaustion comes on my confidence goes down again." C-10[fg2-comb] p.14 L.5-9 and 1.32
As the stress intensifies and the cycle remains unbroken carers express almost a sense of desperation as revealed in this next quote.

"I gave up working 12 years ago to look after my husband. I think I have had a steady decline in my health. I get very stressed at times and just feel you don't know how much longer you can go on that way, but something happens you go on a holiday and you go on." C-11 [fg2-Noarlunga] p.39 L.17-19

For some carers they don’t bounce back, reach burnout [C-17, C-23], or experience an acute clinical episode. Several of the carer participants referred to as a nervous breakdown, one at the point when she felt she could not leave her disabled child in care.

"I was working at that time - I had a nervous breakdown, I managed to keep it all together until - ... the car blew up on the way down to go to the hospital..." C-22 Int. p.14 L.51-

After medical attention one carer realised that the medications rather than helping her were making her worse and that the caring related problems causing her emotional distress were still there. As the carer she had to deal with the issue and work out solutions herself.

"So it's that stress of .... all of that - I went down to - I saw Doctor - she said we'll put you on some medication. And 2 days of that and being stupid, I said enough. I rang her up and said I can't I can't. I had lost my edge - I couldn't keep my head around things so I decided that it was better that I solved the problems and got rid of the problems as much as I could ... " C-22 Int. p.11 L.18-25

CARER MENTAL HEALTH

Depression

This last example raises some very important issues for consideration by clinicians when carers are being treated for depression or related conditions with medications, which in fact might not be the optimum or preferred first approach. These carers, unless adequate respite and other carer support, is part of the management, will because of their responsibilities at home, continue to keep on caring whilst on medication. As already described by the carer above, they may feel they don't want to be dulled down whilst taking tablets so that they can't function and understand that caring role competently under medication. In those circumstances many carers will not comply. The problems that may be causing the depression, in cases relating directly to their caring role, need practical solutions.

For some carers therefore, the grinding problems of being an isolated caregiver with no end in sight, compounded by the stress, worry and anxiety it brings can lead to depression as one carer suggests below. Almost a third of the carer participants in this study had either experienced depression or wanted to discuss it during the focus groups.21

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21 [C-1, C-4, C-7, C-11, C-17, C-22, C-23]. 153
"It happened when he was younger - that's when I couldn't cope well with other things in my life and became very depressed, often waking at 2-3am." C-23

"I think the stress then leads to some sort of a depression and then it can only be alleviated by a holiday of some sort. Just charging your batteries again somehow and with most of us we don't know how long it's going to be. Sometimes if you could see an end to the caring you might feel more optimistic, but I think the daily stress is not good for your health." C-11 [fg2-comb] p.15 L.15-20

It was not until I interviewed the GPs that some very interesting views on carers and depression emerged. [See Chapter 16.] In relation to mental health of carers, there were some significant findings from the Health Omnibus population health survey using the SF-36. [See chapter 21.] It should be pointed out however that carers did not show scores of those in the population with clinical depression or mental illness. It was more an indication that the mental health of carers had been mildly affected or that it could be at risk.

CARERS - SOCIAL FUNCTIONING

It is clear that there is potential for a flow-on effect on the social functioning of these carers. In addition there is potential for specific social problems associated with the caregiving lifestyle, like loss of friends, isolation, loneliness, lack of personal freedom and other restrictions, to impact on the physical and emotional health status of carers. I suggest it would be inappropriate to try to maintain these as separate entities, but for the purposes of presenting research results in this thesis, the data have had to be dealt with separately in this chapter.

Not surprisingly, some of the most passionate and erudite responses from carers were in relation to their social experiences of caring. This area is closely aligned with comments about their needs, so I have focused on those problems which seem to have impacted on their ability to cope as the carer, or continue in the caring role. I start by revisiting the concept of the carer being 'engulfed by the caring role', and the need for carers to fight for their survival.22 This image permeates many of the carer testimonies.

Vingette-3 [This vingette follows on from conversation on the importance of carers participating in outside activities apart from caring ]

"I think a carer has to do this for their own survival. ... "I belong to about eight organisations. I've tried to keep up what I was doing before mainly for my own sanity and so that when that time comes that my mother's no longer there that I'm not just sitting at home with nowhere to go. I want to be able to keep on with these other things that I'm doing, but between the two you get a bit rushed sometimes.

22 [C-11[fg2-comb] p.16 L.1-21].

154
"And I couldn’t do it without the sitting service which has been so good, the Noarlunga Sitting Service, and my brothers and my sister help too. But I think you’ve got to do it for your own survival or you can just be engulfed by the caring role ..."  C-11{fg2-comb} p.16 L.1-21

The experience of multiple loss in each carer’s life

This study shows that the other important impact of caregiving on social functioning is one of loss. Multiple losses in fact. Carers described not only their loss of friends and their social life (leading to emotional isolation), but the lifestyles of carers are illustrated by loss of jobs and loss of income, many having given it up to take on full time care of a family member.

"I just didn’t realise how much I relied on my work for conversations, contacts, all those things that were of benefit... all that contact went." ... C-9{fg2-Noarlunga} p.39 L. 8-15

"You do give it up [freedom]. - that's logical. You see you have nothing left. No've no life, no sex life, no nothing. And I mean, sex life that means nothing now at our age, but you’ve got to give up everything else. ...I play bowls once a week... It is the conversation that is the main thing. I like bowls, but you get into the club rooms and talk to somebody...."  C-10-{fg2-Noarlunga} p.39 L. 45-49

Also loss of their relationship if the person is dementing or behaviour changes. Added to this for some is the lack of opportunity to enjoy normal conversation with the other individual, (a married partner for example), not only on present day issues, but about their shared past.

"Intelectually. I'm fortunate that I've got friends who think the same way I do now. There was a time that I felt starved for people who think ..."  C-22 Int. p.20 L.22

It is not usual for spouse carers to talk about losing their past as the husband or wife's condition declines.

"We’ve lost the past, at least I’ve lost the past. We celebrated last month, our 52nd wedding anniversary, and showing my wife the photos of the wedding and all of this, she doesn’t even recognise herself. So, that is something that is lost, and gone."  C-4{fg1-comb} p.6 L. 17-20

This compounds their sense of isolation and loneliness, despite living in the same house with the loved one they are caring for.

"You are lonely because if you go anywhere, you can’t share, you can’t tell them, it doesn’t go in...and even though they are there, you can’t talk about it when you get home.. Well I can talk about it, but he’ll say, like this morning, “Tell me”. I tell him but... This is like the negative side, but if you dwell on that, you’ve had it "  C- Z{fg1-comb} p.7 L.10-17

"What I find is... emotional isolation... like I can’t share things, although he can speak, with him now like I used to, because the perception of anything emotional,..."  C-6{fg1-comb} p.6 L. 10-12

For parents of severely disabled or brain damaged children they mourn the child they will never see develop normally to a full life. Carers feel angry for themselves and the child and
Chapter 13: Carer Health (The Carer Perspective)

despite it is usually their decision to be the carer, they are acute aware of what they have missed out on or what they may miss out in life.

"Their loss of their life, their loss of their kid's life, the loss of the rest of the family's life, C-22 Int. p.19 L.35-37

"...I made a conscious decision to bring my daughter home but I still get angry about what I've not been able to do... what I've missed out on. I make a real effort not to miss out on too much, let me tell you. " C-22 Int. p.19 L.46

Being attached so intimately to the constant care of a sick individual who requires additional support by paid health care workers, family carers lose their privacy both in terms of personal space in the home, and the knowledge by outsiders or formal agencies of their personal life. The latter group play an important role in negotiating government funding for carer support, but the trade off is sacrifice of each carer's privacy.

"... I know that I've missed out on being very independent and not having to tell anybody my business, you know. To be able to get what I've got I have to tell people my business and I don't like that." C-22 Int. p.19 L.52-

"... I laugh about the confidentiality bit... I think every government department in Adelaide knows more about me than I know about myself. It's just a bit of a joke. " C-7[fg1-comb] p.6 L.1-3

Overall there is a loss or reduction in the actual quality of life some carers experience that results from their sharing the life of another person who is sick, disabled, frail and dependent. When discussing this during an interview one carer described her idea of quality of life, which she was unable to achieve at the time. Hers was a fairly basic concept.

"Quality of life for me could be having a reasonable income, good friends, a decent car." C-22 Int. p.20 L.13-14

I have already highlighted the serious consequences of sleep interruptions for carers. Carers may also change their own eating habits and diet to suit that of the chronically ill person so that it makes shopping and meal preparation easier for them. However their caring role may also mean a serious loss of freedom as their caring responsibilities as well as their chronic tiredness leads to restrictions in the carer's ability to leave the house to go out day, or at night.

How it has affected me, I no longer have friends. They went by the wayside many years ago because, you could not plan more than a day ahead. So if they said to you, would you like to go out Saturday week? You would say, Now hang on, I've got to get through today and tomorrow, so therefore ... no friends, so my friends have gone." C-19[fg3-comb] p.11 L.34-

For many this reduces the spontaneity in their life, the inability to follow up intellectual pursue like study, or with hobbies, and other recreational past-times.
Vingette-4

... hadn't been able to pursue my hobbies, play the organ... I've got wonderful neighbours either side, but to have a little chat with them... I find that difficult because if I get into a conversation with my neighbour, ... then all of a sudden I think, ... I'd better check B and I go in and he'll say, "where were you? I just wondered where you were I've been all round the house and couldn't find you ..." Because it was a spontaneous thing. It wasn't like, if you know I might tell him, I'm just to pop over to D's, and tell her so and so, you see that's alright because I was going to do it and I've told him. You know anything spontaneous..." C-6(fg1-comb) p.4 L. 25-36

Some carers even relinquish the most basic right of a taking holiday for themselves. Many are not able to plan ahead, lead their own life, or control their own life any more.

"I could do a lot more things than I do... probably would have more holidays too. I just feel as though I am marking time. Not leading my own life." C-11(fg2-Noarlunga) p.39 L. 23-32

"The problem was not actually being able to go away ..." C-22 Int. p.13 L.16-17

Multiple loss, restriction and self confidence

As these losses and restrictions mount up some carers talk of a loss of self confidence to interact as they used to, before taking on the caring role, and they question their social abilities and skills. These emotional deficits are for some, worsened by ageing or a decline in their own physical and mental health as their world shrinks ever more within the four walls of their home. Finally as their resilience is sapped and their very ability to cope as a carer in that restricted world may be challenged by an additional burden placed on them or an unexpected crisis and they find it too much to continue. The catalyst for their demise is often the sudden change or deterioration in the health of the cared for person.

"When it starts to tell is when there are other demands from other members of the family or the condition of that person you are caring for deteriorates "

"You can actually cope with a certain amount, I could cope with the first five years pretty good, but then when a had a second major stroke suddenly I couldn't cope any more and that's when ...suddenly I went to pieces and couldn't cope anymore." C-17(fg3-comb) p.31 L.20

The above summary is a very negative and one sided account of the demise of some carers, and does not represent the two thirds of very successful and able carers who carry out their home care duties most ably and efficiently. Carers gain important coping and caring skills themselves and a large proportion of carers do see their caring role through to an end point when the person dies peacefully either at home or in hospital. A more positive example is where younger disabled individuals who are able to, assume a limited level of independence and live in supported accommodation in the community - apart to the parent carer. However, whatever the outcome for the cared for person, too many carers tell stories
of extreme sacrifice and great cost to their own lives, and for that reason I included the selection of statements above from participants in my own study.

Below I list a summary of the types of losses reported by carers from my study:

Loss of friends, conversation, social life, lifestyles, quality of life, opportunity, jobs, income, hobbies, intellectual pursuits, privacy, freedom, relationship, sex life, family life. Loss of the past, (if the cared for person has dementia, and loss of the future with a physically/intellectually disabled child, ie Loss of experiencing the child's normal life and development - especially if problems start from birth.

WHAT WOULD HELP CARERS' HEALTH AND WELL BEING?

Finally carers were asked in the questionnaire, Q.3.8 for suggestions on what might contribute to their health and well being. For purposes of clarity and brevity I present this as a 'wish list'. Their priorities again focused on key areas examined above, ie more sleep with overnight respite; more private time for rest; to be themselves rather than always the carer; to have a break away and extra services to help with the caring and help alleviate the stress. More understanding by people and General Practitioners and other doctors / clinicians; plus adequate funding and an appropriate environment were highlighted by the parent carers. Interestingly the carers were still not specific about what type of medical care and emotional support they would prefer. Listening to their conversations during the focus groups I sensed that they were keen for doctors and other health professionals to take more of an interest in their health, but were hesitant to do anything to detract from their caring role.

<table>
<thead>
<tr>
<th>Q. 3.8</th>
<th>Can you think of anything that might help to maintain or improve your own health and well being?</th>
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| **Sleep** | To be able to sleep without disturbances at night C-17  
Having weekly 1 or 2 nights sleepover and more when my husband was walking and yelling all night. C-20 |

| **Break / Holiday / Respite** | To be able to take a week off more often C-17  
Access to respite needs to be improved on both long and short term C-12  
Regular short respite (once a fortnight) therefore less stress C-19  
The ways and means to go abroad and other places - the impossible that my husband will want to go too. |

As my husband and I get older we shall probably need more assistance, but at the moment he has a sitter once a week and goes to a day centre 1and 1/2 days per week to

If I could rely on staff at nursing home to do what I asked of them for my husband's best interests. Also to be able to have a short holiday more often C-15
Yes, an absolute break away from the caring for at least a month. Some form of complete relaxation from all pressures on the mind and body. When my caring ceased, I noticed that my mind of its own accord, was constantly trying to shut out al memories of my caring period as though trying to mend itself, and I soon forgot many of the small things I did for my wife. C-21

Be seen as self
To be considered by other as a person - not mother’s carer C-18

Time For myself
Quality time to myself C-17
A little time on my own to rest C-1
Time alone - seems impossible! C-7

Services
Getting the extra help I need C-10
Suitable services for my son, alleviating stress on myself; More understanding by other people and GPs in particular of my difficult role C-11

Being aware and availing oneself of the support provided through community carers programmes C-4
No. Since I have been included in Community Options Program I have felt much more relaxed. C-8

Funding
At least double the current pension or an adequate living wage with higher levels of funding. to provide adequate support for daughter. Individual funding managed by me which removes the necessity to be continually telling people your plans. C-22

Environment
Living in a community with other families and support workers and disabled people C-23
To know that my son could live in his own home and be supported by others to maintain the lifestyle I have been able to create for him C-9

OVERVIEW SECTION II- CARERS - SUMMARY PARTS 1-4

Carer responses to the 4 parts of this section illustrates the human face of carer experiences of their caring role, their needs, their interactions with their GPs and carer health. The satisfaction of maintaining the familial relationship, accepting responsibility for and protecting the quality of life of the cared for dependent sick or disabled adult or child, is central in all carer accounts. Many carers felt their was no acceptable alternative for the care of their loved one. Being able to trust (or not trust) others to care for their loved one, even temporarily, is pivotal to the carers’ choice to care, and to keep on caring. However with the caring role and responsibilities come multiple personal losses, lifestyle restrictions, limitations and challenging changes as each carer lives the life of someone else’s illness, disability or frailty. Older married carers of partners, recognised that their own ageing made the caring role more difficult, but they seemed to be more accepting of their circumstances than younger parent carers of disabled children. Parent carers touched on the overwhelming feeling of burden they felt facing a lifetime of caring for a disabled child who might out live them. [It became clear that today’s parent carers will be tomorrow’s ageing parent carers.]
Chapter 13: Carer Health (The Carer Perspective)

Despite the demands on them, carers needs were simple and practical reflecting the ongoing caring role (nursing or supervising) in the family home. Their list of needs were broad, changeable and time bound, according to the stage of the cared for person's illness or condition, as well as the age of the carer and the dependent adult of child. Carer needs can be interpreted as both role oriented and service based, while the personal needs of carers can be explained in terms of Maslow's hierarchy of basic human needs. Unmet individual needs of carers, can make it difficult for carers to achieve their full potential and this impacts on their social functioning, health and well being.

The majority of carers are in frequent contact with their GPs (5-15 times a year) either for the cared for person or themselves, and most carers report that they are recognised in that caring role by the doctor. Some carers were reluctant to be open and honest with their doctors about their own health problems for fear of appearing not able to cope, but carers reported their doctors had been very helpful, reassuring, supportive and generous with their time. Where carers had the same GP as "the patient", the carers' own medical problems did tend to be overshadowed by that patient's needs. Although attendant to the carers' medical information needs, most GPs of the early to mid 1990s were unaware of the newer carer, respite, or community support resources to which carers might have been referred. Information about practical aspects of caring services and benefits were hardly every offered to this group of carers.

Discussing their health, half of the carers reported their health only as fair to poor, and about three quarters of those experienced a moderate or major affect of caring on their health. Some carers complained that their own health was actually worse than the person being cared for (eg where that dependent person had dementia or other cognitive problems). Carers' physical health problems focused on their existing clinical conditions or additional musculo-skeletal strains and injuries associated with lifting heavy patients and wheelchairs. It was clear that the main problems faced by carers centred on their social and emotional functioning, worsened by sleep interruptions, tiredness, exhaustion, distress, worry, stress and anxiety. Lack of confidence, fear of not coping, burnout and depression were compounded by multiple personal losses. One important catalyst for the demise of carer health was the sudden change or deterioration in the health of the cared for person. Carers felt they needed sleep, extra home support services, a break and time and space for themselves.
GP DATA

FINDINGS FROM INTERVIEWS, FOCUS GROUP & QUESTIONNAIRES

GP OBSERVATIONS

PART 1: IDENTIFYING THE CARER IN GENERAL PRACTICE
PART 2: NEEDS OF THE CARER
PART 3: HEALTH OF THE CARER
PART 4: THE NEEDS OF GPs TO SUPPORT CARERS
DISCUSSION SCHEDULE and INTERVIEW GUIDE
FOR GENERAL PRACTITIONERS

Part I Identifying the carer in General Practice

(1) What is your understanding of a "carer" or "informal caregiver"?
(2) How does the GP perceive carers’ roles and responsibilities?
(3) How do you recognise carers in your own practice?
   What about parents of disabled or chronically sick children, or close friends and
   neighbours who are maintaining a mentally or physically ill person at home - are they
   also seen as carers?
(4) Why do you think some people are not seen as "carers" in general practice?
   What makes it difficult for GPs? What assists GPs to recognise "the carer"?
(5) Is it easier to identify carers in the surgery or when the GP visits the patient/family at
    home?

Part II Needs of the carer

(1) As GPs, what needs of carers are you aware of amongst your patients and their families?
   Can you give some examples of those needs?
(2) Do you spend time talking with family members/carers about how they feel about being
   the carer, and what their needs are?
(3) Can you give some examples of what GPs are already doing for carers?
(4) Where could carers go for help with their non-medical (social) needs?
   i.e. does the GPs see this as their role or refer the carer elsewhere?
(5) What "outside", community services do GPs refer family members/carers to?
   What about HACC, local government,
(6) Do GPs feel they have enough information about local community services, counselling,
   home support services, support groups?
(7) What would assist GPs to have access to more useful information for carers?

Part III Health of the carer

(1) Have GPs noticed if the caring role has affected those carers with existing health
   problems or who are at risk? Can you give some examples?
(2) Are GPs aware if the caring role has been a direct cause of health problems amongst
   people who are in a caring role?
   e.g. Have GPs noticed if when a carer is ill, requiring bed rest or hospitalisation,
   does that person have adequate care themselves?
(3) How can/does the GP help
(4) What other measures are GPs already taking to support the health needs of carers? Can
   you give some examples?

Part IV GPs needs and suggestions

(1) Can you suggest what would help GPs in meeting the needs of carers?
   Information, backup and other support, resources, short courses
(2) What do as a GP want or need regarding issues of reimbursement/rebates for time spent
   with carers?
CHAPTER 14
PART I: IDENTIFYING 'THE CARER' IN GENERAL PRACTICE

Introduction
The purpose of asking about the recognition of carers in general practice was to provide an overview of GP knowledge on carers - drawing on the actual language GPs used and the ideology on which their knowledge was based. This was in the context of the term 'carer' having emerged relatively recently within policy and academic arenas over the past ten to fifteen years. Carers in relation to informal carers and other family caregivers, was not necessarily part of the medical or clinical vocabulary prior to the early 1990s. In many ways this terminology has been imposed on the medical, professional and wider community. However the tradition of family medicine has always offered a unique approach to supporting relatives, spouses, family members and significant others - in essence, supporting the informal family caregivers. More recently 'carers' have been specifically identified and referred to in many parts of the current GP Training Curriculum of the RACGP 1999, but this does not assume that GPs 'in the field' are as familiar with or accepting of this language. Hence the first part of my study that focuses on GPs.

Five main questions about GPs recognising carers were posed in Part I of the Discussion Schedule (See opposite page). Also in the GP Questionnaire, there were another three questions referring to identification of carers which included:

1.1 How familiar are you with the term "carer" (ie informal caregiver)?

1.2 What is your understanding of the role and responsibilities of a person who is an informal carer to a dependant person (adult or child) in the home?

4.4 Some family members and other carers have perceived a lack of recognition by health care professionals of the carer's role and responsibilities. (Why do you think this is occurring?)

The reader will recall in the methods chapter (p.78-9) I discussed that my General Practitioner respondents were gathered from a number of attempts to recruit GPs in the southern region of Adelaide and environs. The first group (most of whom were also interviewed) are coded D-1 to D-13 and the second group who returned survey questionnaires, are coded D-14 to D-25. With due care I have incorporated their recorded answers and comments as if they were one population. (A summary of all questionnaire results are included in the Appendix.)
Chapter 14: Identifying 'the Carer' In General Practice


How familiar are you with the term "carer"?

Four out of the twenty five GPs indicated they were not familiar with the term 'carer'. Most however responded that they were either very familiar [16 out of 25], while the remaining 5 GPs marked they had some familiarity with the term. Question 1.1 also asked: If you are not familiar with the term 'carer', how would you describe that person in an informal caregiving role (eg as a spouse, relative, parent, friend, neighbour.) Very few GPs provided written answers to this part. Only one wrote "relative". During the Focus Group GPs were more descriptive, commenting, "... 'carer' is ... a broad term ... and could involve a family member - probably spouse or daughter, rarely a son ... might be a caring neighbour." D-11 [INT.3] p.2 L 12-13.

Another GP similarly described a 'carer' as "... a spouse, or husband, wife, daughter...", concluding, "...generically speaking I guess they are carers."

Exploring the meaning of 'carer' on a face-to-face basis with GPs yielded a slightly different response and highlights the value of research methods that are not just based on brief written responses. Amongst the GPs who were interviewed, including those at the focus group, all GPs indicated some degree of familiarity with the term, but several quickly rejected 'carer' as a term that they themselves would personally use on a day-to-day basis.

'Carer' - A label

Several GPs were quite reluctant to use the word. For example, they commented, "I guess it is not my term"; and "... it's like a blanket term ... it is a term which has an increased understanding in recent years and carers have been identified more as a group with particular needs." Another added; "I use the term when ... talking to agencies ... is not the term that comes into my mind." The same GP summed it up by saying, " I suppose I have dealt with it without ever putting any label to it...". This idea of imposing the label of 'carer' on people concerned several of the GPs when interviewed. For example, "I am uncomfortable putting labels on people because it sticks - and they never get rid of it." A second GP agreed adding reflectively:

1 D-10 [GP FG: p.1 L.16-19].
2 D-10 [GP FG: p.1 L.11 ]
3 D-13 [GP FG: p.2 L.5-8].
4 D-10 [GP FG: p.1 L.32-34].
5 D-3 [ GP FG: p.1 L.41-43]
"I don't like labels because they remain a carer for the rest of their lives and they have their own rights and needs." D-3 [GP FG: p.1 L.50-52].

The main priority for GPs seemed to be to maintain the dignity of each person as an individual: ie "...you always try and refer to them as individuals." Several GPs preferred to talk about carers as "support people".

"I am familiar with the word 'carer' but I tend to use the word 'support person' which is a broader term ... covers any person whether it be a relative or a person from outside of the family." GP [D-8] INT.2 p.1 L.7-10.

At its most simplistic, carers were perceived by GPs as looking after patients at home - "People in the home, people looking after them." Expanding on this one GP saw carers as:

"...anyone who has responsibility for assuring that the needs of the patient are supplied. The health, welfare, food..." D-10 [GP FG: p.1 L.19-21]

The concepts of role and responsibility are now explored in more detail below.

**Part 1 (2): THE CARERS' ROLE AND RESPONSIBILITY**

Question 2 of the Discussion Schedule asked: "What is your understanding of the role and responsibilities of a person who is an informal carer to a dependant person (adult or child) in the home?"

The Role of the Carer

When considering the role of the carer, many General Practitioners again cited the provision of 'support' (that was reliable, friendly, and sympathetic support). They described it in both terms of physical and emotional support, as well as care, company and nurture and "TLC". It was recognised that such assistance was needed by "a dependent person in activities of daily living", "to do things they would not normally be able to do themselves". Several GPs indicated that the role of the carer involved supervision of all

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6 D-9 [INT.1] p.1 L.16-17
7 D-3 [GP FG: p.1 L.41-43].
8 D-3 [GP FG: p.1 L.41-43]
daily needs including medication and medical treatment, also the administration of all cares for dependent person(s). Only one GP mentioned that the supervision involved 24 hour care & the need to watch for safety.

Terms such as to 'help' and 'look after' a (dependent) person in whatever areas he or she needed help were occasionally used, more in common with the idea of a carer being 'similar to a parent of a young child'. However the greater emphasis was on a more intensive approach, evidenced by several GPs describing the type of care as that of "an unpaid nurse". One GP summed up the type of care involved as:

"This is usually quite intense in a physical or bodily sort of sense (like a nurse) but often involves psychological support too." D-9.

This view links the idea of the carer's role not only with responsibility, but also with a form of accountability or reporting back, described in the following way:

"To provide a reliable, friendly support/aid to a dependent to meet daily living requirements to meet and to communicate any difficulties in meeting those requirements to any appropriate person/body." D-8

The Responsibility of the Carer

GP responses in the Questionnaire about a carer's responsibility, not only referred to the general care of a dependent person, and "being responsible for the dependent's needs being met", (either in person or by someone else), but also being responsible for someone's health, well being or welfare. For example:

"...seems to be full time job-with significant responsibilities for health and social well being of (the) dependent person." D-24

Even more specifically another GP referred those responsibilities to someone who was a 'patient'. Ie "Physical care and/or overall responsibility for all aspects of patient's well being." D-10. Other descriptions of carer responsibilities were specifically task and activity oriented. For example carers were:

"Responsible for the day to day care of the dependent, ie dressing, feeding, toileting, medicating, entertaining etc." D-15

"Responsible for all day to day activities of living and organising all affairs - dressing, feeding, giving medication, taking to appointments, helping with mobility, helping with toileting and bathing etc." D-25

Finally, as an example of the commonest and hardest responsibilities for carers, one GP suggested that might be managing dementia (Alzheimers). "Spouses manage year after year... don't want to put their spouse away."10

10 D-11 [INT.3] p.3 L. 6-10
When care is over and above the expected

At interview, GPs were also asked to further reflect on their understanding of the role and responsibilities of a carer in the home. Many of the themes to emerge from the questionnaires, (ie of providing nurture, total care and support for a person's daily living needs, or their individual welfare) again appeared and were expanded in the GP interviews and focus group. Of most significance was the perception, by at least three GPs, that the role and primary responsibility of carers in terms of the provision of care, was over and above that of the normal relationship and involved supporting patients with an illness.

"I think a carer then becomes a person who has to provide over and above what we consider normal for a patients to cope with their illness... when an illness lasts longer than one month or so."  
D-8 [INT.2] p.3 L.1-6

"Families feel trapped but they... have a responsibility. If it goes on for a long period ... then they're likely to break down a bit, but they do often feel they have a responsibility."  
D-11 [INT.3] p.2 L. 52-55

One GP acknowledged however that some carers are non-related, in the case with neighbours. For example:

"It's a long term responsibility and where it breaks down .. is when the responsibility goes past a period then feel trapped and then it breaks down at that stage. I'm thinking of neighbours."  

Such a role of carer, added another respondent, "comes with a high degree of responsibility and a clear understanding that the person receiving that care is dependent on the caregiver and what happens to the recipient is very much the caregiver's problem". The idea that a lot of responsibility also has, "a lot of potential for stress and anxiety" soon emerged in the conversations. One GP in a separate interview volunteered a description on carers of psychiatratically disturbed people, the caring he considered to be "...usually more psycholoigcally stressful, especially if the psychiatric patient is unstable." He described elderly parents looking after a psychiatric son ... The GP had observed:

..."they were just falling apart. Their health was suffering because of it."  

What The Carer's Role Involves - What the carer does

Referring specifically to the carer’s role, one GP commented that, "It depends on the severity of the disease ....can be everything from feeding, bedding them, dressing them showering them, toileting them, the whole lot." Another observed similarly that it "...depends ...on the disability ... what the role of carer has" adding that, " with some

13 D-9 [INT.1 ] p.5 L. 25
conditions the roles of the carer are going to greater ... roles are going to vary depending on the types of conditions ..."14 A GP reflected that with 'carers', you "can't...lump them all together into one group...some may do a bit more than others ...depends on the illness you're ... dealing with as [to] what the carer actually does ..." 15

As revealed by the questionnaire responses, interview responses indicated the carer's role was related to the type of care provided. Carers were seen as similar to that of a nurse.

"...often take on the role of being a nurse,...carer is doing the equivalent duties that the nursing staff would do if the patient was in hospital, and that's everything." GPa [INT.5] p.2 L 51-56

However GPs readily recognised the limitations of the carers themselves. " The caring role was seen by GPs as depending on what the carer could do and could cope with, and the fact that carers "fall into a position where they will provide what is required..." and "usually dictate their own role..."16 Summing it up, one GP offered that the varying nature and roles of caring depend on disability and types of conditions, some roles are greater, but carers "do what they can do rather than have anything imposed on them]" 17 Another GP commented:

"I see their responsibility in a way that I hope they would which is to do what they can do rather than have anything imposed upon them by society as to any sort of role or responsibility." D-9 [ INT.1] p.5 L. 34-7

On the notion of 'duty' and the carer coping, the same respondent offered a reminder of the hard reality of caring.

[It] "Can be a real shock to people that they can't cope & - have to let someone go - they aren't able to fulfill this duty - needs counselling support to say -you have done the best you can... " D-9 [ INT.1] p.6 L. 2-7

Part 1 (3):

HOW DO GPS RECOGNISE 'CARERS' IN GENERAL PRACTICE?

GP responses on how they recognised carers in their own practices was most notable for what was not said rather than with the few comments which emerged. GPs were aware that they could "... miss some [carers]... providing care behind the scenes."18 On a practical level carers were seen by GPs as having an important role in providing information - in addition to information provided by the patient:

14 D-9 [INT.1] p.5 L. 31-33.
15 D-6 [INT.5] p.3 L 18-25
Chapter 14: Identifying 'the Carer' In General Practice

[GPs] "recognise them [carers] by being the people who accompany the patient... give you information about them, know about their needs, talk about them, ... run the show." D-10 [GP FG] p.2 L. 29-32

[The carer] "... not only just doing the talking to communicate information, may... be giving you different information to the person that patient has given you."

One the whole respondents found it hard to express themselves in this part of the interview. The GPs who did try to answer, indicated the recognition was related mostly to the GP's own intuition, - something that 'evolves'. Recognising a carer is "...something that people build up over time ... unless it was glaringly obvious" 19 GP's therefore appeared to be reliant on more subtle pointers, explaining the recognition of a carer as "...more an intuitive thing rather than actually specifically picking out the individuals." 20

One saw it as part of the intuitive nature of his skill in general practice explaining how the GP gets "... a feeling from the way people are behaving when they see you, whether they are coping or not in their caring role." 21 In this instance the GP is perhaps also suggesting the person's distress or problems could be a way GP recognises that a person is a carer- a view that is repeated again during the interpretation of GP data from later questions. One particularly acerbic response from a GP stated in the questionnaire:

"Why do GPs need help to identify carers? The carer's presence at consultations should be all that is needed. If that doesn't do it - change GP" D-18

RECOGNISING PARENTS AS CARERS

The second part of this question explored whether GPs recognised parents of disabled or chronically sick children as 'carers', rather just seeing them as parents, and if non-relatives like close friends or neighbours were seen as carers by GPs. The latter issue surrounding non-relatives was poorly explored at interview 22, perhaps due to the GPs preference to focus on their experiences of parent issues. The reason could be that the majority of informal caring is provided by family, with whom GPs have most interaction. The first few comments sum up the essence of what the one very observant GP had to say about the plight of these parents.

"...is often not until you as the GP can see the person [parent] breaking down, and say look - it is time you had some respite." D-9 [INT.1] p.4 L. 3-5

22 Neighbours as carers were recognised by one GP who stated that...


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"...for the head injured it certainly has been a very difficult road and initially they were not recognised at all." D-9 [INT.1] p.4 L. 14-16

Most disconcerting was his realisation that, "It's not until the child actually becomes an adult that the caring role is even really recognised, and even then not well." The same GP emphasised that, "the role of the GP is to recognise first of all the parent does have a caring role... there are stresses on them... and even to assist the parent find support... Very often people won't ask for support." 24

One GP interviewed had mixed responses to parents as carers, seeing them in both roles, but very much 'carers'. He felt however that "it depends on the severity of their condition," he said - "the two that I'm talking about I mostly see them as a parent." When asked if he might see parents as the long term carers over a period of ten, twenty or thirty years, he maintained that he would not see them differently.

"Not greatly so. Not with a parent with a child, because I think that probably even if you have a healthy child, it's a full time caring role in other ways. I don't see a great distinction in looking after an intellectually disabled child as from looking after an ordinary child. ...There are degrees of what we are talking about." D-11 [INT.3] p.4 L.46-54

One clue to this stance comes from earlier questioning of the same GP when he was referring to parents in his practice who he knew extremely well. He said that the parents themselves regarded their role there as just what they would do for their other children.26 He and many other professionals like him might therefore be taking cues from the parents - as it is often reported, most parents of disabled children tend not to see themselves as 'carers' - in fact many prefer to remain 'the parents'. The doctor is perhaps also mirroring the broader public perception he referred to which is that "parents are expected to be all powerful carers and omnipotent"27, adding that,

"... they too fall into the societally accepted role - that they ought to be able to care because they are the parent." D-9 [INT.1] p.4 L. 1-3

One particular GP was well aware of parent carers in his practice, provided the greatest insight to parent carer experience, answering that he saw them:

"All the time... they are carers. It's beyond the duties of a parent what some of them take on and particularly these people are often frustrated and over tired." D-8 [INT.2] p.2 L.6-8

24 D-9 [INT.1] p.3 L. 48-52
27 D-9 [INT.1] p.3 L. 26-27

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Part 1 (4): WHY DO YOU THINK SOME PEOPLE ARE NOT SEEN AS CARERS IN GENERAL PRACTICE?

What makes recognition of carers difficult for GPs?
When GP respondents focused on the lack of recognition of carers in general practice they saw it mainly as a communication problem involving the doctor, D-8; Some also understood it as a lack of understanding that depended "solely on the GPs and their interests", D-6. Other GP respondents pointed out many GPs were "never taught about carers - it was "not part of medical training...". In addition there was "no data on carers' needs" [for GPs to access] which highlighted the disadvantages GPs faced in recognising carers. D-3

At the practice level GPs' involvement with carers was voluntary and unpaid [D-12], suggesting GPs were unaware of the level of caring by the carer, as "not many GPs .... see the real situation at home" D-4. These issues were compounded by the ongoing frustrations experienced by GPs regarding "lack of time and lack of payment for doing this work" especially within the constraints of "10 minute medicine" which leads to pressures on doctors to practice and also "GP burnout". Despite that, one GP wrote that GPs should be entitled to counsel carers and probably should be paid for it." D-8

Don't think, don't see, not told!
Responses from GPs as to why they think people are not seen as carers in general practice seemed to revolve around three main factors. Firstly, the approach of the doctor, secondly the behaviour of the patient, and lastly the visibility of the carer. The first relates to the the special focus of the doctor-patient relationship where GPs don't routinely think beyond the patient. As one GP volunteered,

"... perhaps as a GP I don't identify carers very well, perhaps I identify my patients better than I did my carers. " D-12 [GP FG] p.13 L.7-17.

Another added:
   it "...is something we [GPs] don't routinely think about asking somebody -whether they are a carer or if somebody is caring for them...is probably something that we could be more aware of."

A further dilemma for the doctor is that very often neither patients nor carers tell their GP that they have a carer or are a carer. "They don't present to you", complained one.28 Several GPs also stated that "patients don't mention they have a carer" or that, "the patient

may present and not say anything about the fact that they are quite dependant on their daughter or whoever it might be.\textsuperscript{29}

\textit{More than one carer at home}

Compounding this lack of communication is the confusion surrounding what doctors observe about carers - in particular the idea that carers are very diverse and that "the carer" is necessarily one person. It is more common for example in big families, that there may not just be one carer. There may be "...a carer in charge" another as the translator," and..."another who might be a carer in another sense.\textsuperscript{30} Even when the GP has recognised the carer, according to the GP, "...it’s difficult to immediately identify what you could actually do with them."\textsuperscript{31}

\textbf{WHAT WOULD HELP GPS RECOGNISE CARERS?}

This next question was designed to focus on GP skills in identifying carers and draw out as many practical suggestions as possible from GP respondents. The sum of all their ideas when pieced together yielded a most comprehensive strategy, which if were to be put into action by in general practice, would surely result in improved carer recognition. Their suggestions ranged from having better definitions of carers within general practice, the need for greater GP awareness and training about carers, and most importantly, the improvement of GP access to (and integration with) information on carer issues and carer support. Practical aspects of taking a good family or social history were highlighted, especially asking patients about their home situation and who they were living with, to better identify other family members who were caregivers. Although it did not seem to be practiced by GPs in this study, documenting identified carers in case notes was considered helpful.\textsuperscript{32} Repeated references were made about the value of home visits in assisting GPs recognise carers.

Several comments encouraged GPs to be more proactive and holistically oriented when dealing with carers, also to "spend more time inquiring exactly what a particular carer sees

\textsuperscript{29} D-10 [GP FG] p.2 L. 35-37.
\textsuperscript{30} D-13 [GP FG] p.3 L. 13.
\textsuperscript{31} D-13[GP FG] p.7 L.39-45
\textsuperscript{32} There is already a precedence for this - in the UK the practice of 'flagging' case notes to indicate that a patient was carer had been introduced during the 1990s.
Chapter 14: Identifying 'the Carer' In General Practice

that their role entails." D-9 A few GPs suggested that carers be encouraged to question GPs to enhance two-way communication of problems faced by carers.

One idea was:

"Make carers feel they could establish liaison for themselves with the GP"...or "encourage liaison through Patient Information Sheets ..." D-8 [INT.2] p.3 L.36-38. 44.

Better definition of 'carer' - well and ill carers

A GP commented with some exasperation, "How can you say we don't identify them [carers] when we can't define them except in a nebulous sort of motherhood statements."33 Another voiced his frustration saying, "There are people who come in with a pension card that says 'I am a carer' and they are easy to identify, and then there are all the rest of the population ... To me everybody who looks after someone else is a carer, ...So where is the borderline that says we do or we don't identify them? Where are we going to create a definition ...a cut off point."34

The confusion evidenced above was extended to identifying 'ill carers' as the first GP explained his dilemma. "There is the grey zone ... where does someone become ill? Where does it become illness-based ... and where can we decide to intervene?" He then added: "Maybe the carers have got to do some more work sorting out [or may be someone has to work with them] to define what is an ill carer and what is a well carer who is coping?"35 There are obvious constraints on GPs in the practice environment, even with addressing something as basic as the GP taking a good family or social history. "...as medical students we were taught to do [it] but GPs just don't have the time ...on an initial visit"36 However an obvious strength of GPs is that they "are pretty good picking up the people who are having problems", hopefully also whether they are patients or carers.37 During a separate interview it was recognised that "If we give a GP a chance to be involved we should identify those people who are carers."38

Flagging carer status in case notes

This raised the issue of making note of carer status in case notes which varies with the size of the practice as GPs in the solo or smaller practices felt more confident in their personal

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35 D-3 [GP FG] p.15 L. 13
knowledge of patients and families. One GP replied at interview, "I recognise a carer by observation...not noted in records." Another stated, "I have on my own case records... people who are caregivers, or next of kin - it is recorded...but not that they have a formal title." In his case he added, "...is such an individual practice...not necessary to write that down." He conceded though, "I should modify that to some extent..." In contrast, a GP from a larger practice emphasised his preference to document carer status in the notes, as it was "...very important to identify people who have an extra burden stress-wise, particularly in a multi group practice where others may have to take over your role."  

**Being proactive**

When prompted at interview on how GPs could better recognise carers, much of the emphasis was on the GP being proactive, although it was acknowledged that being proactive about carers was a thing that GPs don't do well. One GP was adamant however, suggesting,

"We have got to ask it, if we are going to actively identify them [carers]..."We have to ask the person who comes in the door...Who else is at home and what problems do they have? Maybe we don't always answer that question." He added- "Maybe some places have a questionnaire that they give to patients. It could be one of the questions on the questionnaire that you give to all your patients," he suggested. D-12 [GP FG] p.15 L. 42

**GP Awareness / Training / Information**

At the core of the dilemma of lack of carer recognition, is the obvious need to raise GP awareness of 'carers' and improve GP training and information on carer issues. It has become almost a catchcry when talking with GPs and other health care professionals, but few specific suggestions emerge and even less are followed up and actioned. One respondent in the survey questionnaire wrote, "Awareness raising, which is occurring via frequent correspondence from carers support group(s)". D-21 Another GP listed the following areas for attention, "Training and information at CME sessions, during medical school, during RACGP training program". D-18

**Part I (5): WHERE IS IT EASIER TO IDENTIFY CARERS ?**

**Benefits of GP making home visits - helps identify the carer**

In both the GP Questionnaire and at interview, GPs were asked whether they had a preference for the surgery or visiting at home to identify carers. Also asked if they had

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40 D-11 [INT.3] p.3 L. 27-32  
made special times (either in the surgery of during housecalls) to talk to family members about their own needs but there were no obvious preferences or trends. Without a doubt GPs thought that the home visits, ("domiciliary visiting") was very important. For example "housecalls by GP quickly identifies carer". D-11 "If carer and dependent person has same GP it is hard to GPs to ignore it". D-18 "Do home visits to see how they cope and what the true situation is. You can't always tell in the Rooms what their difficulties really are." D-25. There were obvious benefits of gathering more information about the carer with home visiting which..."is fairly much the key really. You see what they are like at home..."

"You would alternatively pick up things when you visit, that you don't see in the surgery, like you might find ....the carer you thought who was doing the work was in fact not the person. There might be another individual in the home who is providing the care, unrecognised." D-10 [GP FG] p.2 L. 39-44

For many if not most GPs, the vast majority of the doctors' work is done in the surgery. "It depends whether the patient in question is house-bound or not. Often in that situation there would be quite a lot of house calls he said, "I've been in both situations."44 One GP from a country practice observed about carers seeing him at the clinic:

"Early on I tend to find that they [carers] come in here often because it gives them a bit of a break and it also gives them a chance to discuss things without the patient actually being around. They can talk frankly and not worry about anything." GPa [INT.5] p.2 L 34-41

Finally, GPs were asked what other individuals or health professionals could assist them to identify and support carers. This question did not elicit many responses other than references to local social workers who know local networks and agencies such as Day Care. It is recognised that there are actually two separate problems here, one is the identification and the other the support of carers, the latter which attracted much activity in the late 1990s.45 However the problem remains that the carer has to be identified before support can be initiated. To that end the GP is still very relevant as GPs remain the first port of call for carers in most instances. What was pointed out by one GP respondent was the crucial role of the hospital discharging doctor in assisting GPs in identifying carers who are going to need support when patients are sent home. For example there are "problems when person sent from hospitals, but no communication with GP by hospital or other referral centre".46 I raise this again in Part 4 on GPs' on needs.

43 D-3 [GP FG] p.2 L. 47-49
44 D-6 [INT.5] p.2 L 27-32
45 It is pointed out that this exercise predated the introduction of the Commonwealth funded Carer Respite Centres and Carer Resource Centres and most recently the 'Care Link' initiative- all designed to offer easy phone access to information on carer support services.
46 GP [D-8] INT.2 p.2 L.29-35
DISCUSSION SCHEDULE and INTERVIEW GUIDE FOR GENERAL PRACTITIONERS

Part I Identifying the carer in General Practice

1. What is your understanding of a "carer" or "informal caregiver"?
2. How does the GP perceive carers' roles and responsibilities?
3. How do you recognise carers in your own practice?
   - What about parents of disabled or chronically sick children, or close friends and neighbours who are maintaining a mentally or physically ill person at home - are they also seen as carers?
4. Why do you think some people are not seen as "carers" in general practice?
   - What makes it difficult for GPs? /What assists GPs to recognise "the carer"?
5. Is it easier to identify carers in the surgery or when the GP visits the patient/family at home?

Part II Needs of the carer

1. As GPs, what needs of carers are you aware of amongst your patients and their families? Can you give some examples of those needs?
2. Do you spend time talking with family members/carers about how they feel about being the carer, and what their needs are?
3. Can you give some examples of what GPs are already doing for carers?
4. Where could carers go for help with their non-medical (social) needs? i.e. does the GPs see this as their role or refer the carer elsewhere?
5. What "outside" community services do GPs refer family members/carers to?
6. Do GPs feel they have enough information about local community services, counseling, home support services, support groups?
7. What would assist GPs to have access to more useful information for carers?

Part III Health of the carer

1. Have GPs noticed if the caring role has affected those carers with existing health problems or who are at risk? Can you give some examples?
2. Are GPs aware if the caring role has been a direct cause of health problems amongst people who are in a caring role?
   - e.g. Have GPs noticed if when a carer is ill, requiring bed rest or hospitalisation, does that person have adequate care themselves?
3. How can/does the GP help?
4. What other measures are GPs already taking to support the health needs of carers?
   - Can you give some examples?

Part IV GPs needs and suggestions

1. Can you suggest what would help GPs in meeting the needs of carers? Information, backup and another support, resources, short courses
2. What do as a GP want or need regarding issues of reimbursement/rebates for time spent with carers?
Introduction
The initial aim of this thesis was to identify the health and related social needs of carers. This chapter therefore explores with GPs, their own observations of carers in their own practices. Exploring first the carers' personal caring role and other social needs, the inquiry leads on to specific questions about the health of carers the following chapter. As with the format used for the previous chapter on identifying carers in general practice, the data presented below is a distillation of verbal GP responses from the focus group and interviews with GPs 'in the field', plus the relevant written responses from multiple questions in the GP questionnaire.

The first three questions on the needs of carers in Part 2 of the Interview Guide are listed opposite: Questions from the GP Questionnaire (relating specifically to needs of carer, as observed by GPs), include the following:

1.5. Have you identified carers as people with special needs (emotional, physical or social support needs)? What needs in particular have you observed?

1.7 What have been some of the issues and problems that bother family caregivers, which they have raised with you?

Part 2 (1) : WHAT NEEDS OF CARERS ARE YOU AWARE OF AMONGST YOUR PATIENTS AND THEIR FAMILIES?

The general observations of GPs were related to carers' needs for physical aids to assist them in the home, supportive visitors for the carer, interaction with others who they are not responsible for, respite or time out for themselves, including holidays. During the face-to-face interviews GPs highlighted the need to deal with carer isolation, (something that did not emerge from the written Questionnaire responses.) In terms of the carers' needs in the general practice domain, they highlighted the importance of time being made available for carers to talk to GPs to identify problems and needs. Also to address the need for information, or if necessary, to bring family members together for a family conference.
Chapter 15: The Needs of Carers - GP Observations

Physical aids to assist carers in the home

Only one GP emphasised and described the need for basic physical aids like toilet seats, incontinence pads, handrails, help with cleaning in the home and laundry services. An example was the case of a spouse caring for a [sick] husband and trying to look after the house, especially if the spouse herself is not strong. This response was more relevant to care of the frail aged or older spouses of chronically ill patients and probably reflects the dominant (older) patient profile of this particular GP.

Interaction with others who they are not responsible for and other supportive visitors

GPs were aware that carers wanted and needed a different form of interaction with other people where they’re not responsible for them. Carers also need to feel that someone has been there and spoken to them and been supportive and they are not alone. "Just the presence of a person visiting [the carer] ... is a constant support", commented the GP. This in turn contributes to carer well being as the GP also added "... people can do things if their psyche is in good shape ... but if they become depressed, then as a carer, they become very ineffective..." The issues of isolation and depression become two recurring themes later in the chapter.

Respite and time out for themselves, including holidays.

Without doubt, respite dominated all interviews with GPs who talked about carers’ need for free time, or time out for themselves. "Release, relief - its relief going to day care - it’s absolutely vital so that the carer has some free time." There were differing interpretations of respite, some recognising in-home support or day care while another defined it as more of a separation. For example "I think of respite as a ...specific type of support where the cared for person is removed from the situation or the family is removed from the cared for person for a length of time". This could be seen also as a need for ‘holidays’ for carers, however it is more often a lack of holidays which occurs in the case of over burdened carers. One GP pointed out, “...if you think of the average [paid] workers taking 4-6 weeks off per annum for the annual holidays I would say that most carers don’t have adequate holidays." He added:

1 D-11 [INT.3] p.9 L.1-7
4 D-11 [INT.3] p.10 L.15
5 D-9 [INT.1] p.4 L.50-54.
...their ability to cope will go down gradually and then it will become obvious that they need a holiday". D-9 [INT.1] p. 10 L. 23-24 In contrast to respite, "Pills don't help them".

Part 2 (2): DO YOU TALK WITH FAMILY MEMBERS / CARERS ABOUT THEIR BEING THE CARER AND THEIR NEEDS?

GPs highlighted the importance of their time being made available for carers to talk with them. They saw it as part of their role. At the time, one GP stated, "I am really disappointed that it is not recognised by the government but I just feel that that's our lot in life and we just go on doing it..." Many others were not so circumspect as will be noted later in the chapter. When questioned more closely during interview, GPs agreed that providing information for carers about services was part of normal medical family practice to care for the carer?

The GP questionnaire aimed to contrast what the GPs themselves observed with what the patients and their carers were telling them. The first, question (1.5) asked, "Have you identified carers as people with special needs (emotional, physical or social support needs)? What needs in particular have you observed?" The second searching question (1.7) asked GPs, "What have been some of the issues and problems that bother family caregivers, which they have raised with you?"

What needs in carers have you observed?

GP responses to this question in the questionnaire were quite prolific. GP observations of carer needs can be summarised under six main headings that are predominantly service oriented: The need for respite, a need for information, a need of emotional and financial support, counselling services, and help with planning for the future care of the dependent person if or when the carer's health fails.

Respite for carers

The GP responses in the questionnaire, including those returned from the survey were very consistent in their observation of carers' need for respite. Ten out of all twenty five GPs specifically used the word 'respite'. Only one GP mentioned the carers' need for sleep

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6 Readers are reminded that this comment was made in 1995, which pre-dates the federal government's Enhanced Primary Care initiative. Introduced in 1999/2000 the program recognises the GPs' role and by 2001 had been modified to include carers under the Medicare Schedule for care planning and case conferencing with GPs and other health care professionals.

while others referred to the need for rest D-20; Several referred to "guilt-free" time away from the caring role D-1; a break or time out from caring - short term, plus long term for holidays D-18; or "time out" for themselves physically and emotionally D-20, D-4, and respite from the emotional stress D-16. As a result the GPs often needed to organise respite for carers, D-8 but saw the lack of longer term respite care a problem - especially at short notice D-1.

**Need for information**

As caring is always unpredictable, carers constantly need information on the most recent changes in the 'cared for' and what they mean D-4, D-8, particularly through consultations with the GP. However other doctors are often involved and carers had difficulty with lack of information from hospital specialists D-6. Carers not only need to discuss changes in the dependent's condition and expectations, but as one GP stated, "they need to discuss strategies they, the carer, have improvised in an emergency or to meet a need." D-8.

**Carer Support**

Under the theme of carer 'support' the majority of GPs addressed the need to supply emotional support, as one GP described it, because they become exhausted or trapped by the ill health of the one they are caring for. D-22 Sympathetic support D-23 and consideration D-24 and especially psychological support to those caring, for example for people who are terminally ill, or have severe mental illness. D-8. One or two GPs referred also to carers' need of social and financial support D-9 while others observed the need of carers to be able to recruit outside services D-25 or coordinate as many 'helping' factors to keep the person at home and the carer physically and emotionally healthy. D-25. Three GPs mentioned the need for support for carers in caring for themselves, D-12, need to take care of themselves D-21, including a decline in own health D-2.

**Counselling**

To be able to talk to someone about the 'difficulties' D-25, have access to a listening ear D-3, or someone to talk to to clarify how to meet the carers' needs D-18 was identified by several GPs. Other respondents however focused more specifically on the need of carers for stress counselling D-7, or access to counselling and therapy as needed D-10. Other comments touched on the lack of acknowledgement of their caregiving role D-1 and the need for recognition of their work D-20. It was noted by one GP that social [needs] usually not brought up D-2.
When GP's were asked to recount issues and problems that had been discussed with them by carers, similar themes surrounding respite and lack of other services continued, (as described above), while carer issues surrounding lack of information emerged as more distinct problems. However in responding to this particular question, the GP comments provide a far greater insight into the emotional and health worries of those carers. For example, these GPs had obviously listened to what carers had described about their feelings. What bothered carers can be grouped into three main themes: concerns about their own health; and what is going to happen to the dependent person if the carer's health fails; Feelings about their caring role and life restrictions associated with it.

**Health & safety and well being**

These issues included the physical demands of caring, of being left to do all the work by other family members. The overwhelming demands put on carers, were obviously very tiring and often heavy work. Carers complained to GPs of tiredness; stress, insomnia; and burn out. In some carers there was an awareness that due to either the deterioration of their health or death, they would not be able to continue caring and they worried about the future well being of the dependent person.

**If carer's own health fails**

What really worries carers is that their own health may fail. They carry a fear of what will happen to their loved one if their own health deteriorates. They are concerned about how the dependent person will be looked after if they are no longer able to care for them. They complain about getting tired and are bothered by hard decisions facing them when it is time to give up and hand over the role. Carers therefore have a need for information on what to expect, and what will help with these future dilemmas regarding placement of their loved ones.

**Feelings / own life restrictions**

According to the GPs carers expressed a wide range of feelings ranging from grief, guilt and anger, particularly in relation to their predicament; Isolation and loneliness; difficulty in getting time away from carer role; not enough time for themselves; and restrictions on their own independent activities and recreational limitations. A sense of injustice prevailed. Carers were reported as expressing a feeling of hopelessness of some situations; especially a sense of hopelessness that they will ever be able to relinquish caregiving role and also guilt when this is reality.
Chapter 15: The Needs of Carers - GP Observations

GPs reported a perceived conflict in needs in carers between the cared for person and those of the carer. D-20. There was both anger with "the patient" D-12; demands of the person D-21; issues with behaviour problems and aggression D-17; frustration with the (care) recipient e.g. irrational behaviour and not being able to express anger in dementia. Other carers were troubled by the feelings of the dependent person if the carer was not 'perfect' D-18.

Extra issues listed by GPs under this question included the compounding effects of the lack of support D-13, and financial issues on the carer D-10; as well as their own health problems. This leads us to the next predominant theme highlighted by GPs - that of carer health (or lack of it D-23, safety and well being mentioned by carers.

Isolation and Loss of social contacts

Dealing with the problem of carer isolation and loss of social contacts generated considerable discussion during the GP focus group interview. This phenomenon was something that GPs observed about carers (rather than carers mentioning it to them) and suggests some carers may themselves be unaware of the impact on their quality of life and health. One GP was particularly concerned at "the cost of losing social contacts with their own peers" and on their well being.

"A lot of them experience a sense of isolation..."They kind of figure that their experiences are not really being shared by anyone else, and that I guess... the role of caregiving can take up so much of their time and energy..." D-13 [GP FG] p.4 L. 45-50

Another added,

"If they did have a network before its OK, but if they didn't have a network before and say they'd moved away from their families etc they get desperately isolated... But if they don't have that and don't have a family around then they can end up very isolated." D-12 [GP FG] p.6 L. 48- p.7 L. 2

He also pointed out, that these carers are very different to other isolated people.

"We are used to isolated people people in the community being...on their own. When they're really isolated, they really are alone. They don't have anybody to talk to so when you offer them a group they can talk to that fulfills a need. "[Carers] are very isolated in a different way. They have someone to talk to constantly, but they are sick of talking to that person. They may find it overly stressful interacting with another human being constantly." D-12 [GP FG] p.6 L. 48- p.7 L. 23
Chapter 15: The Needs of Carers - GP Observations

SUMMARY OF COMMENTS FROM GP QUESTIONNAIRE

QUESTIONNAIRE Q. 1.7

*Issues and problems that bother carers were discussed with GPs. - What have been some of the issues/problems that bother family caregivers, which they have raised with you?*

**Need for respite and lack of respite services**

Physical demands - very tiring and heavy work often
Overwhelming demands. No Sleep. No break, tiredness, lethargy, burnout.
Lack of respite care/facilities.
The need to have a break and the guilt associated with this
Need for respite and support in the home, financial issues, own health (stress, insomnia etc.)
Insufficient respite and relief, when will it end!

**Need for information**

Lack of information from hospital specialists
Knowing what is available
The need to discuss the changes in dependent's condition and expectations
The need to discuss strategies they, the carer have improvised in an emergency or to meet a need.

**Need for carer specific support**

Stress management
Behaviour problems, aggression
Need for some professional support
Co-ordinating services to make it 'easier' for carer

**If carer's own health fails**

Their own health (as lack of it)
Worries own health may fail. - Fear of what will happen to their dependent loved one if their own health deteriorates, and they are no longer able to care for them.
Getting tired, worry about how the person will be looked after if they are unable to do so.
Deciding when it is time to give up and hand over the role

**Dealing with feelings/own life restrictions**

Being left to do all the work by other family members
Demands of the cared for person
Conflict in needs - the person they care for and their own
Guilt and anger at their predicament. Guilt, anger with "the patient". Frustration with the (care) recipient e.g. irrational behaviour and not being able to express anger in dementia.
A sense of injustice
Isolation. Loneliness.
Recent changes in the 'cared for' what they mean.
Not enough time for themselves. Lack of 'time out', restrictions on their own independent activities and recreational limitations.
The feelings of the dependent person if the carer is not 'perfect'.
Hopelessness of some situations. Sense of hopelessness that they will ever be able to relinquish caregiving role and also guilt when this is reality
The future, what to expect, placement.
Part 2 (3): CAN YOU GIVE SOME EXAMPLES OF WHAT GPS ARE ALREADY DOING FOR CARERS?

The above conversation on carer isolation revealed what the GPs were doing or what they thought they could do to tackle carers' loss of social contacts, as well as addressing other pressing problems for carers. GP support of carers seemed to follow three main approaches, as would be expected in general practice today. Firstly in their role of adviser/counsellor, a few GPs personally supported the carer, working towards empowering him or her to make informed decisions about their own needs and well-being. This sometimes involved facilitating a new realisation for the carer or eliciting a behaviour change in either the carer or the cared for person.

Secondly, drawing on their own knowledge base, the GP provided additional information to carers on services to assist them maintain or enhance their carer role. Thirdly, GPs referred carers on to other social and community organisations to provide carers with additional advice and support specific to their caring role and associated problems. It is pointed out however that there were far fewer carer specific resources in 1995 than there are today.

*Empower the carer, help set limits to the caregiving and facilitate a new realisation*

The GP explained he would "... foster the idea in the caregiver that their own needs are important ". As well as that, "... it is important to set limits to the caregiving ... impose some sort of structure and build in time that the caregiver identifies as his or her own...". Just pointing that out to somebody, as the GP emphasised, there seems to be a relatively new realisation for them "because often, ...they don't know... they have needs themselves. That is probably worthwhile to do." Commenting on his colleague's approach another GP reflected, " I probably haven't done it enough to be honest". Adding, "...perhaps I am not perceptive enough. There may have been occasions when I have done it ... we try and arrange respite for the person ..so that the caregiver can have some rest."
Chapter 15: The Needs of Carers - GP Observations

Information and Referral [See Q 3.1 - GP Questionnaire]

A third GP indicated he helped them [carers] make list of things where they think they need support\(^{11}\). It is often necessary to point people in the right direction of the organisations\(^{12}\). In particular "...refer them [carers] to organisations where they feel they can ask for help to fulfill those needs."\(^{13}\) However, as one of the GPs admitted a little later, "...I don’t think we know enough about getting access to that sort of thing."\(^{14}\)

Commenting on the situation (in 1995), the GP said the trouble with some support services there was a nine months wait. For both the GP and the carer, "It is wanted today, not in 9 months time!"\(^{15}\) Adding to this dilemma for the carer is the issue of affordability. "If there is availability of home nursing or anything extra we’ll use it but ... not many people are covered for that, generally we find that people can’t afford that sort of thing," even if they are on a Carer Pension.\(^{16}\) As to what happens to carers in the meantime with the day to day grind, a GP recounted, "She just manages and I go to see her and they cry on my shoulder and I just support her through."\(^{17}\)

Several other points GPs made during interviews in relation to respite should be mentioned here. GPs commented repeatedly on the difficulties they had securing respite for carers, but the issues were not only in the provision, of and access to, adequate respite services, they also include process issues involving the wider public health system. "Part of the problem I think is actually getting respite beds for people. In this area I think that is a nightmare."\(^{18}\) He referred to the continuing dilemma of the public/private divide: "You can’t actually get them unless they have private insurance ... to go into hospital. Public ones have got no options...The problem with the public hospital system ... the interface is so horrific to get across for a public patient - it is very hard to get them through the door."\(^{19, 20}\)

\(^{11}\) D-9 [INT.1] p.5 L. 2-11
\(^{12}\) D-9 [INT.1] p.5 L.2-11
\(^{13}\) D-9 [INT.1] p.5 L. 2-11
\(^{14}\) D-3 [GP FG] p.8 L. 8
\(^{15}\) D-11 [INT.3] p.9 L. 18-22
\(^{16}\) D-8 [INT.7] p.6 L. 30-32
\(^{17}\) D-11 [INT.3] p.9 L. 28-30
\(^{18}\) D-3 [GP FG] p.5 L. 28-32
\(^{19}\) Six years later- 2001, GPs and carers still face similar problems, and despite government attempts to allocated respite bed for carers, the reality is that the beds, mostly in nursing homes and hostels are very often not there for the carers and the dependent people when needed at short notice.
\(^{20}\) D-3 [GP FG] p.5 L. 28-39
Part 2 (4): WHERE COULD CARERS GO FOR HELP WITH THEIR NON-MEDICAL NEEDS?

Several GPs felt it was really important for carers to join a group where they meet other carers "because they they get some idea of ... not only the things that are available but... ...to meet other people who have changed [their] attitudes...[that they don't have to 'soldier on' - it's not necessarily their 'duty']" I think that is just as important as learning about the physical supports that are available." 21

The dementia (Alzheimer's) Support group was one of the few such groups readily identified by GPs. "...it is probably the one that applies to me the most".22 "I put people, say with dementia, ...onto the association and I know that there are local support groups... I have put them on to the central body... but I don't actually know that local support group". 23 Many metropolitan GPs interviewed indicated they were unfamiliar with most other support groups in their area, and did they know specifically about local carer support groups. Local government services were accessed for volunteer visitors for carers as were the established services of Domiciliary Care and District Nursing. 24

MAIN GP PERSPECTIVES AND OBSERVATIONS OF THE NEEDS OF CARERS

Role needs of carer
Legitimise their role as carers
Discuss symptoms of the dependent person's condition
Discuss changes in person's condition
Discuss carer's expectations
Discuss strategies - especially in emergencies
Need for a break
Need for free time
Respite to be with people
Relief from caring duties / responsibilites
Set limits on the caring role
Release from caring
A need to deal with social isolation
Important to have interaction with people they are not responsible for
Encourage to join a support group to find out available resources and possibly learn from other carers they can change attitudes about caring

Personal needs of individual per GPs
Counselling
Someone to speak to, share experiences/grief
A supportive visitor
A need to deal with social isolation

21 D-9 [INT.1] p. 10 L. 41-51
22 D-11 [INT.3] p.10 L.41-43
24 D-10 [GP FG] p.8 L. 15-23

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Chapter 15: The Needs of Carers - GP Observations

The three remaining questions in Part 2 on Needs of the Carer have not been included in this chapter - They are covered in Chapter 17 (GP Needs and Suggestions). Actual GP responses on their use of community and carer services as well as the challenges of acquiring the information on those services, are provided in detail in the complete GP Questionnaire in the Appendix. Because there have been many changes to both carer and community services in the time that has elapsed since the GPs (and carers) were interviewed, all the data has been re-analysed and presented more in terms of process issues so that the findings remain relevant to the realities of 2002. However before discussing those topics, I next present a chapter on the health of carers based on GP's own perceptive observations of the carers they have assisted in their daily work.
### DISCUSSION SCHEDULE and INTERVIEW GUIDE FOR GENERAL PRACTITIONERS

#### Part I  Identifying the carer in General Practice

1. What is your understanding of a "carer" or "informal caregiver"?
2. How does the GP perceive carers' roles and responsibilities?
3. How do you recognise carers in your own practice?
   - What about parents of disabled or chronically sick children, or close friends and neighbours who are maintaining a mentally or physically ill person at home - are they also seen as carers?
4. Why do you think some people are not seen as "carers" in general practice?
   - What makes it difficult for GPs? /What assists GPs to recognise "the carer"?
5. Is it easier to identify carers in the surgery or when the GP visits the patient/family at home?

#### Part II  Needs of the carer

1. As GPs, what needs of carers are you aware of amongst your patients and their families?
   - Can you give some examples of those needs?
2. Do you spend time talking with family members/ carers about how they feel about being the carer, and what their needs are?
3. Can you give some examples of what GPs are already doing for carers?
4. Where could carers go for help with their non-medical (social) needs?
   - i.e. does the GPs see this as their role or refer the carer elsewhere?
5. What 'outside', community services do GPs refer family members/carers to?
   - What about HACC, local government,
6. Do GPs feel they have enough information about local community services, counselling, home support services, support groups?
7. What would assist GPs to have access to more useful information for carers?

#### Part III  Health of the carer

1. Have GPs noticed if the caring role has affected those carers with existing health problems or who are at risk? Can you give some examples?
2. Are GPs aware if the caring role has been a direct cause of health problems amongst people who are in a caring role?
   - e.g. Have GPs noticed if when a carer is ill, requiring bed rest or hospitalisation, does that person have adequate care themselves?
3. How can/does the GP help
4. What other measures are GPs already taking to support the health needs of carers?
   - Can you give some examples?

#### Part IV  GPs needs and suggestions

1. Can you suggest what would help GPs in meeting the needs of carers?
   - Information, backup and another support, resources, short courses
2. What do as a GP want or need regarding issues of reimbursement /rebates for time spent with carers?
CHAPTER 16
PART 3: THE HEALTH OF CARERS - GP OBSERVATIONS

Introduction

The purpose of this part of the study was to seek GP opinions based on their observations of the clinical health of persons they recognised as carers. In particular, GPs were asked if they noticed if the caring role affected existing carer health, and might be the cause of health problems amongst people in the caring role. In 1994 when I was planning this study, there was limited 'hard evidence' to suggest whether there was some link between the caring role and poor health status of the carers. Also to my knowledge a project specifically on carer health had not been conducted before within general practice thus my research approach was both explanatory and exploratory.

This descriptive study therefore represented a starting point which aimed for an overview of carer health rather than to produce definitive clinical data on carer health. Although some GP responses appeared unsure and speculative, the majority proved to be more explicit than expected and showed a far greater understanding of how carer problems might impact on their health. This summary, when combined with the responses from discussions with carers about their own health status from my own study and the SF-36 population survey data presented in the next section, offers a useful baseline for future research and evaluation on carer health issues. The information may also provide some direction for

1. There was a steady stream of small studies in Australia investigating carer health at the individual level as mentioned throughout this thesis, but for many years I could find none which had been conducted with carers within General Practice in Australia. Although the 1993 ABS population based research of 'Disability, Ageing and Carers' was underway at the same time as started on my research project, I did not have the benefit of the results of that Australian survey to assist me in planning the finer details of my own study in 1994.

2. For example it was not assumed that all GPs were familiar or comfortable with the term 'carer' so most references about 'carers' added the qualifying phrase of 'persons who were in a caring role' or 'family caregiver'.

3. Although my study aimed to compare what the carers were saying about their health, with what the GPs had observed amongst other carers in their own practices, I did not access the opinions of the GPs of the participant carers. The GP and carer participants were kept quite separate in an endeavour to draw on GP knowledge about carers from as wide a cohort as possible. It was therefore not possible for me to validate any of the carer perceptions of their health with their personal medical professionals, nor did I try to conduct any assessment of carer health status, to compare with their statements from the focus groups or interview. That would have necessitated a very different study and substantial funding to use an instrument like the SF-36.

In the intervening years, whilst completing my own thesis, several larger studies and surveys concerning carer health status have been conducted both in Australia and internationally which provide additional information and descriptions of ill-health that occurs in at least a third of all carers.
programme development, curriculum planning for GP, nurse and health worker training, and policy making.

Main questions on carer health explored with GPs
In the focus group and interviews with GPs, four main questions were raised around carer health. Similar questions were also included in Sections II and III of the GP questionnaires in an effort to gather written data to substantiate the verbal data - as a form of ..... triangulation. This chapter does not strictly follow the format of the Interview Schedule questions in Part III on Health of the Carer. See questions 1-4 opposite. Questions about carer health were included in the GP Questionnaire in Section II: 'The effects of caring on carers’ health and well being'.

These include:
2.1: How often have you observed that the health and well-being of persons in a caring role can be affected negatively?

2.2: How often have you observed that persons in a caring role exhibit each of the following? [carer behaviour]

2.3: Any other [negative] effects/impacts of caregiving on the health of carers, especially those who have pre-existing illnesses / conditions?

2.4: What have you observed to be the positive effects of caregiving on people who are carers?

2.5: Have you talked to family members / carers about how their caring role might impact on their own health and well-being?

Another question relevant to carer health, in the GP Questionnaire: Section IV: 'Future Support for Carers in General Practice'; ie

4.2: If the carer became ill, how could the GP offer additional assistance (eg with prescriptions, emergency respite while the carer is needing rest).

Findings from GP responses to all most of these questions are amalgamated in this chapter however where possible the data has been arranged within the following subject areas which have some similarities to categories of the SF-36. Although the SF-36 questionnaire was only used for the population health survey, interpretation of the findings and later discussion can remain focused on these main areas:
Chapter 16: The Health of Carers - GP Observations

- General Health and Well Being (General Health Perception)
- Physical health (Physical functioning)
- Psychological (Mental health and emotional functioning)
- Social Functioning and Quality of Life

Impact of caring on carer health
Through their responses to the questionnaire and during interviews, nearly two thirds of GPs indicated they had observed the caring role to have a significant negative impact on the health and well being of many carers. Nearly all of the GPs agreed that at some stage they had noticed there was a worsening of some existing health problems amongst people who had a caregiving role.

CARER HEALTH & WELL BEING

Only three of the eight GPs interviewed expressed views that caring generally did not affect the carer's health. Others qualified their remarks by saying that they had noticed the impact of caring on carer health "...not in all situations, but in quite a few." For example in "...situations where the carer is just doing a minor role - then probably it's not having a great effect on their health at all." This GP summarised, "... overall a lot of carers who are basically healthy and fit and well probably cope quite well without any other people helping them ...". Interestingly the same GP said later in the interview about a patient whose husband had had a mental illness for many years. "She's certainly had a lot of stress just coping with it and their relationship...has affected her health."7

Referring specifically to parent carers, one GP indicated he had not noticed any health differences - "not with the health of carers ...looking after children ... I see many parents caring for their so-called healthy children affected by strain ....as I would see looking after intellectually disabled children...". The above voices were in the minority, as most GPs observed the caring role to have a significant negative impact on the health and well being of many carers. This was particularly evident from the questionnaire results outlined in Q. 2.1.

5 D-6a INT.5 p.3 L 35-43.
6 D-6a INT.5 p.11 L.55-58.
7 D-6a INT.5 p.3 L 35-43
8 D-11 [INT.3] p.5 L.28-32
Chapter 16: The Health of Carers - GP Observations

What the results in the box below show is that GP respondents clearly perceived negative affects of caring on 'the general health' of carers and especially on 'existing health problems' of carers. Stress, exhaustion, depression, anxiety and were all seen in carers in the range of "sometimes to always" while sleep was negatively affected at least sometimes or more in these carers.

GP perceptions of the NEGATIVE effects of caring on health and well being of carers

Q. 2.1 How often have you observed that the health and well being of persons in a caring role can be affected negatively?  
13 Original GPs  
12 Survey GPs

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<td>Effect on General health</td>
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<td>Exhaustion</td>
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<td>Hypertension</td>
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<td>9</td>
<td>1</td>
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<td>Physical injuries</td>
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<td>4</td>
<td>7</td>
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<td>(lifting disabled person etc)</td>
<td>1</td>
<td>3</td>
<td>5</td>
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<tr>
<td>Sleep</td>
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GP comments: Suppressed anger, guilt, sadness, High degree of depression

Stress and exhaustion were the most notable amongst the listed effects on carers as indicated by the majority of GPs. Physical injuries were less frequently observed although more than half of the GPs acknowledged that carers had had such injuries. More cautious comments by GPs on carer health included: "[It] depends very much on the degree of
severity of the patient's illness as to the impact on the carer's well being". [The]."longer the illness and the more complex...it can even affect their health specifically." Another observed, "They don't look after their own physical health, .. or they don't eat ..."  

PHYSICAL HEALTH PROBLEMS OF CARERS

GPs interviewed did appreciate the potential for physical health problems amongst people in a caring role due to complications with their own medical conditions, injury or ongoing effects of psychological stress. In particular a GP had noticed carers with back problems. He commented, "Lower back pain was worsened because they've had to do a bit more round the house, looking after the husband. One in particular hurt her back by having to lift him up when he fell..." From a preventive perspective, the importance of maintaining the health of the carer was highlighted by a GP. "That's something I'm aware of and most other GPs are very aware of - the health of the carer as well - and having to maintain their...health whilst they are looking out for their ... patient." Also, another GP reflected, "... looking after a patient day in day out, 24 hours a day, must cause physical illness after several years - The question is how much psychological stress plays a part in physical illness?" Some GPs did not notice the carer until physical health problems did emerge. "I notice them more when it's physical health." Alternatively a GP observed, "When that carer becomes a patient, for example has hypertension, nothing dramatic, then I start to notice they don't look after their physical health." The neglect of the carer's own health through a reduced willingness of the carers to tackle their own health problems was referred to repeatedly by GPs in this study, both during interviews and in responses from the questionnaires. It was of concern to the doctors who complained that:

"... carers will ignore their own health - put off seeking help", D-4, or "They bring in the person they are caring for, but they themselves don't bother to come in ... they don't bother to make an appointment."
Chapter 16: The Health of Carers - GP Observations

Immune system
What was quite unexpected to emerge from the GP observations was their perception of the impact of the demanding caring role on the person's immune system. For example a GP said, "Don't know if this is scientifically proved, but I get the feeling that their immune system changes and they are susceptible to illness and maybe even malignancy."18, 19 Another reported, "General resistance to infection ... that's another one that I don't think is mentioned a lot ..."20. A respondent in the questionnaire wrote, "Possible decrease in own immune levels - more infections, aggravation of own illness - arthritis/cancer." D-8 Some other references were made during interview to the effect of "over tiredness" on the carer as "... part of the reason why it may be tied in with that immune thing ... It's all intimately tied up - certainly with sleep problems."

General deterioration in the caree's condition - a catalyst for carer health status to change
A second important unexpected observation of GPs to emerge from this research, was the deterioration in the caree's (patient's) condition as a specific catalyst in changing carer health status - both physical and mental. GP participants in the focus group volunteered the following observations. "I've [noticed] worse things, like blood pressure control....with deterioration of the patient's husband's illness."21 This issue is raised again and discussed under the psychological health of the carer and depression.

PSYCHOLOGICAL HEALTH ISSUES FOR CARERS

Chronic caring is psychological business
As with the GP questionnaire respondents, the majority of GPs interviewed indicated that they observed physical injuries less frequently in carers. Rather, they saw the psychological and emotional impact of caring on carers. As one GP said most succinctly:

"I don't see the physical side as a big issue. Chronic caring is psychological business."22

This astute remark leads my discussion of the next category of findings into the area which dominated so much of the GPs responses. The emotional and mental health issues associated with informal caregiving.

20 D-9 [INT.1] p.7 L. 39-42
22 D-11 [INT.3] p 8
Chapter 16: The Health of Carers - GP Observations

Carer mental health and emotional functioning
"Yes it [caring] does affect their lives... main things are the mental health of the carer," commented one of the GPs interviewed. Carers "don't have any easy outlet for it because they have enough inherent understanding to know that they can't put that onto the person that they're caring for," he explained. His and other GPs' interpretations were very definite in acknowledging the psychological impact of caring and the serious changes it brought to the life of many carers known to them. However despite much experiential evidence which clearly points to the negative consequences of caring, this chapter endeavours also to present a balanced view featuring positive aspects of caring as highlighted by the same group of GPs. After all, two thirds of carers are not affected.

Constraints on a normal life of the carer and the psychological burden of caring
GPs see depression, tiredness, anger, frustration, and often anxiety in the carer", one of the GPs, adding the possibility of carers being more susceptible to illness and malignancy. Another observed;

"Their mental health and psychological well being is greatly altered from what I'd class as 'the norm', or what could have been, because of the constant burden and the restraints on the normal life'.

Later in the conversation, this GP went so far as to say:

"The mental side is what I see as the big destructor... it's totally destroyed."

Impact on carer of caring for a dementia patient
Special mention was made by one GP of the effect of caring for a partner with Alzheimers. From his experience these carers are at risk of becoming demented themselves, "... because they spend all day long with a demented person; effectively they can never leave the home because the person has to be supervised. They have sleep deprivation because they spend half the night awake as the person with dementia likes to run around at night. They have a guilt complex - they want to put him away but they...can't do it, so mentally the carer ends up with no insight and a very shallow person." The GP concluded with conviction, "I see it regularly... I just see two people... destroy each other rather than one person being somewhat healthy."
Depression and precursors of depression in carers

As noted earlier there were similar comments from interviewed GPs about the deterioration of the cared for person's condition affecting the carer's physical health. The same appears for a carer's mental health - but more so, as one GP declared, "Depression made worse by the caring role? It's caused by this role! Most of the time the illness of the person being cared for is such a psychological blow that that starts the process off. If they already have some illness then the ongoing struggle takes its toll." However another GP was much more circumspect and cautious. "I can't really ...., say, oh yes they'll come in seeking tranquillisers for depression more often than other people. Overall, the recurring opinion expressed by participating GPs in this study was that depression was very common amongst carers. Insomnia was also mentioned but..."whether that insomnia is related to a little bit of depression is often hard to say," commented the GP.

Another GP discussed the very interesting idea of pre-depression in carers, talking about important 'precursors to depression'. He summed it up as "tiredness ....and the lack of energy , the feeling of unhappiness and unfilled roles, unfulfilled life goals are precursors to the clinical depression. ...It is sort of pre-depression." He suggested one factor that pushes it from pre-depression to a clinical stage is "...deterioration in the caree's condition - that seems to push people over a bit."

Stress

In addition to depression, the stressful nature of the caring role was often implied and sometimes energetically emphasised by the GP respondents. For example, "The carer's health can be "... made worse through the caring and stress of ... looking after someone..." However the clearest overall indications were gained from the GPs' answers to Question 2.1 in the questionnaire as mentioned earlier in this chapter. Stress was the most frequently observed negative affect on carers, with 12 of the 13 GPs recognising it in carers either always (5 on the scale ) or not quite always (4).

It was beyond the aims of this study to explore the carer stress phenomenon further however GPs' observations of carer behaviour paint a vivid picture of the challenges that
face carers, GPs and their patients as a result of trying to cope with those stresses. For example, "...sometimes the carer will present a picture of your patient ...as being in some need of intervention when really ...its their own needs that aren’t being met," commented one GP.37

**HOW THE CARER PRESENTS AND CARER BEHAVIOUR**

During the focus group another GP described how carers, "...blow up the illness of the person who’s sick, the person they are caring for, a much greater extent."38 For example one patient’s wife " was obviously keen for him to stay in the hospital to give her a rest".39 Some GPs find this hard to understand" as one explained his thoughts. "I think that’s all fairly classic,... where they [carers] embellish the symptoms, and you think well, ‘this person’s not too bad’. When in fact, we are perhaps missing what is actually the underlying agenda is that, “you’ve got to get this patient out of our hair because I can’t cope".40 ... that could well be a cry for help," concluded another.41

How carers present, the frequency of consultations and phone contacts with the doctor can therefore be reasonably important in assisting GP understanding of the carer’s situation.42 As one of the doctors in the focus group explained, "What may change is if they [carers] are going through a period of crisis themselves, their pattern of seeking help may change and they may all of a sudden start seeing you more often for a range of different things."43 "They blow up in your face and you can’t do anything about it." said one GP quite despondently. The same GPs commented later:

"I usually get frustrated and say what in the hell is happening - I can’t seem to be doing anything right, and in fact probably what’s happening is they’re not coping either.45

The following descriptions present an even more vivid snapshot of what the GPs observe from their daily work with family carers.

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40 D-3 [GP FG] p.6 L. 33
44 D-3 [GP FG] p.6 L. 33.
"They just sort of walk in with no smile on their face, they’re sort of classic burnout almost. Tiredness and really not being able to sleep or cope are some of the things, depression and stuff that I usually find...they’ve got a really drab look about them and they’re weary, physically worn down." 46

There are additional warning signs that GPs have learned to pick up. For instance:

"they may also get quite stroppy and demanding in regard to the person in question. When they are hard to please I am sure alarm bells should be ringing." 47

Without doubt, GPs become frustrated because carers " keep coming back". 48 "Sometimes you almost want to hand it over to your partner and say, can you have a look at this person and see what’s going on? That’s something I don’t think we use very much, that a second opinion... which may be a help" concluded the GP. 49 I was also reminded of an earlier observation by a GP during the focus group which was interesting. He admitted that "..if I was a more home based practitioner then I’d probably notice their psychological problems and their social problems." 50 This leads into the next questions put to GPs about when the carer is ill, requiring bed rest or hospitalisation and whether carers have adequate care themselves.

WHEN THE CARER IS ILL

Carers sublimate their own needs
A very important question to consider is what happens when carer’s own condition starts to decline. Carers, according to some GPs, do not cope well if their own illness/health starts to deteriorate and they are often people who sublimate their own needs. 51 What has been described above suggests that the carers, despite health problems of their own, hide them, often refusing to discuss them with their doctor - rather continuing to focus on the condition of the person they are caring for - the patient. Doctors’ constantly face this dilemma referred to by one as "that grey zone" where "...you’re not quite sure if they’re coping or not coping. You don’t want to confront them in case they get embarrassed or they don’t want to face that they’re not coping." 52 One GP referred to this as the phenomenon as "an issue of ‘perception’", adding: 53

48 D-3 [GP FG: p.14 L. 26]
52 D-3[GP FG] p.5 L.50-54.
53 D-3[GP FG] p.5 L.50-54.
"I find it very difficult to pick it unless they collapse in front of you almost, and say they can’t cope."

It has been suggested previously by researchers, that carers in comparing their health with that of the person(s) they are looking after, may perceive their health problems to be far less important than those of the 'patient'. One such case of withholding information from the GP was described in my study: "They [carers] often come to you eventually and say, "Oh yes I have had cancer for the last three years but I didn’t want to tell you because I wanted to keep looking after Fred." Hence the neglect of their health which occurs, often deteriorates to quite serious levels before any action is taken or the doctor recognises it as the GP described above.

A second issue in carer neglect revolves around the carers' priority of protecting the stability of the caring relationship as well as the underlying longer term intimate social relationship (whether it be marriage...) "They don’t want to separate. Some actually find the dependence very satisfying." However it is probably even simpler than that, as one GP explained:

"Often we see this with aged couples where they both care for each other... certainly in that situation we have seen a carer, the partner, often refuses an operation because they are frightened that something might happen to their spouse."\(^{57}\)

Carers discharge themselves early and reluctance to undergo surgery

Two observations concerning GPs from this study confirm that carers are known to discharge themselves early from hospital so as to return to the cared for person at home, particularly if no alternative arrangements have been made for their care. This is evidenced in responses from the GP Questionnaire. (Q. 2.2 in the GP Questionnaire - See over.) Also of concern, as referred to by a GP, is the reluctance of many carers to undergo surgery in the first instance, denying themselves early treatment or elective surgical intervention. 21 out of the 25 GPs had noticed carers do this 'sometimes' and always, which was a rather surprisingly consistent finding from both groups of GPs. The responses for 'carer discharging self from hospital early' was not so marked, although this was noted by 16 out of the 25 GPs.

\(^{54}\) I refer here to Spackman's ideas described in Chapter 3 as part of the literature review on the Health of Carers. My own study with carers and GPs confirms her original thoughts on how carers use the cared for person's health status as the benchmark for assessing their own health.


\(^{55}\) D-12 [GP FG] p.6 L 6-12.

\(^{56}\) D-3 [GP FG: p.5 L. 50-54.

\(^{57}\) D-8 [INT.2] p.5 L. 40-53
### GP OBSERVATIONS OF CARERS' RELUCTANCE TO CARE FOR OWN HEALTH

**Q. 2.2** How often have you observed that persons in a caring role exhibit each of the following?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor compliance with drug regimes (for self)</td>
<td>3</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Poor compliance with other treatments (for self)</td>
<td>1</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Reluctance to seek medical attention (for self)</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Reluctance to have surgery (being away from dependent)</td>
<td>0</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Carer discharging self from hospital early</td>
<td>1</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

'Reluctance to seek medical attention for self' was only answered by 20 of the 25 GPs but 19, the majority indicated they had observed this in the range of 3-5, 'sometimes or more'. There were non-definitive results to 'poor compliance with other treatments' with GPs. Obviously GPs found that some carers did comply, others didn't - as would be expected.

In comparison, fewer GPs had noticed poor compliance with drug regimes for the carer, which suggests perhaps that as the taking of medication did not require the carer to leave the patient or the home to do so, there were no barriers or fears of their being separated from their loved one. Also taking tablets it would be least time consuming for the carer (in comparison to other types of self administered 'treatments'). These few responses suggest some very important issues that must be taken into account by attending physicians when treating people in the caring role.

In their general comments during interview, GPs indicated some sensitivity to the problems outlined above. "I certainly feel that where you are involved... and we try to be, those situations don't arise. Generally we in general practice can do something to help those
Chapter 16: The Health of Carers - GP Observations

situations and organise something as an emergency. It is not always easy but we can do it."58

**HOW GP SUPPORTS / HELPS WHEN THE CARER IS ILL:**

(Qs 3 & 4)

The second half of the Interview Schedule: [Part 3 on Carer Health] focused on those occasions when the carer is acutely ill or injured, requiring immediate bed rest, medication or care themselves. This study sought information on the practical support and initiatives GPs had already provided to carers when in these situations. It was clear that many GPs were personally going out of their way to ensure that sick, housebound carers received their medication and had extra home care services.

"This is where the GP takes on the role of ringing up Domiciliary care or who ever... [ and asks] 'would like you to increase your visits to Mr Bloggs... or if necessary arrange for some respite care for Mr Bloggs'."59

A few used in-home Emergency Care and social admissions, but as the GP said,

"...I have to weigh these kinds of things up. If someone gets sick [and] they've got private health insurance then I might put that person who is being cared for in hospital, and not the one who is sick."60

GPs provided many examples of the doctor arranging medication to be delivered to the carer, for example through RDNS, neighbours or relatives in addition to the GP making him/herself available for problem shooting. That sort of approach "usually makes those situations work."61 Here is a selection of what the GPs had to say about meeting the carers' urgent needs for medication. "In my practice in the past I have always carried a range of spares with me - sample packs to start a treatment."62 "Fortunately at the clinic here we've got the chemist next door.... but what I'll do is I'll always take a prescription and get it filled myself, and then I'll take it back if needs be or I'll get the chemist to deliver ... That's standard - I think we all do that."63 "I often deliver scripts, ...or ...I have often rung chemists and the chemist will deliver it."64 In some instances however the usual backup for the GP failed:

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64 D-8 [INT.2] p.6 L. 42-43.
"Yesterday I took a script up to the chemist...[who] grumbled... wouldn't do it ... because some of the staff were sick - so I actually took the medication back [to the carer] myself."

In this and similar cases doctors recognised there was no alternative way of the carer receiving their medication but to do the running around themselves. But it takes time going to the chemist, waiting for the script to be filled and driving back again to the carer's home as the GP emphasised. Also "You don't get paid for that."

Q. 4.2 GP QUESTIONNAIRE

If the carer became ill, how could the GP offer additional assistance (eg with prescriptions or emergency respite while the carer is needing rest)

GP SUGGESTIONS

HOME VISITS
Frequent home visits D-17; Home visits , Regular home visits to recipient D-1
Frequent review D-25 / ... work referral D-16

DELIVER MEDICATION
GP do all he could eg deliver or arrange to have delivered prescriptions & food D-11
Organising delivery of prescriptions and Meals on Wheels etc. D-4
Prescriptions, emergency respite while the carer is needing rest D-6

SUPPORT SERVICES / REFERRAL
Advising support services to help with dependent D-7; Coordinate other services, D-25;
Service referral etc, Try to provide other support D-17

RESPITE / HOSPITALISATION
Respite is the main one D-4, D-5, D-23 ; Respite Hospitalisation of patient D-2, D-11;
Mainly respite or additional home care D-9 + emotional support for the carer D-9
Treating carer & providing respite if possible D-15
Respite for the dependent patient, D-25
Emergency respite care D-17 / Emergency respite D-24 / emergency respite D-18 / emergency respite D-21
Emergency admission D-24
Home sitter service - limited hours D-21
Day care D-18

OTHER COMMENTS
Routine GP care D-3
By doing all of the things we do now D-8
Reality check needs of patient (i.e. reduce the demands etc.) D-2
Identify other potential carers D-2
Uncertain what to do - may contact S.A.R.T. D-22

65 D-9 [INT.1] p. 12 L. 1-5.
PART 4:
GENERAL PRACTITIONER NEEDS
TO SUPPORT CARERS
## DISCUSSION SCHEDULE and INTERVIEW GUIDE FOR GENERAL PRACTITIONERS

### Part I Identifying the carer in General Practice

1. What is your understanding of a "carer" or "informal caregiver"?
2. How does the GP perceive carers' roles and responsibilities?
3. How do you recognise carers in your own practice?
   - What about parents of disabled or chronically sick children, or close friends and neighbours who are maintaining a mentally or physically ill person at home - are they also seen as carers?
4. Why do you think some people are not seen as "carers" in general practice?
   - What makes it difficult for GPs? What assists GPs to recognise "the carer"?
5. Is it easier to identify carers in the surgery or when the GP visits the patient/family at home?

### Part II Needs of the carer

1. As GPs, what needs of carers are you aware of amongst your patients and their families? Can you give some examples of those needs?
2. Do you spend time talking with family members/careers about how they feel about being the carer, and what their needs are?
3. Can you give some examples of what GPs are already doing for carers?
4. Where could carers go for help with their non-medical (social) needs?
   - i.e. does the GPs see this as their role or refer the carer elsewhere?
5. What 'outside', community services do GPs refer family members/carers to?
   - What about HACC, local governments?
6. Do GPs feel they have enough information about local community services, counselling, home support services, support groups?
7. What would assist GPs to have access to more useful information for carers?

### Part III Health of the carer

1. Have GPs noticed if the caring role has affected those carers with existing health problems or who are at risk? Can you give some examples?
2. Are GPs aware if the caring role has been a direct cause of health problems amongst people who are in a caring role?
   - e.g. Have GPs noticed if when a carer is ill, requiring bed rest or hospitalisation, does that person have adequate care themselves?
3. How can/does the GP help?
4. What other measures are GPs already taking to support the health needs of carers?
   - Can you give some examples?

### Part IV GPs needs and suggestions

1. Can you suggest what would help GPs in meeting the needs of carers?
   - Information, backup and other support, resources, short courses
2. What do as a GP want or need regarding issues of reimbursement/rebates for time spent with carers?
CHAPTER 17
PART 4: GENERAL PRACTITIONER NEEDS

Seeking the missing voice - of the General Practitioner
This chapter completes the main data collection from General Practitioners for my study in the domain of general practice and home based care. Here I describe the thoughts and experiences of GPs in relation to their support of family caregivers. I tell their stories, and highlight the barriers which confronted them in the mid nineteen nineties. GPs 'in the field' are rarely sought out and asked about their own problems and frustrations in trying to help the informal carer. My research illustrates the benefit of providing opportunities for GPs to express their opinions about themselves and carers. I seek their suggestions on what could make their work days easier in relation to carer liaison / support.

In featuring the personal views of General Practitioners I have endeavoured to capture those voices most often neglected in research on carers. Input from all the GP respondents produced a far greater volume of comment and empirical data than I expected. In weaving their many ideas together, a picture emerges which offers a more comprehensive overview of GP needs and solutions that are general practice oriented and GP friendly. It is my firm belief that one cannot expect to assist carer ( or patients) without first assisting the GPs.

GP Needs : Interview Schedule and Questionnaire questions
The two final questions put to GPs in Part IV of the Interview Schedule were:

(1) Can you suggest what would help GPs in meeting the needs of carers?
    (eg information, services and resources, back up [support], and education / short courses for GPs). ¹
(2) What do you as a GP want or need regarding issues of reimbursement /rebates for time spent with carers?

Where appropriate, similar comments by GPs which had emerged from earlier parts of the focus group and interviews are incorporated into this chapter. For instance, from Part I on Identifying the carer'. In Part 2 on Carer needs, Question (8), GPs were asked: What would assist GPs to have access to more useful information for carers? Their comments have been added to the section on Information in this chapter.

¹ The question included examples as a prompt based on my preliminary reading on carer and consumer comments in relation to general practice. Unfortunately no equivalent literature about supporting carers, from the GP's or physician's point of view, was available at that early stage.

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Chapter 17: General Practitioner Needs

In Section III the GP questionnaire, 'Support for Carers by GPs', GPs were encouraged to list the frustrations or barriers they experienced when trying to access services [Q 3.2] and support carers in general, [Q.3.8]. Question 3.9 teased out the causes of those problems. Q. 3.2(d) asked which individuals could help GPs assist carers while Q 3.2(e) enquired of the type of format GPs would prefer their information about local community, social and carer services. Also in the questionnaire's Section IV: 'Future Support for Carers in General Practice', and the General Comments page, GPs wrote down their suggestions on how they felt they could provide additional assistance and medical care for carers in their practices.

There is an intentional overlap and duplication of some questions between the GP questionnaire and interviews so as to provide methodological and data triangulation. Therefore many questions from the questionnaire were repeated in the Discussion Schedule for GPs. This chapter includes summaries of GP responses from Sections III and IV the GP questionnaire. The are not necessarily in the order they appear in the questionnaire.

Categories of GP need identified by GPs in 1995 study

After a thorough thematic analysis of GP data from the questionnaires and the interviews, I featured six main areas dominating the needs of GPs in supporting carers. They were:

1. Time: the amount of time it takes to support and advise carers
2. Remuneration: payment for the time spent assisting each carer;
3. Information: on carer support; access to/referral to appropriate carer respite services; Use of Information Technology in General Practice.
4. Resources/services for carers and a resource person for GPs
5. GP awareness regarding carers and knowledge about local/state services
6. GP education and training on carer health, social and service needs

These themes are represented in the diagram below and are further illustrated with GP comments throughout the remainder of the chapter.

<table>
<thead>
<tr>
<th>1. TIME</th>
<th>2. REMUNERATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. INFORMATION (GP FRIENDLY)</td>
<td>4. CARER RESOURCES/SERVICES - for referral</td>
</tr>
<tr>
<td>5. GP KNOWLEDGE/ AWARENESS - carer needs</td>
<td>6. GP EDUCATION &amp; TRAINING</td>
</tr>
<tr>
<td>on carer health, social and home support needs</td>
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Chapter 17: General Practitioner Needs

For the purposes of discussion, the six themes have been further reduced to three key headings that relate to GP needs regarding and carers:

- **Time and Remuneration issues**
- "GP Friendly" Information; and Carer resources/support/services
- **GP Knowledge and Awareness of carers; Education & Training issues**

These areas are examples of the significant barriers GPs were facing in 1995 when trying to assist carers. Referral is the issue which predominates in the last two headings. GPs were predictably vocal on *time* and *payment* barriers which were troubling them. They found carers very time consuming which was as problem because in 1995 there was no mechanism whereby GPs could be reimbursed through Medicare. As time and payment issues were the question (2) of Part 4, they will be featured at the end of this chapter.

**Barriers GPs felt they had to overcome to support carers**

My study identified serious *information barriers* for GPs which pre-dated any widespread introduction of information technology into general practice. GPs complained it was impossible to keep up with, or make sense of, the constantly changing kaleidoscope of community services and carer resources. GPs talked of their lack of education in how to handle that type of information, compounded by a lack of awareness of carer support needs and services in general. This *knowledge barrier* impacts on the GP's ability to make effective referrals. The introduction of information technology into general practice in the mid to late nineties has helped but has not yet bridged that problem for GPs and carers. Whether IT or hard copy directories are used, the presentation of information about services is often not GP friendly enough to help GPs understand how or when to use them, or for whom, highlighting the subtle language barriers that continue today to exist between the various health, community and social support services.

The ideological differences between carer/community oriented agencies and general practice also created *structural and organisational barriers* that often affected the integration of services with general practice. Compounding this are the age specific barriers to 'clients' within many community based services. Organisational differences also blocked attempts at shared accountability of staff which might have provided important bridges in building relationships and trust between the GPs and non-medical staff. Ideological and organisational differences often lead to a lack of confidence of GPs to use services with which they were unfamiliar or have no established links.
Geographical barriers impacted on the availability and accessibility of services to carers and so on GP needs. Metropolitan GPs found the variability in carer services between suburbs, council areas and regions to be confusing and inconsistent. Some country GPs in rural and more remote areas had the added disadvantage of lacking the variety of carer support, respite and community services they could refer carers to. This reduced their capacity to offer adequate assistance to family carers and patients. Alternatively in some country towns there were well organised health services whose staff coordinated their local resources for the GPs. In that instance the country GPs found it simpler and easier than their city colleagues who often had to cope with patients and families from several catchment areas, all with differing services (and eligibility criteria) where the carer could be referred.2

Finally GPs spoke of their difficulties with attitudinal barriers at the carer level (as well as at the family and patient levels) any of whom could be resistant to, or fearful of, change. My findings represent a snapshot, albeit taken in the mid 1990s, but from my assessment of the current status quo of GP-carer interaction, many GP-carer needs remain unmet and are just as relevant today in 2002. Addressing GP needs therefore will involve overcoming the barriers outlined above.

It is acknowledged that in the intervening years since this study started, there has been some progress in establishing government funded information networks on carer resources and respite which are now available across Australia in each capital city. Significantly there is no formal link with general practice however. Provision of in-home respite care services for carers and those they are caring for have increased. In reality, unfortunately, the proposed residential respite has not I venture to suggest that the Australian picture of carer support may be even more confusing for GPs than it was in 1995. As well as the existing local Carer Support Groups with which GPs were not familiar at the time, GPs now have to grapple with at least three new national carer support schemes. I refer to the Federal Government funded Carer Resource Centres, Carer Respite Centres and most recently, CareLink3. These unfortunately are poorly integrated with general practice as they have been developed and introduced without local GP representation or participation.

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3 It is the height of irony that the national program 'CareLink' was originally proposed around 2000 so as to provide Australian GPs with information on how to access community and carer resources. But that did not eventuate. CareLink 2001 has been modified to serve primarily as a consumer/carer service, which although will be a valuable structure, probably duplicates many aspects of the already established Carer Resource Centres. Again GPs have been by-passed as active participants in...
Another national initiative is the Enhanced Primary Care (EPC) programme introduced over 2000-2001. Although EPC is patient centred, it is slowly becoming carer oriented with Medicare Items which include carers as formal participants with the GP and other health care providers in care planning and case conferencing. EPC shows some potential for promoting carer specific services within General Practice in the future, however in the short term I see little opportunity for improved integration with current organisational structures. Hence voices and GP needs will also remain sidelined.

'GP FRIENDLY' INFORMATION ON CARER ISSUES

Information : GP Frustrations and problems
Not unexpectedly, issues on availability of information or the lack of information about carer needs and carer resources dominated responses of General Practitioners in this part of my study. Lack of concise, current and appropriate information for GPs about locally available carer and community services topped the list of their problems. As busy clinicians they found it very difficult to keep up with the latest in community services and even more difficult to remember the complicated jigsaw of available carer and home based services, especially HACC funded services. GPs own needs for information were changeable according to their patient profiles and local demographics.

"My need for information - it keeps changing, new services arise, others fade, some change very hard to keep up" GP D-18

"I know people that work in the area, but ... things change so quickly..." D-6a INT.5 p.10 L. 2-17

"Yes we certainly need more information on them. As much as I think I am involved at the moment I know very little about those [HACC ] programmes." D-8 [INT.7] p.6 L. 40-42

developing such a linking programmes and thus there is less likelihood of their accepting or using CareLink in the future.

4 I have purposely not included the Coordinated Care Trials here which are about to enter a second round. Thus far carers have not been adequately recognised nor incorporated into the trial hypotheses, methods or evaluation. Despite the critically important role of carers in supporting patients with long term chronic conditions, the Trials have failed to afford them a formal position and status.

5 In my own state of South Australia I have worked with the Carers Association to develop closer working links with both academic and Divisional GP representatives with the aim of improve that integration between general practice and carer respite/resource centres.
Overall, GPs indicated they needed quick and easy access to reliable updated information on a specific locality basis for carers. It was important that it be presented in a format that was practical, useable and in a language readily identified by GPs (ie which incorporates carer support with clinical conditions like stroke, mental illness, aged care etc).

"Good information of available RESOURCES so that info is appropriate, relevant & concise GP friendly" information that is coordinated / integrated / localised "

**GP suggestions on information needs**

The following list includes what GPs thought would assist them access more useful information for carers. This addresses Question (8) in Part II of the GP Discussion Schedule which asked GPs: *What would assist GPs to have access to more useful information for carers?* Many answers overlap with the section on carer support and community services.

**SUMMARY OF WHAT GPS SAY WOULD ASSIST THEM TO ACCESS INFORMATION:**

In the short term - directories and telephone line most useful
In medium- long term - a data base as we become more electronically ... organised in the future
[ would need regular updating yearly]
A community services data base - kept updated
One number to ring for all
Kit for carers - for GPs to give to carers
A resource kit specific to local area - updated
Information Technology - "it will be better once we learn to use it.
List of telephone numbers and contacts - localised information about available services and resources for carers
List of carer groups
Divisions of General Practice [to assist GPs in information gathering and distribution of carer related services]
Up to date / revised list of telephone numbers
-of contact numbers for carer and home support services
-of access places ... or carer groups that could come in for an afternoon depending on the type of respite it is".

For many GPs the complaint was that information was never at hand when needed. If referring-on, GPs had real problems with having to make two or more phone calls just to find out where to go for services to assist carers. This was sometimes due to the changing nature (structure and funding) of community based services, but often due to GPs not being familiar with carer support services in their local suburb or council area. They also found it difficult to access appropriate information that could offer immediate and practical

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help to the family caregiver. Even more frustrating was when they did finally find the right service, there were unacceptable waiting lists, leaving the carer, patient and GP no further advanced. Pressure was still on the GP.

Information overload
On a day to day basis GPs complained of ‘information overload’ - a perrenial and unsolvable dilemma that frustrates most doctors but few are taught how to adequately deal with. Information overload creates confusion in who the GP should refer carers to. Even with the introduction of information technology into general practice during the 1990s, the comments below still stand today. The challenge remains for the GP to sort out which service is best to refer the carer to. Most importantly GPs need to feel confident about using those services.

"... all of your colleagues have the same problem with overloaded information and if you want any updated information and access to identifiable resource people."

"The problem is that GPs are bombarded with so much information that they are only going to retain the stuff they are interested in. If they don't have an acute interest in it, then it is probably only going to be filed in the waste-paper bin and that is where it will stay." D-6a INT.5 p.10 L. 26-35.

One GP felt that there was inadequate communication to GPs from the service providers about how to contact them, however many service providers had reported circulating their details to general practices only to learn that they were ignored. The prospect of sometimes valuable service information ending up in the office bin sums up the dilemma faced by most organisations trying to provide GPs with information they will use. This is perhaps was what prompted another GP to mull over how one might get information successfully across to his colleagues. He felt that something "...new and interesting was needed a ... new way of handling what we have to deal with ..." He continued, "...maybe we need to think about .. [sending] things to GPs that says, "this is your job to look after the carers and you should read this". The recent RACGP Guidelines in EPC are one step in this direction however progress will only be made if GPs can refer on to services they feel they can trust.

Information gathering
There were fewer comments volunteered by doctors about the actual process of 'information gathering' other than GPs drawing on the knowledge of others associated with their own practice like practice nurses and allied health workers. The assumption was

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7 D-3 [GP FG: p.21 L. 32-]
Chapter 17: General Practitioner Needs

that GPs would need to have that information about carers provided for them - a not unreasonable expectation in view of the sheer diversity of general practice and the broad knowledge base GPs must accumulate for their daily work. Some GPs suggested that Divisions of General Practice could play an important role in gathering some of the information on carer and community services together and coordinating its distribution. This will be discussed further in the next part of the chapter which addresses carer support and other service needs of GPs.

Information Technology

The idea of using information technology to better access carer support services appealed to quite a few GPs, as illustrated below. GPs could see themselves becoming more electronically organised in the future and therefore more willing to seek the extra information on carers. In 1995, IT in general practice was still being talked about amongst GPs, but since that time the Divisions of General Practice have introduced many IT training programs and software programs which go some way to addressing the other two comments below. What has not happened is a coordinated effort to include useable and practical information on respite, carer support and other home and community services that would help GPs identify appropriate resources for carers.

"We don't actually know how to educate GPs (about carers). We can't get information across very well and maybe information technology will be the end point." D-3 [GP FG: p.21 L. 32-]

"I actually think it will be idealistic once we learn to use information technology better." D-3 [GP FG: p.18 L. 15-23]

"...if you had a little box up on the screen which said 'Dom Care' or 'Carers' Needs met' and you just punched in a '3' and it printed out and you gave it to the patient, I think that is the key." D-3 [GP FG: p.18 L. 15-23]

Information also needs a face and a voice the GP can trust

Closely linked with the need for information by GPs is the source of that information, as quite a number of GPs indicated very strongly in their responses. In other words, it seems that information for GPs needs a face and a voice who they know and trust. Information per se is not enough for GPs who indicated they want access to reliable information and access to identifiable resource people.

"GP can't be familiar with every one of the care services ... and every social service that's available. I am familiar with some of the social services. I think we need a social worker and Domiciliary Care have social workers ..." D-11 [INT.3] p.7

208
My interpretation of what GPs were saying is that they wanted resource persons who added the personal touch, not only to information gathering but most importantly to the prompt provision of that information customised to each carer's needs. The GP could then feel confident about using that service information, the same as with using clinical services.

"If you have got someone who can link into the networks -EG- to ring up the Carers Network and say, Can you call in on this lady? She is not coping." D-3 [GP FG] p.21 L. 32-

"Somebody involved in care provision in the home would be a good resource."

D-10 [GP FG] p.19 L. 44-

Some sort of resource person like you mentioned you have in your practice would be good ... if that could happen in every practice." D-10 [GP FG] p.19 L. 44-

"The resource person I think is very crucial... saying, can you sort this out, and that will get across the Fee - for-service issue."

"Each support agency runs its own show - (needs) a central coordinator, (ie social worker), under direction of primary medical provider, ie GP."

However there was a subtle difference in what the GPs wanted in relation to resource persons and links with other agencies. One doctor (like others) felt he needed resource persons also to be part of general practice and accountable to GPs, something that was not happening in the mid 1990s. A similar concept has been tried in a limited and temporary way as part of some Coordinated Care Trials which have been primarily patient focused.⁸

"Dom Care have taken on the role of finding domiciliary care... and all the other services which are available - They are like the father of it all. Someone has to co-ordinate this from a point and Domiciliary Care a few years ago took it on... Someone has to be the central provider of this care - non medical care, If it's not Domiciliary Care then it has to be a social worker for the district. There has to be someone who is a central figure. At the moment we don't have that central figure."

D-11 [INT.3] p.7 L.7-17

"I would like domiciliary care, but it would never happen, to be more accountable at the general practice level, rather than to its own organisation." D-11 [INT.3] p.13 L. 14-16

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⁸ Similar responses from GPs were noted in the Co-ordinated Care Trials. In the Summary Report, Section 7.3.3. New coordination roles, I was interested to read the following about GPs working with outside service providers and care coordinators (mostly nurses). "Establishing effective relationships with GPs was critical to the success of the new coordination roles. Trials recognised this by attempting to establish a "team" or "partnership" concept with respect to care coordination. However this was only successful to small degree. ... Some suggested that linking the position to GP practices, rather than to clients, would have structurally assisted in more effective relationships being formed. The report also highlighted many problems with the non medical personnel lines of accountability to GPs.

Commonwealth of Australia, 2001, The Australian Coordinated Care Trials: Summary of the Final Technical National Evaluation. Report on the First Round of Trials, Commonwealth Department of Health and Aged Care Publications Approval no. 2911, AGPS, p. 40. [see also p. 38: 7.2.1] Also when I was on study leave in the UK (1998), several primary care projects featured carer support workers within general practices, then rotating throughout other GP practices in the region (Cornwall). Preliminary reports of that trial sent to me by the Cornwall coordinator of carer support, showed GPs were very happy with that model. GPs did not adapt well when the carer support workers moved on.
Chapter 17: General Practitioner Needs

"...a person you know at the end of a phone is very handy... but one person doesn't know all the answers - they are usually either the person at Dom care or ... Hostel Options or something. D-9 [INT.1] p. 14 L. 22-25] - Now there's something that could have more money put into it... Hostel Options - it would be great if that could be widened for the whole of Australia ... it is HACC funded”. D-9 [INT.1] p.14 L. 25-27

GP RESOURCE / SERVICE NEEDS
CARER RESOURCES AND COMMUNITY SERVICES

Comments and suggestions from GP respondents about service needs for carers were:

- Practice linked resources
- More public respite facilities to support carers' respite needs
- Improved GP-agency relationship
- A Safety Net/buffer zone to support carers in immediate short term, eg after hospital discharge
- Practical help for GPs to support carers: eg particularly from Divisions, community and carer support agencies, and from hospitals
- Protocols - for GPs on how best to assist carers (eg with different types of respite or different types of persons/patients being cared for)

There was much uncertainty amongst GPs at the time as to what services were best to recommend to carers. It was hard enough for them to find where the services were located let alone know which one to select even for the simple home support equipment.

"I don't think you can pretend that GPs are always going to know exactly which group to refer to for paramedical aids and things that help. I don't know an easy answer to that." D-6a INT.5 p.10 L. 26-35

One GP summed up very succinctly his own needs in terms of using carer and community services to help family caregivers (below). What challenged him was his ability to refer on carers to appropriate support services. Prompt and appropriate referral therefore is the cornerstone of successful carer support.

"GP knowledge, information, communication - this leads to better referral - having better knowledge and up-to-date revised...list of telephone numbers". D-8 [INT.2] p.11 L. 1-10

After examining what the GPs in this study were concerned about, it became clear it was mostly about the process of referral, (ie the what, how, who, where, and when of referral). Other aspects revolved around GP confidence (or lack of it) to refer-on to specific
services for carers and the persons they were looking after at home. Most important to GPs was the usefulness, suitability and quality of that information available on carer and community resources. It can be seen as a cyclic process for both GPs and carers.

Accessability, suitability and reliability of services

The broader aspects of service needs in general practice were identified by GPs, notably the accessability, suitability, reliability of services for carers and home care patients. GPs felt it important with so many different community services available, that GPs be kept informed about any service changes. A doctor's suggestion on how to do that was for agency staff or carer support organisations to visit GP rooms like the "drug reps" call on doctors. They could do a fifteen minute update on what was available and explain what had changed (or what was new) in that service. Such liaison might alleviate GPs' feelings of being alienated from the 'care nexus' as described by one GP below. GP relationships with community service agencies were sometimes seen as problematic in that access to domiciliary care and in-home respite was seen as only through one domiciliary care organisation.

"We get left out of the picture and that's what I'm annoyed about. Before domiciliary care I had far more access and endeavoured to find the appropriate places. But if someone else takes it over then I lose my contacts and my network. ... And that happened ...so that broke the care nexus and there are more care services now than we had before." GP [D-11] INT.3 p.7 L. 21-34

He added,

"Anyone who has been in practice in the two eras would know what I am talking about. If you are just coming into practice now you would not know that. You would know your basic referral unit would be domiciliary care. That's all you would know". GP [D-11] INT.3 p.7 L. 46-49

A major restructuring of General Practice occurred across Australia, but by 1995 it was still two to three years into the establishment of the newly conceived Divisions of General Practice. Most Divisions were grappling with how to improve liaison with community and consumer groups, rather than with carer organisations. Thus 1995 was time when there were few visible carer support networks to assist carers than there are now, so the majority of carers and GPs had to battle through on their own. They were used to being isolated and independent, relying on their own networking skills and 'care nexus', but that was starting

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9 From my own experience of working with a Division of General Practice from 1992-1997, initially as Executive Officer then developing community liaison, carer issues were poorly recognised. Carers were not targeted due to a pre-occupation of Divisions with focusing on consumer liaison, and having to work with so many community groups. Carers were usually subsumed within the more vocal and organised consumer lobby. In the intervening 8-10 years there has only been minimal progress with carer liaison by GP Divisions.
to change with the introduction of new carer support and domiciliary services and GPs felt they were being left out - not involved.

"I was comfortable [with the role of linking people] and we had no trouble at all then it was kind of taken away and another body took it over." GP [D-11] INT.3 p.7 L. 41-42

We know the whole network, we know all the little networks for their families. Maybe there is a double edged sword here that's going the other way, that ...there's some indication GPs don't care for carers. But maybe GPs aren't given a chance to actually get involved." D-3(GP FG) p.10 L.28-35

GPs lose track of the carer. Therefore include GPs in case conferencing. [People assume GPs too busy or not interested, but in fact it's GPs' workload and our life]. ... I think it is very important GPs are involved because you need to be able to summarize a case to an appropriate person and it's got to be at a level where they understand". D-3(GPFG) p.10 L.28-30

Role of Divisions of General Practice

Many GPs, looking at the bigger picture of general practice following the introduction of Divisions of General Practice, reported that they felt Divisions had potential to function as an overall referral agency to busy GPs. Divisions could have a coordination role between GPs and the 50-100 different community, home support and respite services that were dotted across each metropolitan region. Many of these services could be accessed for carer specific support.

A popular idea of two or three GPs was that the Division could be a useful structure to organise information from these diverse groups instead of each different organisation sending their information to individual GPs. Several respondents saw great benefit in Divisions putting all this material onto a data base so that the information on community (and carer) services could be quickly and easily accessed and retrieved by the GP, requesting it by phone or fax. It was also felt that there needed to be a resource person within the Division where GPs could go with their access problems and service questions.

Hospital liaison to GPs and a Safety net / Buffer Zone for carers

GPs identified they needed help from hospitals identifying carers who might need support. Presuming that the hospital staff were aware of the existence of the carer by the time the patient was discharged, one GP wanted more telephone liaison by the discharging doctor to the GP, so the GP could then go to the family immediately the patient returned home, and establish communication with the carer and start all sorts of community and support services. Of course the help was not always possible when services and resources were needed at short notice, so he proposed the idea of a safety net for carers - a buffer zone for carers within the community service structure. As the GP said, carer support was the 'zone to improve'. His diagram is reproduced below.
A BUFFER ZONE FOR CARERS WITHIN THE COMMUNITY SERVICE STRUCTURE

THE BUFFER ZONE FOR CARERS

ORGANISATIONS

COMMUNITY SUPPORT

CARER

PATIENT AT HOME

SUPPORT ZONE
This is the zone to improve

Outer Zone includes domiciliary care, district nursing, meals on wheels

"A GP described that getting beyond the circle of carers into the next buffer (support zone) is sometimes difficult.

"Services are overloaded and often other community support groups have participants with their own needs, who may not understand the needs of carers" he wrote. GP [D-E]

The concept of such a safety net is a compelling one not only for the carer and patient, but it would provide an important back-up for GPs themselves when trying to help distressed family carers requiring immediate assistance. After discharge from hospital or a time of crisis. The Carer Respite Centres now provide access to this type of service so they could be promoted to GPs as a safety net that would assist both the carer and the GP.

The following list on the page is a summary of what GPs said they wanted to assist them with carer support. This is a compilation of comments from throughout the GP Questionnaire. The idea of the safety net / buffer zone described above is incorporated under the first heading of services and facilities.
Chapter 17: General Practitioner Needs

A SUMMARY FROM THE GP QUESTIONNAIRE - WHAT GPS WANT / NEED

SERVICES & FACILITIES
- Greater knowledge and information for GPS on services for carers and for home care patients
- Accessability / Suitability / Reliability / Waiting times
- When GP accessing community services, GPS like to know about any service changes
- More public respite facilities to support carers’ respite needs
- Safety Net / Buffer Zone - within community service structure.

PROTOCOLS
- For arranging Respite services. "It will be better once we learn to use IT:"
- For dementia cases - protocols already proposed by Henry Brodaty in 1995

RESOURCES FOR GPS - LINKED TO THE PRACTICE
- Social worker [working in the practice]
- Community Services resource person in the practice
- GPS need a resource person in practice - funded from another body"
- Localised information about available services for carers and home support
- Up to date/revised lists of telephone numbers of carer support groups etc

PRACTICAL HELP For GPS
- From Divisions of Gen. Practice - Expanded roles - [see summary under 'Divisions' below]
- From Agencies, Allied Health staff / care
- From Hospitals

HOSPITAL LIAISON ABOUT CARERS - from the Discharging doctor / staff
- Hospital can help GPS - identify the carer and provide information
- Need more telephone liaison by Discharging Doctor to GP, so GP can go to the family immediately to establish communication and start all sorts of services

GP-AGENCY RELATIONSHIP
- GP saw [in 1995] domiciliary care as only access to services for carers
- GP access to Day Care & In-home RESPITE is through domiciliary care
- With domiciliary care social worker, GPS get left out of picture
- Agency staff to visit GPS:
  - Carer support organisations to come around to GPS [like drug reps visit]
  - Do a 1/4 hr update on what's available

DIVISIONS OF GENERAL PRACTICE TO ASSIST GPS WITH INFORMATION ON SERVICES
- Division as overall referral agency where you could go with a problem
- Division could be the structure to organise this info for us - instead of each different organisation sending it to GPS. Division to co-ordinate between GPS & agencies
- Division could provide access to data bank + Resource person
- Establish data base for GPS about community services
- Put all this resource material on data base - so that [the information is] quickly and easily retrieved by request by phone / fax.
GP respondents in this study mentioned specific problems and frustrations that highlighted access to service for carers. The causes of GP frustrations were identified mostly mostly in response to Q 3.9 in the GP questionnaire. Some of these issues have been expanded in the following pages with additional comments gained from GPs at interview.

Accessing services for carers
Problems with accessing services for carers loomed large for GPs who reported services as usually closed, not available, or moved. It was a run around for GPs especially getting through to the correct service. This was made even more difficult by their being unaware of some of these services, how to access them, phone no. Of the services they knew, with exception of some local Council resources & delivery of meals, they were unobtainable. Other GPs reported problems with district nursing, and domiciliary care services which provided an incomplete service. From the perspective of meeting carer needs, GPs were frustrated when organisations would not deliver meals to the home if a carer was available, no matter how exhausted they were.

Lack of public resources /support - long waiting times/lists
It was obvious to GPs there was greater need for carer and community services than were available and insufficient support available resulting in a lack of resources, especially in the public sector. A broader cause was linked with the structure of general practice and health funding at the time [1995]. There were reports of long waits for services like district nursing, delays which GPs considered unacceptable. With long waiting times, restrictive target groups and limits to what services could do, sometimes GPs just gave up. One GP complained of overloaded community and support services & often other community support groups had participants with their own needs who may not understand the needs of carers. He had observed that getting beyond the circle of carers into the next buffer zone (the Support Zone) was very difficult.

Respite problems
For GPs, the whole issue of respite was a nightmare. There were constant problems of getting residential and in-home respite, with GPs reporting difficulty finding a place to put the dependent for respite at short notice. It was just as hard to access respite in an emergency and in home respite was rarely available based on the experiences of other GPs. GPs felt that protocols for arranging respite services would help them - along with an adequate data base of the respite services available "...once we learn to use IT.".
GP-Agency Relationship and GP involvement

Other difficulties revolved around some strained relationships between GPs and the various community support agencies at the time. A few GPs felt there was mistrust between community and private health sectors. Another GP referred to 'others' low opinion of GPs. I am presuming he/she was referring to service providers. Another GP felt at the time that 'agencies' didn't care (about carers) as much as they should. One or two GPs mentioned how support agency runs its own show - (needs) a central coordinator, (ie social worker), under direction of primary medical provider, ie the GP involvement was as issue here suggesting...

"If you refer a person to the community - ensure we are not completely shut out."

"GPs use the 'established services like Dom Care but = 'handballing of the problem- we get lost a bit in what happens after that point (become less involved with patients and carers)"

"GPs lose track of the carer. Therefore include GPs in case conferencing. [People assume GPs too busy or not interested, but in fact it's GPs' workload and our life]."

"I think it is very important GPs are involved because you need to be able to summarize a case to an appropriate person and it's got to be at a level where they understand."

Despite access problems with organisations mentioned above, GPs reported that domiciliary care & district nursing were pretty good in terms of how they interacted with GPs, making themselves available and giving information.

Below and overleaf, is a summary of GP comments about community services under the headings discussing the causes of their frustrations in accessing support for carers. The situation today, in 2002 is different in that there are now more 'carer' specific services, respite and programs but without GPs being part of that structure, their frustrations and confusion of where to go and what to ask for will remain unsolved. As a number of GPs said before, when it is all too difficult, they just give up trying.

**SUMMARY OF GP FRUSTRATIONS WITH COMMUNITY RESOURCES / SERVICES**

**Q 3.9: Causes of those frustrations and barriers**

**ACCESSING SUITABLE CARER AND HOME SUPPORT SERVICES**

- Yes, [accessing services] a run around. Usually closed / not available / moved
- Difficulty accessing / getting through to correct service
- Unaware of some of these services, how to access them, phone no.
- I know the services, but with exception of -- Council & meal delivery they are unobtainable
- Problems occurred with district nursing, domiciliary care and meal delivery
Chapter 17: General Practitioner Needs

RESOURCES /LACK OF RESOURCES & SUPPORT

- Lack of facilities - need more respite facilities
- Lack of consolidation of available facilities
- Lack of after hours, emergency support
- Limited hours of various agencies
- Lack of resources available to carers - especially respite care and accessing allied health care (eg podiatrist, physio etc).
- Lack of resources in public sector - long waiting times in some areas that sometimes GPs give up
- Getting beyond the circle of carers - into the next buffer zone (re Support Zone) is .. very difficult. Services overloaded & often other community support groups have participants with their own needs who may not understand the needs of carers
- Insufficient support available
- Greater need for services that are available
- Lack of counselling services for carers, eg psychologist or even support groups

RESPITE PROBLEMS

- Respite is a nightmare
- Problem of getting Respite
- Hard to access respite in emergency; In home respite rarely available
- Can be difficult finding a place to put dependent for respite at short notice
- System overloaded / patient referred back to public hospitals to OPDs, A & Es with inappropriate referrals & letters - frustrating

SUITABILITY

- Domiciliary care provides an incomplete service
- Meals on Wheels - often will not provide meals if carer is available; no matter how exhausted...

WAITING TIME / LISTS

- On long waiting list
- Waiting lists - restrictive target groups
- Is a long wait for district nursing
- Waiting list for RDNS unacceptable
- Either long waits for services or limits to what they can do

AGENCIES/ ORGANISATION / MMT STRUCTURE

- Agencies and support groups don't care as much as they should
- Each support agency runs its own show - (needs) a central coordinator, (ie social worker), under direction of primary medical provider, ie GP
- Current structure of general practice and health funding

GP-AGENCY RELATIONSHIP

- Mistrust between community and private health sectors
- Others low opinion of GPs
- The support organisations are less likely to offer access to GPs that (to) patients and their families
- Dom care & District Nurse pretty good in terms of how they interact with us - make themselves available / give info RDNS are fantastic - they are very good
- My staff currently contact Dom Care/MOW/RDNS/private home nurses/ Resthaven support services

GP INVOLVEMENT

- If you refer person to the community - ensure we are not completely shut out
- GPs use the 'established services like Dom Care but = 'hand-balling of the problem- we get lost a bit in what happens after that point (become less involved with patients and carers)
- GPs lose track of the carer. Therefore include GPs in case conferencing. [People assume GPs too busy or not interested, but in fact it's GPs' workload and our life].
- I think it is very important GPs are involved because you need to be able to summarize a case to an appropriate person and it's got to be at a level where they understand
GP AWARENESS AND KNOWLEDGE OF CARER ISSUES
GP EDUCATION / TRAINING

1. TIME
2. REMUNERATION
3. INFORMATION (GP FRIENDLY)
4. CARER RESOURCES / SERVICE
5. GP KNOWLEDGE / AWARENESS
6. GP EDUCATION & TRAINING

GP Knowledge - on carer issues
Grappling with the non-medical and social aspects of carer and home support which entailed a different and broader knowledge base was a constant challenge and frustration for GPs. It has been continually raised within general practice during the 1990s but to date there have been no satisfactory solutions. With such an emphasis on community and home based care, expectations on General Practitioners today are even greater. GPs are often criticised for not referring-on carers to community and support services, however the crux of the problem is that if they don't know something exists, they can't access it. In addition if they don't trust the service, or understand how it functions and who is involved, they won't refer on.

"... we may not know that something else exists. If you don't know that it exists you can't order it." D-6a INT.5 p.10 L. 10-12

Just as frustrating for the busy GP and the overwhelmed carers, is the withdrawal, restructuring or disappearance of existing services. Below I present what GPs were saying in 1995 about their knowledge of carer support and community services which were kaleidoscopic then and probably even more so now. [This predates the introduction and establishment of government funded Carer Resource Centres in 1996/7 in each capital city across the country.]

"Many GPs not familiar with what is available." D-4
"Probably like most GPs I've got a vague idea of the various supports and resources that are available out there for carers - varies from district to district." GP [D-9] INT.1 p. 14 L. 1-4

"Lack of current knowledge. You may have a pamphlet that's two years old about services, but then find that service has been axed due to funding cuts." D-5

"We like to know about changes and access. I'm always needing to arrange for patients who are depressed and other community things ... important to know if the reading group is still going and ...and what else is available. D-8 [INT.7] p.6 L. 25-29

"...I think with carers ..., people assume the GPs too busy and is just not interested, but in fact it's our workload, it's our life." D-3 [ GP FG] p.10 L. 28-30
Chapter 17: General Practitioner Needs

"If we could slightly re-orient the way we think... We are usually quite good at asking about things about alcohol, psycho-social history, but I would suspect the majority of us don't routinely ask about caregiving - I think that is because we haven't been trained and we haven't had our awareness stimulated appropriately." D-12 [GP FG] p.20 L. 39

Information and service issues were the gaps in GP knowledge and GP awareness of carers, often compounded by the stalwart attitudes and approaches of family carers themselves. GPs acknowledged the need for greater carer awareness amongst doctors, not only at the practice level, but across all levels of medical education.

"...an awareness of what is going on - Maybe that could come under the courses that we mentioned. Clearly there is room for us all to be more attuned to what is going on ".
D-10 [GP FG: p.20 L. 1-10]

"...no one pays us to be, if you like, to be educated for that sort of time. Often these things don't get done adequately. I mean you often learn about these things like access cabs and, whatever it might be, ... simply by experience or finding it out from patients - a patient has told us, or a carer has told you." D-10 [GP FG: p.17 L. 51-54]

Several GPs advocated carer specific education within RACGP GP training, CME programmes, and undergraduate medical training in medical school.

"Build carer issues into the FMP & CME programs"
"Training & info at CME sessions, during Med School, during RACGP training program."

One other interesting suggestion was for GPs who might have a special interest in caring and take it up as a sub-specialty. The idea was they could be offered a re-education program that complimented their medical training, but re-focused on carer needs. Those GPs could then take on a co-ordination role involving carer support within each practice.

"...mainly what we need to look at is ... retraining the GPs so that you have actually got some who have got a special interest in 'caring' over sub-specialty ... - and they have already got the medical training so you don't need to update that, but you could ... just have a re-education type of program where they could actually co-ordinate it and ... know all those things from there. There may even be one or two in each practice that you need to ... do that." D-6a INT.5 p.9 L.7-16

Another GP who was actively involved in GP education at the time made reference to including carer topics in what was then called the Family Medicine Program. [The program has since been renamed the RACGP Training Program and contracted out to other bodies other than the College].

"I have not seen anything about carers in the FAMILY MEDICINE PROGRAM seminar program and I guess in a way, it would be helpful" D-12 [GP FG: p.20]

"What is the important thing now is that it [an awareness of carers, and information,] is built into the family medicine program and continuing medical education programs an awareness of carers, and information. It is the organisation of information that we already have too much of as you said." D-12 [GP FG] p.21 L.5-
His priority also was to familiarise GPs with carers so they will look after them, and secondly for GPs to be formally paid for the extra quality time they need to spend with each carer.

"The first stage is to make the word 'carer' that is something that is on GP's lips and then they will start actually looking for carers."

The next stage is that... we are in a fee for service system ... and GPs have to be paid for spending 15-20 mins to a half an hour with a carer. If you are happy with GPs spending 3-7 minutes with a carer, well they don't have to be paid. But I don't think it is good enough so they do have to be paid for it. The present government is not going to increase the budget for Fee For Service system or produce another item - they are not interested in doing those things...I don't know... I haven't really got an answer to that one". D-12 [GP FG] pp.20-21

**TIME / PAYMENT ISSUES FOR GPS**

<table>
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<th>1. TIME</th>
<th>2. REMUNERATION</th>
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<th>4. CARER RESOURCES / SERVICES</th>
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These previous comments by the GP featured above are a good introduction to this last theme which generated a great deal of comment from the doctors in my study. The last question of the Discussion Schedule asked GPs: Q.(2):What do you as a GP want or need regarding issues of reimbursement/rebates for GP time spent with carers? Frustrations due to the lack of time available to see carers and lack of payment for GP time spent advising and counselling carers drew heated responses from GP as evidenced below. What this showed more than anything else was that GPs were willingly giving much of their time to working with and counselling family caregivers as part of their every day practice - but at a price.

"I believe they [carers] are already getting enormous support from their GPs in this. Already we spend hours per week in unpaid for liaison and organisation". D-8

Responding to the needs of carers was considered time consuming by many GPs - sometimes taking more of the GP's time than patients. As one doctor described it, it was like three consultations in one. The GP respondents felt quite passionate about the topic:

"Time! - In General Practice we already have to work long hours to make a reasonable income (granted we probably employ too many staff and spend too long with patients making this unprofitable). Although we now provide considerable unpaid organisational hours - a lot is in trying to help caregivers. Some recognition of this by a system of payment for carer counselling would improve the quality of care I'm sure (by encouraging more GPs to do it)". D-8
"It takes a lot of time to look after a patient properly and look after the carer and tell the carer all about what you do with the patient and listen to the carer, what they want to do with the patient, and then also look after the carer's needs. It's really like three consultations not one." D-12 [GP FG: p.11 L.3-7

Despite the many barriers, described earlier, GPs in this study presented compelling arguments for GPs to continue working with carers. Many if not most the GPs were already trying to help carers.

"This is an imp. role we should be playing" 
"GP's paying attention to carers is very important .......

They agreed that the support of family carers within general practice was a legitimate and important role for GPs and they were ready and willing to assist carers in any number of ways. One GP wrote about the need for time for listening with carers - "as often emotional support is important". [D-24]

"GP is prime source of providing counselling - should be recognised more." 
"Some recognition of this [time given by GP helping carers] by a system of payment for carer counselling would improve the quality of care. -I'm sure (by encouraging GPs to do it)." D-8

**Home Visits**

Time for home visits was considered "extremely helpful in assessing any situation" regarding carers [D-24]. Home visits are important therefore need GP payment.

"If I was more home based I'd probably notice their psych. & social problems
Domiciliary visiting and house calls by GP - quickly identifies the carer
For GPs to see the real situation at home
Do home visits to see how they cope and what the true situation is. You can't always tell in the rooms what the difficulties really are."

With home visits however, the time and payment factor is again problematic as one GP explained:

"It's very time consuming because you are going to see the patient in the home and you go to walk out to the car...you've got a 20 minute conversation, sorting out what has to happen. Then you have 20 minutes ringing up Dom Care, to sort it out again, and then its an hour.. don't get paid for". D-3 [GP FG] p.11 L.18-23.

GPs gave examples of making time consuming phone calls searching for carer and community support services, filling in forms in their own time, personally delivering medications, all without reimbursement. A GP writing in the questionnaire complained it - often takes a number of phone calls to co-ordinate" D-1. A second respondent stated bluntly, "15 mins on the phone is worth quite a bit - can't afford to be mucked around". D-2. A third GP observed during interview:

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"...lawyers can charge people for time they spend on the phone but GPs can't... we do spend a lot of time on the phone - it's not just with carers but carers is a good example because they are time consuming". D-9 [INT.1] p. 13 L.9

The bigger picture of general practice
Several GP participants at the end of their Questionnaire took the opportunity to consider the bigger picture of carers and general practice, "to try to put this and all other roles we play into an overall context." One GP's insight was very helpful. She felt that the issue of more time and attention on needs of carers was an example of the problems facing general practice today. [D-5]

"Of course, I think GPs paying more attention to carers is very important. However I wish someone would try and put this and all the other roles we play into an overall context" D-5

"GPs are constantly asked to do more / better / longer periods of time, ie care of chronically mentally ill, information about medications etc. The proposed solution to many of today's health care problems seems to be 'educate GP to do it better'" D-5

Putting so much emphasis on educating GPs for every new idea or initiative was considered by this GP to be problematic - quite justifiably so when GPs are the target of so many different stakeholder's demands. She suggested researchers should "study exactly how much more time their proposals are going to take and then work out practical proposals to how the GP can make this time available". Otherwise, she warns, GPs "are pulled apart by different interest groups". This is a very real problem that can lead to GP overload and burnout.

"GP burnout. Sometimes I just feel tired and that I'm unable to supply the level of support that I perceive some people want." D-5

Divisions of General Practice are partly addressing this dilemma, but it does not reduce the continual expectations and pressures put on individual GPs in their own work place. It is no wonder that GPs just 'give up' trying to find elusive resources, etc.

"Lack of resources in public sector - long waiting times in some areas that sometimes GPs give up".

Payment barriers
During the focus group, GPs raised the issue of a possible impact of payment barriers on the actual care of the carers themselves. Although salaried payments 10 for time spent with carers might help, it was not necessarily the answer. The GPs felt they needed carer specific funding of some kind, one adding, "... there are whole lot of other examples of

10 A short debate over fee-for-service and capitation versus salaried payments ensued. However as they soon acknowledged, whether it is an Australian fee-for-service or British capitation system, both put subtle pressures on the GP to keep time per consultation to a minimum.
things that we need funding for that are perhaps appropriately covered under fee for service. The discussion moved onto how GPs did or might cope within those constraints. One GP's opinion was very telling:

"...my personal feeling is that [by] identifying the word [ 'carer'], you'd have to have a re-imbursement for it, because they [GPs] won't do it otherwise, so carers have to be turned into patients - they have to have illnesses. So you almost have to ask the carer, have you got a disease that I could see you for a consultation - to be blunt about it. So that needs more work... right across the spectrum". D-12 [GP FG] p.21 L. 16-22.

This view is interesting in the light of an earlier comment shortly before in the focus group.

"...if you identify a carer as having needs, psychological needs, being anxious or depressed, ...., it's OK to label them as carers [and] maybe it's OK to label them as people who are distressed, .... then they become a patient according to Medicare then they can be billed.... I don't know how morally right that is though". D-12 [ GP FG] p.12 L.14-19

A few other GPs suggested carers needed to make appointments for themselves to see the doctor to discuss the many aspects of their caring role and needs. Unless they became 'patients' themselves, the GP could not claim reimbursement for this time. Whatever the strategy used, GPs showed they were at least responding to carer needs in whatever way they could even without the benefit of a formal means of doing so through Medicare. They admitted though it was especially difficult to help, for example, "if that carer happens not to be your patient as well..." It is important to consider because it is often the case is it.

Obviously within the structure of general practice and health funding, GPs were not satisfied with Government policy on rebates for time spent with carers. In fact GPs claimed that Medicare Rebates were structured to discourage it. At that time there was no item number for helping a carer ... so GPs were keen to be funded (fee for service), for time spent with carer and on the patient's behalf. A clear majority of GPs felt strongly that they needed to have their efforts on behalf of the carers recognised by government and properly remunerated through the Medicare system, one suggesting carers need to make appointments for themselves.

12 Under the present Medicare system, even with the new Medicare items for EPC, the GPs can't be reimbursed for that time spent with carers on a one-to-one basis.
13 D-13 [ GP FG] p.11 L. 9-10

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SUMMARY OF COMMENTS ON
TIME AND REMUNERATION NEEDS OF GPS

DR-CARER CONSULTATION MODEL

Educate GPs to consider a Carer-GP consultation model
Take a good social history of new patients
Spend more time enquiring exactly what a particular carer sees that their role entails
More time. More understanding. (Data on carer needs)
If carer & dependent person has same GP it is hard for GPs to ignore it!

SPENDING TIME WITH CARERS AND NOT PAID FOR IT

I believe they are already getting enormous support from their GPs in this. Already we spend hours per week in unpaid for liaison and organisation. D-8

I spend a lot of time outside consulting time attending at home visits etc. and usually don't get paid for the majority of it. The patients and carers are very appreciative though and this is worthwhile in itself. D-25

Time! - In General Practice we already have to work long hours to make a reasonable income (granted we probably employ too many staff and spend too long with patients making this unprofitable). Although we now provide considerable unpaid organisational hours - a lot is in trying to help caregivers. Some recognition of this by a system of payment for carer counselling would improve the quality of care I'm sure (by encouraging more GPs to do it). D-8

Time - they [carers] need to make appointments for themselves D-21
Time, constraints on the part of the GP - often takes a number of phone calls to co-ordinate. D-1
Time for listening as often emotional support is important D-24
Time for home visits - extremely helpful in assessing any situation D-24
Time factors D-2, D-3, D-7, D-18, D-20, D-23, [carers are time consuming]

FINANCIAL REIMBURSEMENTS FOR CARER CONSULTS [time and effort]

Should be some mechanism for GP to get re-imbursement for meeting carers' needs" and funded / paid for liaison & visits [with carer]
GPs have to paid for spending 15-20 mins to 1/2 hr with carers.
15 mins on the phone is worth quite a bit - can't afford to be mucked around. D-2
Recompense other time pressures on GPs
Lack of payment for doing this work D-5, D-12
GPs not paid / not adequately funded for time D-10 D-12, D-18
Funding / Finance D-10, D-18, D-19; Financial recognition, help D-9
Payment for community services D-12

MEDICARE SCHEDULE / ITEM NUMBER / REBATES

Financial no item number for helping a carer -D-7
Medicare Schedule / Item No for "carers" D-12
Money ... and a restructuring of the schedule which is going to happen eventually
Be funded (FFS - Fee for service) for time spent with carers on patient's behalf
SUMMARY OF NEEDS OF GPS
TO MEET CARER NEEDS IN GENERAL PRACTICE

TIME
PAYMENT
RESOURCES
INFORMATION
KNOWLEDGE
EDUCATION

- A resource person for community services at practice (or Division)
- A social worker associated with the practice or work between several practices)
- Co-ordinated / organised provision of INFORMATION
- Localised information that is regularly updated
- DATA BASE of local community services - with quick and easy retrieval
- A list of access places
- A list of carer support groups
- Representatives of carer support groups to visit GP surgeries
  (in similar way to 'drug reps', who GPs make time to see)
- A protocol for arranging respite services
- Better knowledge and training in handling community information/services
- Remuneration for time spent with carers
SUMMARY - GP DATA : PARTS 1-4

Part I: IDENTIFYING THE CARER IN GENERAL PRACTICE

GPs who contributed to my study were, as family doctors, intuitively 'carer aware' but not all of them used the label 'carer'. The GPs' priority was to maintain the dignity of each person - carer or patient, but they were very perceptive that carers were indeed supporting or nursing patients with an illness at home. Carer role and responsibilities were understood to be over and above that of the normal relationship for all aspects of the patient's well being, and carers seemed to be identified through their distress or problems and whether they were coping or not, later referred to as "the grey zone". This was related to the type and severity of the patient's disease or disability.

On the whole GPs appreciated that the cared for persons would not normally be able to do for themselves, and the person receiving that care was dependent on the carer. More GPs had difficulty relating to parents of disabled children as carers. Some doctors did not identify these 'carers' until they saw the person [parent] breaking down or when the disabled child became an adult.

GPs were mindful that with carer responsibility there was a lot of potential for stress and anxiety, especially those carers looking after persons with dementia or psychiatrically disturbed people. Lack of understanding or recognition of carers depended on the GP interests and approach of the doctor, the visibility of the carer and some GPs pointed out carer issues were not part of medical training. At the practice level GPs' involvement with carers was voluntary and unpaid, and so don't routinely think beyond the patient and doctors lacked data on carers' needs. This was compounded by many carers not telling their doctors about their caring role or patients mentioning they were being cared for. Also there may be more than one carer at home.

GPs therefore wanted better definitions of carers, (both well and ill carers), greater awareness training on carer issues in CME and the RACGP Training Program. They suggested asking about the home situation and taking good family/social histories so the carer status is flagged in the notes (so other doctors in the practice will be aware too). Carers should be encouraged to question GPs and talk about their caring role. Home visiting helps identify the carer and
provides a reality check on the home situation. Lastly the role of the hospital discharging doctor/staff was considered an additional way of identifying carers.

Part 2. NEEDS OF THE CARER

GP's observations with carer needs were very consistent with those raised by carers with the GPs differenting between the carers' role needs and their personal needs as individuals. As family doctors they were aware of the benefits of respite relief, time away / holidays, extra home care services but some of the doctors said that social needs were not usually mentioned by carers.

GPs were lacking in detailed knowledge of the range of services and carer support available, even the different types of respite options. Their ability to pass on carer specific information was therefore limited, as had been reported by carers. This might account for GPs mentioning the benefits of carer education (highlighted by carer participants).

GPs were however sympathetic and concerned that carers could feel exhausted by trapped in their role, emphasising the importance of carers having access to both informal and formal emotional support (friendly visitors to talk to) to offset their isolation. Also support and counselling for carers of the terminally ill, or those with dementia or severe mental illness. Planning for the future care of the dependent person was often mentioned by GPs.

Part 3. GP OBSERVATIONS OF CARER HEALTH

GPs were very perceptive on the subject of carer health, with two thirds of GPs reporting caring to have a negative impact on carer health and well being. GPs mirrored what the carers reported -that existing health problems were worsened, while constraints on living a normal life of the carer, their loss and isolation, stress and exhaustion, tiredness, anxiety, anger, frustration, sadness and sleep disturbances, could be linked with immune system changes, and depression. They identified how many of those influences could act as precursors to psychological illness leading to a state of pre-depression. The cared for person's illness was seen a psychological blow to carers that starts the process of and is complicated by existing illnesses. Therefore the deterioration of the cared for person's health, could be the catalyst for the carer experiencing health problems. Carers didn't seem to cope well with their own illness and had a tendency to sublimate or ignore their own health needs. These and other
behaviours were a concern to the GP participants who also observed that carers' don't cope well in the caring role. GPs needed to be aware of their cries for help.

Finally when carers were ill, they were constantly worried about the safety and well being if their own health failed. GPs acknowledged that neighbours had their limitations as proxy carers. GPs gave many descriptions on how they helped when carers were will, delivering prescriptions to the chemist or back to the carer, arranging extra help in the home.

**Part 4. GP NEEDS**

GPs experienced many barriers which made their daily work difficult and frustrating when trying the assist carers. There were information, structural, organisational and attitudinal barriers, geographical barriers and payment barriers. GPs also experienced their own sense of isolation - from information and resources, and sometimes felt isolated from the carer. GP needs were time and payment related because they found carer support very time consuming. They required targeted, GP friendly, local and up to date information on carer services that was suitable for use in general practice, (including IT), accessible carer services they could trust and refer carers on to, reliable resource persons associated with the practice, and additional resources such as respite for public patients. One GP suggested they and the carers needed a 'buffer zone' within the community service structure to better support carers.

GPs acknowledged that their knowledge base and awareness of carers was limited and again suggested GP education and training at all levels of learning. It was suggested that 'caring' could be taken up as a sub-specialty by GPs who have been through a re-education program focused on carer needs. Each practice could then have a 'trained' GP to take on a coordination role regarding carer support.

GPs saw Divisions of General Practice as fulfilling several roles for GP education, information provision and assistance with referral to services, to linking with community and carer services. Most needed was a Medicare Schedule Item Number to recompense them for their time spent with carers, especially home visits.
SECTION III
SECTION III

INFORMAL CAREGIVING AND CARER HEALTH AT THE POPULATION LEVEL

Disability, Dependency & Informal Caregiving

Prevalence Of Informal Caregiving: Literature Review


[Health and Socio-demographic Status of Adult Carers in the South Australian Population]

A: Population Survey Background Details and Methods:
   (S A Health Omnibus and SF-36)

B: Population Survey Data and Findings:
   SA Health Omnibus, 1994, 1998
   (Includes SF-36, GHQ and AQoL)
DISABILITY, DEPENDENCY & INFORMAL CAREGIVING

PREVALENCE OF INFORMAL CAREGIVING:
Literature Review
CHAPTER 18
DISABILITY, DEPENDENCY & INFORMAL CAREGIVING

Introduction
The purpose of this paper and chapter 19 is to construct a profile of carers in the population and describe their main characteristics based on a review of the available literature. Much data collected on carers in the past has been confined within the parameters of the care relationship and related to the disabled people themselves. Carers have usually been described in the literature in terms of the type of illness and level of disability or handicap of the persons they care for. Therefore before giving a general view of the carer profile it is important to clarify a number of concepts surrounding caring and disability. This establishes the link between disability, dependency and the underlying need for assistance from the informal sector. In this chapter I put informal caregiving into perspective by focusing firstly on the concepts of disablement and dependency, then on issues of population morbidity, disability and ageing. These are central to understanding the processes leading to dependency and their impact on the need for informal care.

'Disablement' is now a somewhat dated term but has been used within the context of the ICIDH since the 1980s. Up until the early to mid 1990s, 'disablement' incorporated the three concepts of impairments, disabilities and handicaps. In recent years the term more often used has been 'dependency', but it remains a rather controversial 'label' and is still opposed by many disabled groups and aged persons. Nevertheless the concept of dependency persists and today is measured in terms of impairment, disability and activity restriction (which was previously referred to as 'handicap').

1 'Caregiving', the relationship between the person with a disability and the informal carer, is based on the carer assisting that person with core activities where the person is restricted by their impairment. This assistance is beyond the normal reciprocal support that commonly occurs within families and other social relationships in our society.
2 ICIDH is the International Classification of Impairments, Disabilities and Handicaps
In the older population disability was relatively stable across the first three surveys [1981, 1988 and 1993]. In the 1988 there was an increase in rates for disability and activity restriction [handicap] also increased. This was partially explained by improved measurement techniques by the ABS.
Chapter 18: Disability, Dependency and Informal Caregiving

It is worth pausing momentarily to consider two useful theoretical models of 'disablement'. The first one, a disability model promulgated by the WHO in 1980\(^5\) describes the disease or disorder (interpreted as an *intrinsic* situation), which may lead to an impairment. The *impairment* (an *exteriorized* term) can in turn lead to a *disability* (the *objectified* term) and it may also result in a *handicap*, (by this stage the concept has been 'socialized'). Although a person's impairment can lead directly to a handicap, this link between impairment and handicap should not always be seen as a linear process. This is especially so in a mental health context as stated in an earlier AIHW report.\(^6\) Instead, "impairment, disability or handicap may be related independently to the underlying disorder with the possibility of a two-way interaction". This is evident in disability surveys where high rates of chronic disease and disability occur in the community and are increasing, but where the levels of handicap (core activity restrictions) may remain stable or appear much lower.

A second but similar approach to 'disablement' is to focus on the way disability is analysed and expressed in relation to *the person*.\(^7\) Disability is therefore associated with the *activities of that person*. By contrast 'impairment' is used to relate specifically to the affected *body organ* [its structure and function]; while 'handicaps' are measured in relation to the barriers or restrictions to the individual (eg in terms of schooling or employment), caused by their environment and as *a result of impairment*.\(^8\) Handicaps thus tend to be interpreted in the context of *society* and a person's roles in that society.\(^9\) Many frail aged and younger people with a disability which results in severe or profound handicap need assistance from caregivers - thus challenging their independent role in society.

In summary "disability" is an all embracing term currently used to describe a person's physical or intellectual restrictions, limitations or impairments. Disability is recognised as occurring in all age groups - from the cradle to grave - and usually exists as a consequence of disease, disorder or injury.\(^10\)

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6 ibid, p. 87.
8 ibid Jennie Widdowson
10 ibid
Too narrow a view of disability

Informal care of the frail aged and disabled has dominated the political agenda to the point where family and informal caregiving, by default, has been tightly coupled with a rather narrow concept of physical and intellectual disability and its associated handicap. Initially this was almost to the exclusion of other categories of caregivers supporting family members at home. For example those with long term and chronic illness, care of the terminally ill or the caregiving associated with earlier rehabilitation following injury, sudden illness or surgery. This restricted view of disability has changed since reviews ABS surveys on carers of the handicapped and disabled. The emphasis has since moved away from 'handicap' per se, to 'core activity restrictions' that are now also associated with long term health conditions and chronic illnesses. Most have now been included by the Australian Bureau of Statistics as causes of 'disability' and dependency.

This change in emphasis and interpretation of 'handicap' considerably broadens the scope of disability and informal care. Such an approach therefore prompts a closer examination of rates of disability for instance in terms of disability linked with changing morbidity rates, life expectancy and the total burden of disease and injury [DALYs]. Other significant factors impacting on disability rates include population growth and population ageing.

There were two companion Australian Bureau of Statistics publications produced in 1998 to complement the 1998 ABS Disability, ageing and carers' survey. They were: Care in the Community [ABS Cat. No. 4436.0] and Disability and Long Term Health Conditions [ABS Cat. No. 4433.0]. These, as well as a separate ABS publication, Older People, Australia. A Social Report 1999 (that was part of another series), and an AHW publication in 2000 Disability and ageing, provide a more comprehensive view of older carers and caring for older people. In addition current government reports on the federally funded Home and Community Care Programme are the other major source of useful data on older carers who are also recognised and supported as part of this Commonwealth / state initiative.


12 Data collected on disability and caregiving however still does not include all those situations where family members take on the role of informal caregiver to someone at home who is debilitated or dying. Therein lies the dilemma of tying caregiving too tightly with the concept of disability. Discussing how disability is defined is well outside the parameters of this thesis.

In the Box below, I list at least ten factors mentioned in that same report affecting overall prevalence of disability in Australia. These influences are expected to continue into the twenty first century, many of which can also be expected to impact on need for and demands on informal caregivers in decades to come.

Factors affecting overall prevalence of disability in the Australian Population

- population AGE structures
- incidence of specific types of condition[s] and disability
- age of onset of specific conditions and disabilities
- the diagnosis of disabling conditions
- the prevention and treatment of specific diseases (effects differ depending on nature of diseases; ie chronic non-fatal disease or highly fatal diseases)
- mortality and life expectancy of the general population and among people with particular diseases, conditions or disabilities;
- perception and awareness of disability and health
- social attitudes and economic incentives concerning sickness and disability
- personal behaviours and exposure to violence and environmentalials that cause disease, injury or disability;
- mortality due to the number of significant external causes such as transport and road injuries has decreased in recent years. This could potentially result in increased disability prevalence, if people are surviving and living with disability rather than dying as a result of their injuries. [eg surviving with brain injury]
- Also from perinatal data on the incidence of congenital malformations, one can suggest that the higher survival rate of these babies may also affect trends in disability prevalence. Babies surviving with congenital malformations will dramatically impact on their parent carers!!

See Reference 14

These issues are all important to consider in view of the informal caregiving that is associated with long term care of dependent children and adults (including the less often discussed care of terminally ill persons). It is beyond the scope of this thesis to provide a detailed overview of all these issues, however reference will be made to them in terms of how morbidity, and disability in particular, impact on informal caregiving. I am drawing

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on information directly out of the 2000 AIHW Report on 'Disability and Ageing' which is briefly outlined below, firstly discussing the Impact of changing rates of disability on informal care, and secondly describing the Impact of population ageing and population growth on informal care.

Impact of changing rates of disability on informal care.
According to Australian Bureau of Statistics data, up to 1998, the prevalence rates of disability in Australia have increased, as have the proportions of people with specific (activity) restrictions (handicaps). Indications are there is no sign of any declining trends in disability prevalence among older Australians, particularly for severe or profound core activity restriction. This creates an increased 'demand' for home based informal caregivers and will continue to do so in the near future.

The increased prevalence rates of overall disability in the population thus far can be partly explained as a flow-on effect of the rapid decline of mortality and shift in disease patterns (referred to as the epidemiological transition) that has occurred during the 20th century in many OECD countries. Although population death rates have fallen they have been accompanied by a rapid improvement in survival and increased life expectancy - but not necessarily free of disease of injury. This greater longevity has therefore impacted on trends in morbidity and disability which in turn impact on trends in community based informal care for the disabled as will be further explained later.

The shift in disease patterns in countries like the United States (and hence Australia), has been referred to as "an era of delayed degenerative diseases". It means "there are more survivors who are frail and or suffer chronic conditions", shifting and increasing disability associated with degenerative diseases toward older age groups in the population. A longer lifespan means that people have "a prolonged period of life and increased exposure to non-fatal debilitating conditions (like arthritis) and therefore perform daily activities less than..."

16 ibid, [7-77]
17 ibid [7-79]
18 ibid [7-70]
19 ibid [5-19]
20 ibid [5-10]
21 ibid [5-30]
efficiently". Hence their need for assistance with daily needs from close family members and others, like partners, parents, siblings and sometimes friends.

A more recent interpretation of disability, using DALYs suggests that in Australia, "the extension of lifespan is accompanied by increase in years lived with disability". The disability is usually mild to moderate however the AIHW report points out that the 1998 ABS survey shows increases in proportions of people with a disability and specific restrictions, including severe / profound restrictions. The increase in long term morbidity in Australia over the past two decades (from 16.2% in 1981 to 19.6% by 1998) has occurred mostly in those aged 75 and over and very old people.

Two decades of surveys (1981-1998) have shown that most common causes of all disability in Australia were due to physical conditions (85%), especially musculo-skeletal disorders such as arthritis, as was described earlier [1998]. The remaining 15% of people with a disability identified a mental or behavioural disorder as their main condition [1998]. In instances where there were persons with head injury, stroke or brain damage, an even higher percentage [72%] relied on informal assistance. Problems of the cared for persons, the main categories and causes of their disability are briefly discussed below and again in the next chapter.

Problems of the Cared for Persons
Detailed population data on the impairments of care recipients remains vague and sketchy despite repeated national surveys over the past decade. The ABS categorises physical impairment in terms of assistance required for mobility, communication or transport. 88% of those persons requiring assistance with mobility are reported as having vision related problems and 80% are merely listed with non-specific physical impairment. Those persons requiring assistance were described as people with musculo-skeletal problems, especially those with arthritis, heart disease and other circulatory conditions.

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22 ibid [6-35]
23 ibid [6-55]
24 ibid [7-79].
25 ibid [6-68]
26 ibid
27 ibid, p.98. [It is noted in relation to disability that 1.2 million Australians reported to have disability due to arthritis and other musculo-skeletal disorders. This represents about a third (34.4%) of people with a disability.
28 ibid
Of people with *communication* needs, 88% are associated with speech problems, 85% with hearing related problems, and 79% with intellectual impairment. People requiring assistance with *transport* are listed as 94% with intellectual problems and 93% with psychological conditions.

It might therefore be argued that informal carers are supporting those patients with the highest non-fatal burden of disease (YLD), especially those in the top 8-10 of major diseases. [These include mental disorders, nervous system, chronic respiratory, cardiovascular and musculoskeletal disorders, cancer, injuries and genito-urinary problems etc.][30] ABS surveys now also highlight increases in long term health conditions in Australia (ie up from 45%, when 6.2 million people had long term health conditions in 1977 to 75%, 13.6 million persons, in 1995. Such an increase in long term health conditions contributes to the overall proportion of people with disability and core activity restrictions [handicaps] in households requiring family support or other carers. For instance by 1998, 19% of this group of people needed the assistance of informal carers in the home and community. So it is not only that persons with the disabling health conditions have to live with their disability, but as often happens, the family/informal carers looking after and supporting them have to live for many years with that person's disability too. As will be mentioned later on, many carers have a significant disability themselves but maintain their caring role for a disabled partner, parent, child, other relative or close friend. There is a double DALY effect for carers perhaps?

*Impact of population ageing and population growth on informal care.*

As mentioned previously, the 20th century phenomenon of 'epidemiological transition' with its impact on population ageing means that there is an increase in size and proportion in advanced aged groups.[31] The shift in disease patterns and age distribution of deaths from degenerative causes has increasingly concentrated in older ages resulting in greater longevity and rapidly changing trends in population mortality and morbidity. This in turn is likely to impact on the future availability of informal care.

The AIHW report features the following five main impacts (not necessarily in the order they were published) some of which, according to the authors, may have 'countervailing'

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31 Page [5-18]
influences on each other.\textsuperscript{32} Of most concern, I believe, will be problems associated with the ageing of carers themselves. This is not only in the case of older carers supporting other frail or aged adults as with spouses and relatives, but those older parents aged over 65 years who find themselves still caring for their severely handicapped "child", now of adult age and prematurely ageing\textsuperscript{33}. Many of these older carers will simply not be able to continue to support these dependent family members. Many carers will die with the effort. In many instances the informal support they provided will need to be replaced by alternative and possibly formal arrangements for future care of the cared for individuals.

As mentioned earlier, although life expectancies across the population are increasing, life expectancy for males is increasing at a faster rate - therefore "married couples may survive longer together " and the proportion of spouse carers may increase. It is to be expected that both husband and wife may need care simultaneously and that extra support will most likely come from other informal and formal sources.\textsuperscript{34}

Another well documented impact that will have ongoing consequences on informal care is the maturing of the baby boomer cohort, currently under 65 years. The authors of the AIHW report point out that 'population ageing of this group will be particularly strong in the working-age population during the next decade, [2000-2010]. There is likely to be an increase in the number of people with severe or profound core activity restrictions [handicaps] in both the working-age population and people aged 65 and over. It is suggested that this will "further increase the need for carers".\textsuperscript{35} As a possible counter-balance to the expected greater demand for informal carers, at least for the period 2000-2010, it is suggested "there could be an increase in potential carers for older people in the next decade". This is because the 45-64 age group is projected to be substantially higher than that of those aged under 65 and over during that period. For example survey data showed that the majority of primary carers [over 43\% ] were aged 45-64 years and 35\% were aged 15-44 years, compared with only 21\% of primary carers aged over 65 years.\textsuperscript{36}
CHAPTER 19
A PROFILE OF INFORMAL CARERS

Introduction
In presenting this general profile of carers, it is helpful to put informal caregiving into some overall perspective both within our community and in terms of international trends. For example how prevalent is informal caregiving in comparison to disability as discussed in the previous chapter, and what proportion of carers are there in Australia compared to other western countries? I will address the last question first which draws on data from the early 1990s.

Prevalence of carers - an international perspective
Howe et al. in association with the principal investigators of a Victorian Carers Program have provided the most comprehensive comparative prevalence data of carers to date. They compared findings of their earlier Victorian study (1993/4) with the 1993 Australian ABS survey, the 1985 and 1990 UK General Household surveys, as well as a state-based Canadian 1994 survey of carers in British Columbia.

Despite sampling and definitional inconsistencies the authors were able to 'reconcile' differences between surveys and show very similar prevalence of carers across the three countries. When applying what was referred to as 'stricter' estimates of principal, or main carers in Australia (using ABS data) and Britain (using 1990 General Household Survey data), both Australia and the UK had approximately 48-50 carers per 1000 households. This figure was within close range of the estimated prevalence of caregiving in the Victorian Carer Project which was 53 carers / 1000 households - the same as a 1994

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2 The Victorian Carers Programme was a joint project funded by the Victorian Health and Promotion Foundation, headed by Schofield, Hilary, and Herman Helen, from the Department of Psychiatry, University of Melbourne. Other team members included Sidney Bloch, Barbara Murphy, Julie Nankervis and Bruce Singh.
4 Howe et al used a 1989 study of caregiving for adults aged 50 years or over (Biegel et al, 1991) for the British Columbia study. The authors also included data from a USA survey and compared it with Canada. The 8% prevalence rate for caregiving seemed comparable but not conclusive due to it targeting only adults over 50 and therefore has not been used in the context of my own comparisons.
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Canadian survey result which was also 53 primary carers per 1000 households in the province of British Columbia.5

When considering the percentage of primary or principal carers per population the authors, Kalucy and Baum, in their 1993 article on the Epidemiology of Caring,6 were able to show how a population at the state level also compared favourably with countries like Britain. From their earlier state-based research in 1993, they concluded that 4% of the population in both South Australia and the United Kingdom were carers. Interestingly this figure is similar to ABS data from the 1993 national survey which later identified 4.2% of the Australian population as principal carers of dependent persons.

A follow-up ABS report,7 however modified that ABS figure for carers down to 3.9%, while my own research in South Australia using the 1994 Health Omnibus Survey [which surveyed a representative sample of the state’s population], identified 3.4% of the population as carers. The slightly lower figure for my 1994 study is most likely due to the different definition used to describe the role of a carer, nevertheless it can be seen that between 3.4% - 4% of the populations in Australia and the United Kingdom were identified as carers in the early 1990s. Family caregiving was therefore remarkably consistent throughout these Commonwealth countries in the early 1990s. When more reliable national data on family caregivers becomes available from other countries such as USA, NZ and Japan, it will be very interesting to see if the similarities continue across these international borders.

Comparing patterns of disability with that of informal caregiving

The following data is extracted from the most recent 1998 ABS Survey of Disability, ageing and carers8 which is a useful starting point for contrasting the level of dependency and patterns of disability with that of informal caregiving in Australia. For example in

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1998, there were 18.4 million Australians of whom 3.6 million,9 both children and adults, were identified with a disability.10 This equates to a fairly high prevalence rate of 19.3% [2000]11 of disability overall within the Australian population. The ABS also reported a further 3.1 million people had an impairment or long-term health condition.12 The 1998 survey had indicated that more than half of people living in households (57%) needed assistance with at least one daily living activity.13 For example almost a half (49%) of persons with a disability received informal assistance to move around or go out, shower or dress, prepare meals, do housework, property maintenance or communication [1998].14 Only 27% receiving formal support.

A more restricted estimate offered in a later report, focused on people with a profound or severe handicap who always or sometimes need personal assistance or supervision with activities of daily living.15,16 This yielded lower proportions of persons who had a profound core activity restriction, [2.9%], while 3.2% reported a severe restriction [1998].17 Again of those people with profound or severe core activity restrictions (1998s) receiving informal assistance, most of it was from relatives and friends, chiefly partners (or spouse), parents and children (ie mostly offspring of adult age). Thus as carers exist by virtue of their caring relationship and responsibilities for the well-being of a frail, sick or disabled person, it is interesting that the percentage of main or primary carers in the population tends to correspond to the prevalence of severe and profound disability in the community (which in Australia in the 1990s has been between 2.4% -3%). One cannot

9 ibid, p. 3
ibid p. 3 [-A Long Term Health Condition is a disease or disorder, including damage from accidents or injuries, which has lasted or is likely to last for 6 months or more. Not all long-term conditions restrict people in their everyday activities and result in disability.]
13 ibid, p. 8.
14 ibid, p. 8.
16 Core activities of daily living include self care, mobility or verbal communication.
assume however, that the informal and family carers themselves are disability free. As will soon be described, carers may have a caring role, but also be physically or emotionally burdened by their own disability - especially those in the older age groups.

Carers
The Australian Bureau of Statistics 1998 Survey of Disability, ageing and carers concluded that 13% [12.6%] of people living in households in Australia were identified as carers [1998]. That is, 2.3 million people (representing 'all' carers), were providing assistance to those who needed help because of disability and ageing. 19% of these carers, or almost half a million (450,900) persons, were identified as 'primary' carers. Thus the total number of primary carers in 1998 represented 2.4% of the total Australian population which means that 1 in 5 people providing help to others, were primary carers, 79% of whom were caring for a person in the same household [1998]. The greater majority of primary carers (352,200 persons) were therefore considered to be 'co-resident'.

According to the 2000 AIHW publication, caring for a spouse was the most common caring relationship among adult primary carers, [aged 15 years and over] accounting for 42.9% of all primary carers. 59,600 primary carers (13.3%) had been in the caring role for at least 25 years, while 35% (161,300 primary carers) spent on average 40 hours or more per week in providing care and 22,700 of those had been caring for at least 25 years. In general, females were more likely to be in the caring role than males, especially with primary carers. 96,400 primary carers were aged 65 years or more, and of those 62.5% were women.

Double jeopardy for carers
It is generally accepted that the disability rate increases gradually over the lifespan [1998], thus the likelihood of having a disability increases with age as do the chances of

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becoming a carer. Carers are therefore twice as likely as those who are not carers to have a disability (32% compared with 17%). As mentioned earlier, this not only means that more older people require the support of informal carers, but that older carers themselves are more likely to develop disabilities and complications from long term illness, whilst they are still caring for a partner, spouse, child or another person. Therefore it has been pointed out that informal carers can help only to the extent that they themselves are functional and available. However many carers continue to support and care for others despite considerable personal discomfort and disability. For the purposes of this thesis the emphasis is mostly on the 'primary' carers who provide the most assistance to people who have activity restrictions (handicaps) and who bear the brunt of a protracted and demanding caregiving load at home and whose personal lifestyle and health is at most risk.

In fact the 1998 ABS Survey data has indicated both primary and other carers have higher rates of disability across all age groups. For example in the same 1998 survey, of all the primary carers, nearly 40% (39.4% or 177,500 carers) had a disability themselves, 9.3% (41,900 carers) had a severe or profound core activity restriction. The 1993 ABS Disability Ageing and Carers Survey showed similar trends with 38% of all co-resident principal carers themselves having a disability. In fact 6% of all carers had a severe or profound handicap.

The proportion of primary carers with a disability in 1998 also increased with age, from almost a quarter (24%) of primary carers aged 15-34 to more than a half (57%) of those primary carers 65 and over with a disability. This unexpected and significant finding is of concern in view of the particularly 'heavy' workload many informal carers carry when looking after older spouses/partners or adult children in the family home who are disabled and chronically or terminally ill. The 2000 AIHW report also stated that rates of disability

25 Ibid
for primary carers were significantly higher than for the total population in other age groups. These high rates of disability among carers are likely to be due in part to the older aged structure of the carer population.\textsuperscript{27}

How many carers? Reviewing the literature

The above overview provides some introductory snapshots of the profile of carers in our country during the 1990s, and this will be more fully detailed later in this chapter. In terms of estimating the actual numbers of 'carers' per se, despite the consistency in prevalence described earlier there remains some disputation both in Australia and overseas about the methods used to acquire those figures. This is partly because identifying and quantifying 'carers' within demographic and epidemiological terms is still a relatively new exercise which will require considerable efforts in the future to 'standardise' carer research and survey methodology across state and international borders. With informal caregiving still a relatively new area for inclusion in modern day demographics there has been considerable methodological experimentation in identifying 'carers' over the ensuing ten to twenty years, with researchers using many different sampling methods and varied definitions of caring. This definitional dilemma plagues all research on informal caregiving, including my own research, with discrepancies commonly found between the various interpretations of 'family caregiving'. A definition of 'carer' therefore needs to be clear and 'tight' enough to efficiently screen respondents and which adequately differentiates carers who are providing care and support that is well beyond the normal expectations of the family and friendships, otherwise some survey figures may appear overinflated.

Other methodological anomalies surround the inclusion / exclusion criteria regarding non-resident carers and the age ranges chosen to categorise respondent carers. Differences in these areas often occur between surveys, some including those aged 15 and over, others only including those aged 18 and over.\textsuperscript{28} Similar variations have occurred in Australian research where the choice of age groups has been slightly different to those used by the ABS\textsuperscript{29} - the usual national benchmark in our own country. Nevertheless, as already


\textsuperscript{28} As occurred between the ABS 1993 and 1998 surveys on Disability, ageing and caring.

\textsuperscript{29} As occurred in 1999 when data from the Carers Association of Australia 1999 survey, based on their own nominated age groups, was compared with data in the 1998 ABS survey, which had quite different age groups.
mentioned, even the ABS changes selection criteria and survey methods from year to year (and between surveys) making results harder to compare. Despite that the data does show some interesting trends. For example there are obvious similarities between the characteristics of 'carers' in terms of gender mix (as seen with usually more female than male carers) and the types of relationships involved (carers are mostly supporting a sick or disabled spouse / partner or frail elderly/ disabled parents).

Counting the carers - in the UK
Mention has already been made of the British data on carers. The British General Household Survey to my knowledge was the first attempt by any western country to formally recognise the role of carers by including them, in their own right, in a national population-wide census. Carers have since been regularly included in the 5-yearly British General Household Surveys which remain a useful point of reference for any country attempting to estimate the level of informal caring in private households in comparison to care provided through formal health and social support systems.

There too has been considerable controversy about the accuracy of the actual number of 'carers' in Britain. The most useful and comprehensive profile of carers was first compiled by Parker and Lawton from a national census in the UK conducted in 1985. Green, who produced the initial UK report in 1988 stated, "...about 3.7 million people are bearing the main responsibility for care of someone". Other British commentators have suggested there could be as many as 6 or 7 million carers in the UK in 1985-1990, but this figure has

30 Australian Institute of Health and Welfare. 2000. Disability and ageing. Australian population patterns and implications. A joint project of the Australian Institute of Health and Welfare and National Disability Administrators. AIHW Cat. No. 19. See page 4 of this AIHW report for detailed descriptions of the ABS Disability series. This document provides very clear explanations and comparisons on the rates of disability in the earlier 1981, 1988 and 1993 surveys. See also Page 12 of the February 1994 AIHW Workshop Proceedings [on Measurement of Disability]. Jennie Widowsen from the ABS presented a paper which describes difficulties with the concept of disability in the early 1990s, and reasons for changing earlier definitions of disability and handicap in particular for the 1998 survey. It was also acknowledged that several groups of disabled people were being missed by earlier survey definitions and methods. For example those people with need for assistance with gripping things, picking things up off the floor and many long term conditions causing restrictions such as arthritis, Alzheimer's disease, dementia, heart disease and asthma. That meant many carers were missed in earlier surveys. Refer pages 4-5.


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been disputed, especially by Parker and Twigg.\textsuperscript{34,35,36} Unlike the Australian situation in the 1980s, where numbers of carers were probably underestimated, Parker\textsuperscript{37} suggested the UK General Household Survey (GHS) figure had been over-estimated and that numbers of "...heavily involved carers were considerably smaller. She also pointed out that, "...not all those identified in the GHS were principal carers", nor were they "co-resident" or caring form someone more than 20 hours a week. This argument was further detailed in Parker's description of 'caring situations'\textsuperscript{38} identified from the 1985 GHS. For example Parker found carers were 'sole' or 'main' carers in more than half (52%) of all caring relationships; that carers lived in the same household in a quarter (25%) of all caring relationships, (showing a trend towards fewer "co-resident" carers in the UK than in Australia).

Results from the second General Household Survey (1990) that featured carers in Britain, were used as a comparison with a recent independent survey of British carers conducted in 1998 through the CNA (the Carers National Association)\textsuperscript{39}, Britain's peak carer advocacy group. Author of the CNA report, Melanie Henwood wrote that the number of [all] carers were estimated to be to closer to 6.8 million, representing more than 1 in 7 adults in the population were carers. 1 in 4 of all UK carers were co-resident, consistent with the previous survey. Henwood suggests however that female carers were more likely to be 'main' carers, or 'sole carers' or those who spent more time than anyone else helping. Male carers she writes, were less likely to be providing personal care as indicated by the Green report in 1988.\textsuperscript{40}

\textsuperscript{34} Parker published her findings on carers in 1992 and again in 1994 to which I will be referring later in this chapter.
\textsuperscript{36} For a synopsis of this data refer to page 6: Chapter One:'Counting care: numbers and types of informal carers'.
\textsuperscript{38} ibid
\textsuperscript{39} ibid
[Henwood reported that data from the 1995 GHS were not available for comparison at the time Henwood was preparing her report.]
\textsuperscript{40} Green, H. 1988, \textit{General Household Survey 1985: Informal Carers}, London: HMSO.
[Refer to Tables 3.5 and 4.0 of this report].

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Calculating numbers of carers in Australia

Although there is a national household census conducted across Australia every five years, unlike the British census, our national census does not identify 'carers' (informal caregivers). Thus one cannot confidently extrapolate data on carers from any of the ABS nation-wide household census data, nor is it likely we can do so in the immediate future until carers are specifically included in our census questionnaires. The Australian Bureau of Statistics has however conducted several smaller-scale surveys in which informal family carers were included, initially relating them specifically to the care of handicapped people in Australia. According to an AIHW report, this occurred first in 1981 and developed into the ABS disability surveys which have provided cross sectional data collected at four points in time: 1981, 1988, 1993 and 1998, over a period of seventeen years.

The 1988 survey identified 322,600 "principal providers of help and supervision." This obviously did not represent the whole range of situations where informal carers were involved, so the 1988 survey methodology was modified, and an expanded survey repeated by the ABS in 1993, broadening the focus on carers to disability and ageing. Terms and definitions in the survey instrument, including how carers were identified, were again changed before the survey was conducted in 1998. The effects of these changes and other factors such as population ageing combined to show an additional 1.4% of the population had a disability and an additional 1.2% of the population had a handicap.

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41 To their credit, the ABS was one of the first countries to try to apply the concepts of the ICIDH to population surveys. This was in the 1981 Survey of Handicapped Persons. Subsequent surveys in 1988 and 1993 [this time on disability, ageing and carers] used essentially the same definitions as the first survey.


Definitions of carers used by the ABS disability surveys

The 1993 disability survey had referred to the 'principal carer' of a person with a disability using the following definition. The 'principal carer' was

"the person, aged 15 or over, who provided the most informal care in the areas of self-care, mobility or verbal communication." (ABS 1993).47

At that time, 577,599 "principal carers" (aged 15 years and over) were identified representing 4.2% of the Australian population in 1993.

The next 1998 survey targeted 'primary carers' defining them as:

"....the person, of any age, who provides the most informal assistance to a person with one or more disabilities. The assistance must be ongoing, or likely to be ongoing, for at least six months and must be provided for one or more of the core activities (self-care, mobility, or communication". (ABS 1999:71).48

This yielded 2.4% of the population or 450,900 as "primary carers" in 199849 (aged 15 years and over), a somewhat lower figure than the 4.2% of 1993.50 It is interesting to note however that when comparing 'all' carers for each survey, there were 1.5 million carers identified in 1993 but a higher figure of 2.3 million carers identified in 1998. Also the 1998 primary carer population contains a greater concentration of carers whose care recipients


47 ibid, p. 137.
48 ibid, p. 137.
This AIHW report quoted the main differences between a carer and a primary carer by the following three points. (1) a primary care must provide 'the most' informal assistance; (20 the care recipient of a primary care must be a person with a disability (as opposed to a person aged 60 or over without a disability as defined in the survey); and (3) for a primary carer, the assistance provided must relate to one of more core activities. (self care, mobility or communication)


In Ch 7: Disability Services, it is reported:
"The ABS 1998 Survey of Disability Ageing and Carers data on primary carers are estimated to be about 60% of what might have been expected, based on the ABS 1993 Survey data for 'principal' carers. The difference between 'primary' carers and 'principal' carers appears to be a consequence of the way the surveys were done...eg in the 1993 Survey, carers living with a care recipient were identified by the care recipient; in the 1998 Survey, carers living with a care recipient were identified by a responsible adult and specifically confirmed by the carer". 

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have a higher frequency of care needs compared with the 1993 principal carers. Thus, making accurate comparisons of the data from the surveys has been rather problematic. Nevertheless these four ABS surveys have provided the major framework of our national demographic data on carers in Australia for over a decade. In addition to providing useful socio-demographic profiles of Australian carers, the 1993 and 1998 ABS surveys on 'Disability, ageing and carers' also asked about the perceived impact of caring on the health of carers, information that was previously only available in smaller research projects and surveys reported in the academic literature. Therefore the ABS data is of particular relevance to my own research questions in this thesis.

By the end of the 1990s, both British and Australian carer organisations had embarked on their own national surveys of carers and their use of the health care sector and social support system. There was the CNA/Henwood report in 1998, already referred to earlier and a similar Australian survey conducted in 1999 by the Carers Association of Australia, which also included detailed information on the health and well-being of carers. In both surveys almost a half of the carers had reported their health affected by the caring role (especially through physical injuries and stress related illnesses).

One separate state-based study which, has to date, generated the most significant and descriptive data on the characteristics of family carers in Australia, was part of the 1991-1996 Victorian Carer's Program. During the early 1990's a Victorian research team from the University of Melbourne's Department of Psychiatry, conducted an extremely detailed three stage population based longitudinal study of 976 carers, randomly selected from 26,000 households in Victoria. Outside of the ABS surveys, this study represents the

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51 ibid, p. 248.
52 The peak carer bodies of UK and Australia are the National Carers Association, London in the United Kingdom, and the Carers Association of Australia, based in Canberra.
53 The National Carers Association, UK, produced the report which included responses from more than 3,000 carers across Britain.
54 Briggs and Fisher from the Carers Association of Australia produced their report from 1,490 respondents across Australia.
55 The Victorian Carers Programme was a joint project funded by the Victorian Health and Promotion Foundation, in association with staff from the Department of Psychiatry, University of Melbourne.
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most comprehensive analysis of informal caregiving available and although is state based, equates well with other carer populations across Australia during the early to mid 1990s. I often draw on the Victorian data as a useful comparison for my own research findings throughout this thesis.

OTHER CHARACTERISTICS OF INFORMAL / FAMILY CARERS

Relationship - of the carer with the cared for person
A consistent trend seen in Australia in 1998 with primary carers aged 15 years and over, is the greater proportion of them (42.9%)$^{57}$ caring for a partner or spouse. This is similar to findings from the 1999 Australian Carers Association member survey where the most common caring relationship was for a partner (52.6%)$^{58}$, and in the 1998 British Carers Association survey where the most common caring relationship was for a spouse/partner (53%),$^{59}$ a very similar figure for both countries. It was reported that partners were most likely to provide assistance to people with physical impairments, ie to 48% of those receiving informal assistance.

The ABS 1998 survey also showed that almost a quarter of primary carers (24.9%) were caring for a child with a handicap and slightly less, (21%) were caring for a parent. The remaining 11% were caring for another relative. Again there were similarities with some results of the Australian and British Carer Association surveys to the ABS figures on who the carers were looking after. For example in the 1999 Australian CAA survey, 23.7% of primary carers were caring for a child and 21.3% were caring for a parent. However as reported in the AIHW document,$^{60}$ the vast majority of a son or daughter primary carers were aged under 65 years, and more than half (53.9%) were not living with their parents.

In the 1998 British Carers Association survey more than a quarter of primary carers (27%)

57 ibid

60 ibid, p. 138.
were caring for a parent (22% of carers were caring for a mother), while fewer primary carers (19%) were caring for a child with special care needs due to disability or chronic illness. It is not clear however how many of these were adult aged 'children' as is the case of some older parents supporting grown up children with intellectual impairment, physical conditions and disabilities or perhaps mental illness. In 1998, which again was reported in the AIHW document, 9,700 parent primary carers (and 73,000 spouse primary carers) were aged 65 years or over. Most ageing carers (8,800) were mothers who were living with the son or daughter they cared for. It was stated that these ageing parents of a 'child' with a severe or profound core activity restriction have a different history from carers because of the long duration of caring relationship.

**Gender of carers**

In the same ABS Survey (1998), both males and females were well represented as carers, but females were more likely to be in the caring role than males. Amongst 'all carers', slightly more than half (56%) were female. However the difference was more marked when considering 'primary carers' of whom 70% (317,500) were women and 30% (133,500) were men. Interestingly when one examines survey results from most other carer research across Australia, the female to male balance is quite consistent, usually around the 70% females to 30% males. There is one exception however which is in the over 75s group. For example the 1998 ABS survey showed there were slightly more male primary carers (18,300) aged 75 and over than females (15,200) in the same age range. If one compares these 1998 results with the earlier 1993 ABS survey, it shows that the number of female primary carers has actually decreased in the over 75s group from 1993 levels.

**Age**

Of 'all' carers providing some assistance in 1998, 887,800 of them (38%) were people in the mid life 35-54 age range, where caring responsibilities involved children, partners and ageing parents. The age group in which people were most likely to be involved in a caring role however differed for men and women. The peak (age) for women was 45-64, 24% of women in this age group were in a caring role and 6.6% were the primary carer.

61 ibid, p. 138.

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The peak (age) for men was in the 65 and over age group. 22.6% of males in this age group were in a caring role and 3.8% of the men were the primary carer.\textsuperscript{63}

Considering primary carers specifically however in Australia in 1998, peak age group was found amongst the 45-64 year olds which accounted for 42.9% (43%) - 46% of female primary carers and 42% of male primary carers.\textsuperscript{64} This group was closely followed with 32% of primary carers in the slightly younger 25-44 age group. The impact of population ageing was also reflected in informal carer and the carer population. Of the 96,400 primary carers aged 15 and over, 62.5% were female. 22% of all primary carers were aged 65 or over, with 14% aged 65-74 and 7.5% aged 75 years or more. At the other end of the age scale, only 3.6% of carers were identified aged 24 years or under, but as already mentioned this is unlikely to be an accurate representation of the real numbers of 'young carers'. In 1998 31,300 primary carers were aged under 30 years.

The 1998 ABS Disability Ageing and Carers survey presents a fair view of adult Australian carers aged over 18 years but I believe does not accurately indicate the true extent of young carers under the age of 18, who are often hidden from society as they are usually not perceived as carers at all. Until the end of the 1990s, community and government awareness of young carers was limited about this issue and a small (unknown) percentage of both children and teenagers remain unrecognised as fulfilling important caring roles to their sick and disabled parents, siblings and other relatives. It is now recognised that an intensive caring role may have a deleterious impact on younger carers, in terms of education and career development in an increasingly competitive environment.\textsuperscript{65}

Work and carer pensions

Although 78% of primary carers were of workforce age (18-64 years), 59% were not attached to the workforce, as many had had to give up work to provide informal care at home to relatives and others. It is therefore not surprising that 69% of primary carers were on a government pension, benefit or allowance and for 56% of those carers, was the


\textsuperscript{64} ibid, p. 138.

\textsuperscript{65} ibid, p. 138.
principal source of cash income. Many carers were existing on less than $200 per week which illustrates the link between this type of informal caregiving with low income/poverty.

**Educational background of carers**
In 1998 about 15% of those in the 15-64 year working age group were carers. Interestingly, carer rates were the highest for people with basic vocational qualifications (20%) and lowest for those with bachelor degrees or higher (12%).

**Hours of caring per week and Duration of caring**
Establishing the actual 'workload' of primary carers is difficult. In Australia one relies on minimal ABS data and other extraneous data derived from smaller surveys and studies to find the number of hours carers spend supporting and attending to the cared for person. This is another example of methodological divergence and confusion where researchers use many and varied descriptors for 'caring' tasks and activities. However it is clear from the ABS 1998 Disability, ageing and carers survey, that 178,300 primary carers (39.8%) had been in their caring role for and least 10 years. Of those, 59,600 (13.3% of primary carers) had been in the caring for at least 25 years. 161,200 primary carers (36%) spent on an average of 40 hours or more per week providing care. Of these 22,700 had been caring for at least 25 years.

Data from the earliest General Household Surveys in Britain (1985) indicated that carers in the UK helped for more than 20 hours per week in 20% of all caring relationships. Parker concluded however that 75% of British carers were providing care for 50-99 hours per week. Using data from the next British GHS (1990), Henwood reported that 5% of all men and 10% of all women (1.5 million people) were caring for at least 20 hours per week, with 11% (1 on 10 carers) providing care for at least 50 hours per week.

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66 Reported in July 2001 fact sheets prepared for federal election by the Carers Association of Australia, Canberra.


69 ibid

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Findings from the later 1998 (British) Carers National Association Survey of its members\(^\text{71}\) revealed 70\% carers spent 7 hours caring per day and 30\% of the carers reported spending more than 105 hours per week. This is twice the average hours worked by those employed person in the health services.

In the same report, Henwood analysed the duration of caring of CNA members.\(^\text{72}\) She found that two thirds (64\%) had been caring for at least 6 years, 24\% had been caring for 3-5 years and 6-10 years, 22\% had been caring for 11-20 years while 18\% had been caring for more than 20 years. 9\% had been carers for 1-2 years while only 3\% for less than a year. This type of information on the duration of caring does not seem to be so readily available in Australia through the ABS, however a similar survey by the Carers Association of Australia of their members in 1999, revealed that 40\% of primary carers had been providing care for a decade or more and 68\% for more than 5 years.

Data from the Victorian Carers study by Schofield et al in the mid 1990s remains the only significant state survey carried out to date in Australia that provides detailed information on the duration of caring.\(^\text{73}\) They reported that more than a quarter (27\%) of their carer respondents had been caring for 3-5 years, and a very similar proportion (26\%) for more than 10 years. 16\% had cared for the sick/dependent person for 6-9 years and 15\% for 1-2 years. 16\% had been carers for less than a year. From the same study, a third (35\%) of the carers spent less than 10 hours a week in the caring role, just under a quarter (22\%) spent 10-30 hours per week caring, 15\% 31-100 hours per week, while more than a quarter (27\%) were caring for over 100 hours per week.\(^\text{74}\) These figures paint a picture of caring excessive hours per week, that for some carers, may extend over many years. Again, far beyond the workload of paid care workers or nurses.

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\(^{72}\) Ibid, p. 13, Figure 2.4.


\(^{74}\) Ibid
Carers’ need for assistance
The 1998 Disability, ageing and carers survey showed that almost a half of all primary carers aged 15 and over received support in providing care. About half of all primary carers aged 15 years or more did not receive any assistance in providing care, although 41.5% of these carers reported they did not need assistance. 9.2% (41,300) carers who needed assistance for their caring role but did not receive any while a further 15.7% (70,300 carers) stated they needed further assistance. Of particular concern from that 1998 survey was the carer response about respite. Only 13.2% of primary carers aged 15 or over reported at the time they had used respite care services. Although it was reported that most primary carers (388,900 people) had never received respite care services, it should be pointed out that the majority of carers stated did not need them (345,100 persons). However there remained 11% (43,800 carers) who did need respite services but had never received them.

Two other aspects of carer assistance are significant. The AIHW report referred to ‘fall back carers’. When questioned about this type of help, a third of all carers 35.7% (or 16,000) reported they did not have a fall-back carer while 8.1% (36,300 carers) did not know if a fall back carer was available to help them. Lastly the document also indicated that primary carers living in non-capital city regions were less likely to receive assistance than those living in capital cities.

OLDER CARERS AND CARING FOR OLDER PEOPLE

"Older Australians constituted only 12% of our total population, but they consumed 35% ($11 billion) of the $31 billion total health expenditure on health services in 1993/94". By 1998, 22% of all primary carers were aged 65 and over. The 1998 Disability, ageing and carers survey indicated that from the total Australian population of 18.6 million people

76 ibid, p. 145. [Refer Chapter 16.]
77 In view of government finding of additional respite services for carers in the community, especially now that each state’s regional carer respite centres are well established and functioning, it will be interesting to compare the 1998 figures with future levels of respite use by carers.
78 Australian Institute of Health and Welfare, [Second Edn], 1999, Older Australians at a Glance, AIHW Cat. No. AGE 12. Funded Jointly by the Department of Health and Aged Care and the Australian Institute of Health and Welfare, Canberra, Sheet 34. This included costs related to nursing homes and acute hospital services. In the same special report (Sheet 34), it was pointed out that some increases were a statistical illusion...as in nursing homes increased costs due to food and accommodation are also classified as ‘health costs’"]
Chapter 19: A Population Profile of Informal Caregivers

there were 2.3 million older Australians aged 65 and over, including almost a million (976,500) who were aged 75 and over. Only 7% of those aged 65 or over lived in cared accommodation. The vast majority (91%) lived in private dwellings, of whom more than half (54%) had a disability. 15% of older Australians were categorised as having a severe or profound disability. Another report stated that 2/3 of older people with a severe or profound core activity restriction (handicap) lived in private dwellings in the community. The proportion of Australians with a disability and specific restrictions (handicap) is reported to have increased between 1993 and 1998. This is partly explained by the increase in population size in Australia as well as some impact of the population ageing.

In terms of age distribution, female carers tended to be somewhat younger than their male carer counterparts. There were more male carers aged 65 and over [Only 19% of female carers aged 65 or over vs 27% male carers aged 65 or over]. Some of these increases were a statistical illusion as reported in the 2000 AIHW special report, but it was also stated that during 1982/83-94/5, real health expenditure per person grew by 2.9% per year, but only 1/5 of this increase (0.6%) was a result of costs associated with an ageing population. Major contributing factors to growth of health expenditure over this period were increased use of medical services, new technologies, and increase in pharmaceutical costs. Despite these findings, the emphasis continued to be on the projected increases in aged care by demographers and the government.

The following information relates specifically to care of the elderly and proportions of older carers. It also indicates the likelihood of older carers themselves having to cope with disability and illness and the added problems inherent in sustaining their caring roles. The 1998 survey reported that less than half (46%) of all older people needed assistance, however it was emphasised that "older people's needs for assistance with every day activities increased with age regardless of whether or not they had a disability."

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79 Ibid, Sheet 34.
82 Ibid
83 Ibid, Sheet 34.

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and friends were the main providers of that assistance, with partners and children the usual informal providers of help to older people. Of the 710,900 receiving informal assistance, 41% (294,900) were assisted by partners who were probably older themselves.\(^8\) The most striking aged-related trend is in the Dementia and Alzheimers Disease category where there is a greater increase with age (ie from <2% in 65-69 year olds, to 19% in those aged 85 and over), but magnitude of the increase is greater among women [2-21% in Females. 2-13% in Males].

Again the most comprehensive overview comes from the Victorian study by Schofield et al where they considered the conditions of relatives being cared for by family caregivers.\(^8\) Findings indicate a quarter of all care recipients were frail aged (24%), circulatory related (19%), congenital/developmental problems (15%), paralysis involving a limb (15%), 12% had dementia, 10% had sensory impairment, 10% rheumatic conditions and 10% multiple sclerosis, while 8% had respiratory problems, 7% neoplasms and 5% mental health problems. This does not necessarily reconcile with the top 25 health conditions.

Clearly informal and family carers have been providing the bulk of the care - which is unlikely to diminish if current trends prevail, that is, as long as the majority of chronically disabled and frail aged persons remain in the family home to be cared for. As was stated in an ABS Media Release, the "... proportion of Australians with disability has steadily increased since the ABS first conducted the survey in 1981. This is partly due to an ageing population ..." Even, "... adjusting for differences in the age distribution of the population ... the rate has increased from 15% in 1981 to 19% in 1998. [NB SA has highest disability rate in Australia 1998:7]"\(^8\)

**BRIEF PROFILE OF CARER HEALTH**

[This information complements chapter 3 on the health of informal caregivers]

*Handicapped carers*

The 1998 Survey of Disability, ageing and carers showed that while most primary carers reported relatively good health, 1 in 2 carers aged 65 or over had some degree of core activity restriction (handicap). 1 in 3 were themselves classified as having mild core activity

\(^8\) ibid


\(^8\) Australian Bureau of Statistics, 1999, *Older People, Australia: A Social Report.* Australian Bureau of Statistics. Catalogue No 4109.0 [From Ch. 2. Living Arrangements and Care, p. 38. Section-Older people as carers.]
restriction (13%), while 12% had a moderate restriction and 9% had a profound restriction.88

Carer general health
Reporting on their health generally, almost a quarter of primary carers rated their health as either fair (17%) to poor (6%)89 [sheet 16]. 40% considered their health as good, 27% as very good and 13% as excellent. Not surprisingly, younger carers reported better health than older carers - eg 47% aged 15-44 in the very good / excellent health category compared to 37% aged 45-64 and only 27% of those aged 65 or over enjoying very good /excellent health. Overall, the survey indicated slightly lower proportions of female carers who reported fair to poor health than male carers.(ie 21% of female carers reported fair to poor health) while 29% of male carers reported fair to poor health.

From a previous ABS survey ('Focus on Families' published in 1996) reported that 67% of all carers noticed some change in their physical, emotional or financial well being related to their caregiving role. 27% felt weary and lacked energy and 31% reported being frequently worried, depressed or angry.90 It was also reported that over a quarter of primary carers said that interrupted sleep affected them in performing daily activities. Only half of the carers (50%) said sleep was not interrupted.91

As mentioned in this report, caring for children with disabilities generally led to greater emotional and physical strains... than caring for parents or partners with disabilities.92 The highest stress-related illness was reported amongst principal carers of children [20.5%], least stress amongst principal carers of parents [8.4%], while 14.6% of principal carers of partners indicated they were affected by stress-related illness. Again more principal carers of children, reported frequently feeling worried, depressed and angry (44.7%) while similar proportions of principal carers of partners (30.4%) and principal

89 ibid. Sheet 16
carers of parents (28%) indicated they were worried, depressed or angry. Similar patterns emerged amongst principal carers who felt weary and lacked energy. 41.2% of those caring for children and 28.4% of those caring for partners affected.

Nearly a third (30%) of all primary carers surveyed said their physical or emotional well-being had changed (as a result of their caring role), and over a third (34%) of primary carers said they felt weary or lacked energy due to their caring role. More than a third (30%) frequently felt worried and depressed and 17% felt angry or resentful. More than 10% of primary carers had been diagnosed with stress related illness. Only a third of principal carers of partners (33.3%) and of parents (35%) reported no change to their well being, and even less (20.1%) of those caring for children.

This and the preceding chapters have provided a general overview of Australian and some overseas carers which provides a useful backdrop to the South Australian Health Omnibus Survey data as part of my own study that follows. From the literature it can be seen that the proportions of carers whose health of lifestyle was affected by their caregiving role were surprisingly consistent at 20-30% in many of the reports, which is repeated in the Health Omnibus Survey. Before presenting those findings I present in the next chapter, background details to the Survey methodology and instruments, in particular the SF-36.
THE 4 PILLARS OF CONCEPTUAL FRAMEWORK
RESEARCH QUESTIONS

[1] First conceptual pillar: CARER HEALTH @ INDIVIDUAL LEVEL
Caregiving as a health issue for the INDIVIDUAL informal carer
Sections I and II

1st conceptual pillar is based on the notion of informal caregiving impacting on carer health.
1.1 Does caring impact on the health of carers?
   What are the ways/how is informal caregiving perceived as detrimental to health of family / informal carers? [Literature Review]
1.2 What effect does caring have on the health, well being & lifestyle of informal carers?
   1.2.1 CARER PERCEPTIONS. What do carers themselves have to say about their experiences of caregiving roles and responsibilities.
   1.2.2 GP OBSERVATIONS- What do local GPs say about carer health and related needs?

[2] Second conceptual pillar GENERAL PRACTICE OBSERVATIONS: CARER/GP NEEDS GENERAL PRACTICE AS THE KEY TO CARER HEALTH ENHANCEMENT
Section II

2nd conceptual pillar is based on notion of GPs as the pivotal health professional with whom carers have most regular and ongoing contact.

Before suggesting a broadening of the GP role in supporting the health/social needs of caregivers, I wanted to know:
2.1 Do GP understand informal caregiving, carer roles and responsibilities?
2.2 What did GPs have to say about their supporting carers? Would GPs themselves be amenable to a more pro-active approach to informal caregiving in the future. [1994/5]
2.3 What is happening in general practice in southern Adelaide re carer issues? I ask selected GPs from across the southern region.
2.4 GP EXPERIENCES: What problems have GPs had in trying to assist carers?

[3] Third conceptual pillar introduces CARER HEALTH @ POPULATION LEVEL
Informal family caregiving as a POPULATION health issue [SF:36]
Section III

The 3rd conceptual pillar focuses on informal caregivers as a group at risk of health problems across various populations.
3.1 Do informal carers, across a population, perceive their caregiving role has affected their health?
3.2 What proportion of surveyed caregivers report they have health problems?
3.3 Can it be shown there are any measurable differences between the health status of caregivers
   and non-caregivers surveyed at the population level?
3.4 If it can be shown informal caregivers have a lower health status than non carers and/or the general
   population, what areas of carer health and well being are most affected?

[4] Fourth and final conceptual pillar examines CARER HEALTH & CARER POLICY & CARGIVING AS PUBLIC HEALTH ISSUE - An overview and discussion
Section IV

I: Theoretical and Ethical Context for Policy-Development for carers.
   - Transformation of domestic needs of carers into public policy
   - Concept of Community Care. Where does General Practice fit in?
   - Carer Policy within an Ethical Justice Framework

II. Australian public policy, carers' health and GPs
4.1 How well does Australian public policy address carers' health?
4.2 Are GPs adequately integrated into Government carer policy.
4.3 Are carers integrated into General Practice policy? (RACGP)

III: Is informal caregiving and carer health to be viewed as a public health issue?

PART A: BACKGROUND DETAILS, METHODS

1994
- SF-36 (Short-Form-36)
- GHQ (General Health Questionnaire) [1994 only]
- Carer Socio-demographic profile

1998
- The Assessment of Quality of Life (AQoL) Instrument [1998 only]
- Carer Socio-demographic profile
CHAPTER 20
CARER HEALTH AT THE POPULATION LEVEL:
SURVEY METHODS

The next two chapters address questions and present data relating to the third conceptual pillar of my research framework which introduces informal caregiving as a population health issue. As part of my research I examine carer health at the population level, re-defining informal caregivers as a group potentially at risk of health problems that are associated with their demanding caregiving activities and lifestyle. In viewing this wider landscape five questions emerge, the last of which is carried forward into the discussion chapter.

1) **Do informal carers at the population level perceive their health is affected by their caregiving role?**

2) **What proportion of these caregivers report they have health problems?**

To answer the first two questions I employed the South Australian Health Omnibus Survey which in 1994 and again in 1998 incorporated my two-part question identifying carers and asking about the perceived effects of caregiving on their health status:

"Do you feel your caring role has affected your physical or emotional health or well being recently, or at any time in the past?" - Minor, moderate or major?.

(3) **Can it be shown there are any measurable differences between the health of informal carers and non-carers at the population level?**

Two health status instruments included in the 1994 survey allowed me to 'fine tune' the carer responses and demonstrate any measurable differences between the health of carers and non-carers. They were the SF-36 (Short Form-36 Questionnaire) and GHQ (General Health Questionnaire). However when the SF-36 was again included the Health Omnibus Survey in 1998, it was coupled with the Australian Quality of Life Questionnaire.

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1 The 1994 and 1998 Health Omnibus and SF-36 Surveys generated a great deal of data, but not all are incorporated into this thesis. For the purposes of my current research, I have extracted data relevant to the four questions above and used it to compliment and support my qualitative inquiry. The population survey component of this research therefore is a way of achieving data and investigator triangulation. The remainder of the survey data is to be incorporated into a larger study which will combine all of the 1994 and 1998 results with a third Health Omnibus /SF-36 Survey planned for mid 2002.

2 When I designed this study in 1994 I was not sure if any differences would be evident between carers and non carers. Australian ABS surveys suggested their might be, but no health measures had been used in the 1993 ABS Survey of Disability, Ageing and Carers.
(4) If it can be shown that informal caregivers have a lower health status, what particular areas of their health and well being are affected?

The 1994 and 1998 SF-36 offered 8 different scales ranging from the physical end of the spectrum to the emotional/mental health end. Then I compared SF-36 findings with the GHQ, a more sensitive psychometric measure.

(5) Can it be concluded that a proportion of informal carers are more 'at risk' than non-carers in the population and therefore need particular attention to prevent health problems occurring or worsening?

IDENTIFYING THE CARERS IN THE POPULATION AND MEASURING THEIR HEALTH STATUS

Phase II: Methodology And Methods
Taking a population 'world view' and answering the questions listed above meant moving ontologically from the reality of the individual to the collective reality of a large group of carers. For this phase of the research I needed to establish a more concise and numerical border to frame the picture that was emerging about carers from my small qualitative study. Secondly it meant changing the nature of the relationship between myself, as the independent researcher, and what could be known to acquire this new knowledge of carers this time at the population level. Methodologically, I needed a more objective, structured and particularistic stance on carer health where I was an 'outsider' to the process. This represents the quantitative aspect of my research.

As the primary investigator with specific questions about South Australian carers, I decided that a larger household survey was the preferred method to acquire that information. However because of the size of the task, (up to eighty interviewers are needed in this type of survey), it required I delegate it to a separate agency with staff and financial resources to administer and conduct it. Subsequently, data collection methods and data analysis relating to socio-demographic questions in the Health Omnibus Survey, the SF-36, the GHQ and AQoL, were the decision and responsibility of the agency.

3 The coordinating agency in 1994 was the Behavioural Epidemiology Unit* of the South Australian Health Commission, in association with Harrison Health Research. This Unit* still co-ordinates population health surveys but is now referred to as the Centre for Population Studies in Epidemiology of the Public and Environmental Health Service within the SA Department of Human Services.
Chapter 20: Carer Health At The Population Level - Survey Methods

The Health Omnibus survey provides ten basic socio-demographic questions in addition to those requested by participating users\(^4\). For the 1994 Survey the two additional population health instruments, the SF-36 and GHQ, were included for the first time. The timing was most fortunate as it allowed me to access the SF-36 instrument. The South Australian Health Omnibus surveys have provided me with the opportunity to gather amongst a substantial sample of the state's population data numbers of carers, their socio-demographic and health profile. Further it would not have been possible for me to do so without this government based consortium to share the cost.

Following completion of the data collected for the Health Omnibus survey in 1994, a brief report on the socio-demographic profile and carer responses was produced for my project by the Behavioural Epidemiology Unit of the South Australian Health Commission. Data relating the health of carers were then assessed and analyzed in more detail, using the SF-36 and GHQ, and compared with non-carers. The use of two population health survey instruments, SF-36 Questionnaire and 12 item GHQ, enabled the general and psychological health status of carer and non-carer populations to be assessed and compared. Accessing data from the GHQ was particularly useful for my study as it provided a psychometric benchmark for comparing the mental and emotional health of carers with the mental health of other groups in the population.

I resubmitted my carer question in the 1998 Health Omnibus Survey when the SF-36 questionnaire was once again included, but this time it was run in tandem with the Australian QOL instrument. Repeating the SF-36 enabled me to compare the 1994 survey findings with another sample of the population (3,010 persons). It also measured any differences between QOL between carers and non-carers. QOL was only a secondary focus of my own inquiry, therefore having that component included was an interesting exercise since caring issues are not only discussed in the literature in terms of health and well being, but sometimes in terms of the carers' QOL.

THE SOUTH AUSTRALIAN HEALTH OMNIBUS SURVEY

\(^4\) The 'users' of the Health Omnibus survey include academic departments of psychiatry, nursing, government health departments, health promotion groups, units and organisations, anti-cancer anti-smoking, accident prevention groups and other public health related agencies. There are also the occasional student users such as myself who are accessing information on a scale that would normally be prohibitive to the individual investigator.

\(^5\) Assistance to clients or users is also provided by a management committee to clients in the preparation of questions. The questionnaire is designed to be completed in about 30 minutes.
Chapter 20: Carer Health At The Population Level - Survey Methods

The Health Omnibus is a yearly household survey of over 3,000 people in metropolitan and country areas of South Australia. It is a well respected service which assists and facilitates research among the state’s health organisations and individual researchers and also enables sharing of data between researchers on topics of their choice. The following information contains background and methodological details provided by the organisations responsible for conducting the Health Omnibus Survey.

**The Health Omnibus Survey**

"The goal of the Omnibus is to collect, analyse and interpret data that can be used to plan, implement and monitor health programs and other initiatives. The Health Omnibus provides organisations in the health, welfare and social services sector with an opportunity to generate social statistics indicating prevalence rates, program impacts and other important data at an affordable cost.

A particular advantage of the Health Omnibus is that an extremely rigorous sampling procedure is adopted for the survey, generating statistical information of the highest quality. For example the group aimed for:

- a non-replacement sample with a guarantee of 3,000 interviews.
- rigorous sample selection with up to six separate visits to selected households to interview the person chosen to take part, based on the alternating criterion of whether the person whose birthday was either next or last in the selected household.
- One person (aged 15+) is randomly selected from each household and interviewed on a face-to-face basis."

This information is taken from the 1994 Health Omnibus Survey Report of Harrison Health Research and the 2000 Prospectus of the Health Omnibus.

**Health Omnibus Survey: Sample Selection, Response Rate and Data Collection**

In 1994: Sampling involved a total of 4,000 randomly selected households within South Australia using a multi-stage, systematic area sample. 75% of the sample were selected from Adelaide metropolitan area with the remainder drawn from those country centres with a population of 1000 or more. 4,300 households from across the South Australian metropolitan and country regions were randomly selected for survey in 1994 and 3010 interviews were conducted by over 60 interviewers. In 1994, the response rate was 72.4% with 1723 (57.2%) females and 1287 (42.8%) males participating. When repeated in 1998, from the 4,400 households selected, 3010 interviews were conducted with a response rate of 70.2%. Of the 3010 people interviewed in 1998, 1801 (59.8%) were females and 1209 (40.2%) were males.
### THE SOUTH AUSTRALIAN HEALTH OMNIBUS

#### Sample Selection, Response Rate, Data Collection Procedure: 1994 & 1998

#### Metropolitan Sample
From the collector's districts (CD's) used by the Australian Bureau of Statistics in the 1991 Census, 330 CD's were selected with their probability of selections proportional to their size. Within each CD a starting point was randomly selected. From this starting point, using a predetermined selection process based on a "skip pattern" of every fourth household, 10 dwellings were chosen. Only one interview was conducted per household, the respondent was the person whose birthday was first or last at alternate households.

This was the same for the 1998 Health Omnibus Survey except that 1996 Census was used.
- In 1994, 2321 interviews (77.1%) were conducted in the metropolitan area
- In 1998, 2378 interviews (79.0%) were conducted in the metropolitan area

#### Country Sample
All cities/towns with a population size of 10,000 or more in the 1991 Census were selected automatically. The balance of the country sample was selected from centres with a population of 1000 or more in the 1991 Census with probability proportional to size. This the country sample was self-weighting.

A cluster of 10 was also employed in the country sample at each of the 100 starting points. Again one person per dwelling using the same procedures as for the metropolitan area.

This was the same for the 1998 Health Omnibus Survey except that 1996 Census was used.
- In 1994, 689 interviews (22.9%) were conducted in the country.
- In 1998, 632 interviews (21.0%) were conducted in the country.

#### Timing of Fieldwork
In 1994: The 60 interviewers who worked on the study were briefed from 30th Sept 1994. Interviewing continued through October, November and was conducted at the end of the second week in December.

In 1998: The interviewers who worked on the study were briefed on 6 March 1998. Interviewing continued through March and concluded in mid April 1998.

#### Weighting
The survey data are weighted by sex, five year age groups and geographic area so that findings apply to the demographic profile of South Australia. Data were weighted by the inverse of the individual's probability of selection, then reweighted to benchmarks derived from the Estimated Resident Population at 30 June 1993, by age, sex and Local Government area from the ABS (Catalogue No. 3204.4).

For questions regarding households rather than individuals, records were weighted by the inverse of probability selection of the household then reweighted to benchmarks derived from the 1991 Census of Population and Housing for occupied private dwelling by location.

Weighting procedures were the same for the 1998 Health Omnibus Survey except that benchmarks were derived from the 1996 ABS Census of Population and Housing conducted in August 1995.

#### Processing
Data were double punched and edited. The relatively few missing responses to questions were followed up by telephone where possible.

#### Pilot testing of questionnaire
To ensure that the questionnaire was constructed in an appropriate way, 50 interviews were conducted during September 1994. Where difficulties were apparent users were contacted and changes were made.

For the 1998 Health Omnibus, 50 pilot interviews were conducted during February 1998.

#### Interviewer supervision and validations
The Field Manager for Harrison Market Research examined all questionnaires prior to data input. 5% of each interviewer's work was selected at random and the respondents re-contacted. A number of questions were asked of respondents to ensure they had, in fact, been interviewed including confirmation that they were the person in the household to have their birthday next or last at the time of the interview. Where a refusal was encountered, another interviewer generally called at the dwelling at a later time to persuade the individual to participate.

Ref: 1994 Health Omnibus Survey Report, Harrison Health Research
THE SF-36: A MEASURE OF GENERAL HEALTH STATUS

**SF-36: Methodological details**

The following details of methods used for the SF-36 component of the Health Omnibus Survey were part of a report which accompanied the findings from the survey in relation to my questions on carers. Again I have made editorial changes to adapt it to this thesis.

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**The SF-36**

The SF-36 was included in the Spring 1994 Health Omnibus Survey for the first time. Each respondent to the survey was administered the Australian version of the questionnaire by a trained interviewer, along with a broad range of questions about other health-related issues, as required by subscribers to the survey.

All respondents were asked whether they were a carer of a dependent person, given the following which was read out: "A dependent person is someone who has a chronic condition that is unlikely to improve. A carer is responsible for the permanent care of that person on a long term basis."

Mean scores for each of the 8 scales of the (SF-36) questionnaire were derived for respondents with and without the specific condition or risk factor of interest and the differences calculated. A negative score signifies poorer health in those with the condition compared to those without it. Since health status varies with age, sex and socio-economic status, comparisons between subgroups of the population need to adjust for these socio-demographic variables. For this reason, multiple linear regression was used to compare the mean score differences whilst adjusting for the effects of age, sex and occupational status.

Thus, for each scale, the scale score was included as the dependent variable, and age, sex occupational status and carer status were included as independent variables. Age was included as a continuous variable, with sex, carer status and occupational status as binary categorical variables. Occupational status was derived from ASCO codes and a conventional method of aggregation applied to categorise respondents into higher (including high and very high) or lower (medium and low) status. In the multiple regression analysis, the partial regression coefficients, and their standard errors, of the carer status variable, were used to calculate 95% confidence intervals for differences between those with and without the particular diseases.

Text provided in 1994, by staff of the Behavioural Epidemiology Branch of the SA Health Commission and Harrison Market Research.

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There were early indications from researchers analysing data from the 1994 Health Omnibus Survey, that the social and emotional aspects of carers' functional status and their mental health, were different to (lower than) non-carers. Further data analysis using the GHQ was helpful as it provided a more in depth measure of psychological well being and mental health of the two populations.

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**Background text on the SF-36 was provided as part of the Survey Report. I have edited and updated that information for inclusion in this part of the thesis. Contributors in 1994 were Dr M Wakefield and Ms A Taylor, scientific and research staff members of the Behavioural Epidemiological Unit of the Epidemiology Branch of the South Australian Health Commission.**

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Chapter 20: Carer Health At The Population Level - Survey Methods

The SF-36 [Short Form] is a 36 item general health status survey measure (Questionnaire) developed by the Medical Outcomes Study (MOS) in the United States. Versions of the questionnaire have been adapted for use in specific countries and the Australian version, (available since 1993), has made minor modifications to the wording of the questions to bring it more in line with accepted Australian language. For example, the original question, "do you feel full of pep?" was changed to "do you feel full of life?" References to walking 'a mile' were changed to a kilometre etc.

The SF-36 [Short Form] measure evolved from the RAND Corporation's Health Insurance Experiment of the late 1970's, continued by John Ware and Anita Stewart and MOS colleagues during the 1980's in an effort to find the optimum trade-off between breadth and depth in a general health status measure. This involved extracting items from other MOS instruments which had already been tested and validated. The validity and reliability of the SF-36 in patient populations has been extensively tested in studies in the United States and more recently in Australia.

In contrast to condition-specific scales, general measures of health status attempt to capture aspects of health that are important to all patients. They are useful for health status comparisons both among patients with the same condition and between patients with different conditions. Such measures can also be administered to general populations to see how a particular condition causes health to depart from a 'healthy standard'. This latter aspect of the SF-36 was most important for carer non-carer comparisons.

The SF-36 questionnaire measures 8 parameters of health status, divided into two summary measures- physical and mental. Items of each parameter are listed on the following page. The physical summary measures include physical functioning (PF) with 10 items/questions, role physical limitations due to physical health problems (RP) using 4 items, bodily pain (BP), 2 items, and general health perception (GH) with 5 items.

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### SF-36 ITEMS | ITEM CONTENT | SF-36 SCALE | SUMMARY MEASURES
---|---|---|---
Item 3a | Vigorous activities | | }
Item 3b | Moderate activities | | }
Item 3c | Lifting, carrying groceries | | }
Item 3d | Climbing several flights of stairs | | }
Item 3e | Climbing one flight of stairs | | }
Item 3f | Bending, kneeling, stooping | | }
Item 3g | Walking more than a mile | | }
Item 3h | Walking several blocks | | }
Item 3i | Walking one block | | }
Item 3j | Bathing or dressing | | }
Item 4a | Limited in kind of work/activities | | }
Item 4b | Cut down time on other activities | | }
Item 4c | Accomplished than would like | | }
Item 4d | Difficulty performing work/activities | | }
Item 7 | Intensity of bodily pain | | }
Item 8 | Pain interfered with normal work | | }
Item 1 | Health excellent, very good, good, fair | | }
Item 11a | My health is excellent | | }
Item 11b | Am as healthy as anybody I know | | }
Item 11c | Seem to get sick easier than others | | }
Item 11d | I expect my health to get worse | | }
---|---|---|---
Item 9a | Feel full of life - Australian version | | }
Item 9e | Have a lot of energy | | }
Item 9h | Feel worn out | | }
Item 9i | Feel tired | | }
Item 6 | Health interferes with social activities | | }
Item 10 | Frequent health interferes with social activities | | }
Item 5a | Cut time on work/other activities | | }
Item 5b | Accomplished less than would like | | }
Item 5c | Didn't do work/activities as carefully | | }
Item 9b | Been a very nervous person | | }
Item 9c | Felt down, nothing could cheer me | | }
Item 9d | Felt calm and peaceful | | }
Item 9f | Felt downhearted and blue | | }
Item 9h | Been a happy person | | }

*SF-36 Health Dimensions, adapted from Table 5.1 [Abbreviated Content for Items in each SF-36 Scale]*

The mental health summary measures include vitality (VT)-4 items; social functioning (SF) with 2 items, and role emotional (RE) using 3 items, and mental health (MH) - 5 items, Responses to questions on each scale are summed to provide 8 scores between 0 - 100, with the higher scores indicating better health.

The SF-36 can discriminate between patients with major and minor physical and psychiatric conditions. Moreover, the scales measuring physical health best distinguish groups differing in presence and severity of physical health conditions. However the scales measuring mental health best distinguish between groups differing in presence and severity of psychiatric disorders. There is strong evidence of the clinical validity of the SF-36 as a measure of patients' or persons' perceived health.

There is some debate in the literature about the SF-36 as a quality of life measure which many researchers claim it is and use it accordingly. The 1998 Health Omnibus survey certainly promoted SF-36, along with the AQoL, as a quality of life measure. I am more cautious with the SF-36 as there are only two items (6 and 10), as questions on social functioning. However as a health status measure the SF-36 it is most useful.

THE GHQ: [ GENERAL HEALTH QUESTIONNAIRE ]

Details of the General Health Questionnaire -1994

The General Health Questionnaire is a screening instrument that can be used to compare the mental health of two populations, as well as detect psychological impairment. It concentrates on symptomatology which falls between psychological sickness and health and is especially useful for detecting psychological distress, anxiety and depression. The 12-item GHQ is the version recommended for use in community settings and was the instrument used in the Health Omnibus Survey. However as the GHQ does not take into account factors like personality differences, effects of the environment, social and cultural differences, (author unknown). It is in conflict with the situational nature of mental health criteria. It was also pointed out that the GHQ assumes a single dimension ranging from normality to 'casedness' with a single cut-off point. Therefore subjects with higher scores might need to be independently assessed by a psychiatrist or psychologist to interpret and validate the results. As the Health Omnibus Survey used the GHQ to study populations, rather than individuals, validation of the results by independent assessment was not

possible. It is also recognised from previous studies involving people in a caregiving role, factors like social differences and effects of the environment need to be taken into consideration when assessing the health and well being of individual carers.

Additional Data Analysis - Health Omnibus Survey

Data Analysis of the Health Omnibus socio-demographic questions, the 1994 SF-36 and GHQ questionnaire results and 1998 SF-36 and Australian AQoL results were carried out by researchers from the South Australian Health Commission Behavioural Epidemiology Unit in association with Harrison Marketing. Both univariate and multivariate analysis was used on carer and non-carer populations. [See below for Data Analysis details provided by the Behavioural Epidemiology Unit in 1994].

Data Analysis - Health Omnibus Survey, SF-36 and GHQ

**UNIVARIATE ANALYSIS**

For the SF-36, the univariate analysis provided norms of the SA population and the carers by gender and age groups.

For the GHQ univariate analysis, the crosstab showed that of the 104 carers, 21.8% had a high/severe disturbance and a further 12.5% had a mild/moderate disturbance using the GHQ. Also this GHQ univariate analysis indicated there was a significant difference between carers and non-carers when the mild/moderate/high/severe groups were compared with those with no or low disturbance. The carers are 1.5 times more likely to have a mild to severe disturbance on the GHQ score than non-carers (odds ratio=1.5(1.0-2.3), p=.045).

**MULTIVARIATE ANALYSIS**

For the SF-36, the multivariate analysis provided mean scores and differences in SF-36 scores and 95% confidence intervals corrected for age and gender. The comparison was analysed as per the literature but there were staff of the Epidemiology Branch who had some reservations. Notwithstanding, the carers showed significantly less mean scores than the general population in three of the eight scales.

For the GHQ: Applying multivariate analysis to the GHQ, after adjusting for age and gender using logistic modelling, the odds ratios increased to 1.6 (c.i. =1.1 -2.5), and were significant (p=0.023).

**THE AUSTRALIAN QOL INSTRUMENT**

The Australian QOL instrument referred to as "a health related quality of life instrument", [HRQoL] may have its limitations for my study. Its main purpose is as a tool to evaluate a range of health interventions for acute patients, in health promotion and to enable economic evaluation of health programs. Although the authors claim good coverage of
HRQoL dimensions\textsuperscript{11}, including some medical and social issues not measured by the SF-36\textsuperscript{12}, it is based on and focuses on 'patient' cohorts such as those with acute illnesses requiring intervention and those undergoing rehabilitation. The authors state it is "sensitive to different affective state levels", is "sensitive to different levels of functional capability " and that "it can discriminate between those with different levels of general health". Whether it can discriminate different levels of general health for carers, as well as the SF-36 is a matter of conjecture and further trialing of the instrument.\textsuperscript{13}

I next present in Chapter 21, the results of the 1994 and 1998 Health Omnibus Surveys using all the above mentioned instruments.

\textsuperscript{11} The 5 main HRQoL dimensions are: Illness, Independent living, Social relationships, Physical senses and Psychological well-being.


\textsuperscript{13} It could also have something to do with the weighting and utility values used in the AQoL as these are also based on patient models of health and intervention.
PART B:

DATA & FINDINGS: 1994 and 1998 Surveys
(Includes SA Health Omnibus, SF-36, GHQ and AQoL)
CHAPTER 21

HEALTH AND SOCIO-DEMOGRAPHIC STATUS OF ADULT CARERS IN THE SOUTH AUSTRALIAN POPULATION

Introduction

This chapter has been collated from two South Australian Health Omnibus Surveys (1994 and 1998) provided for my research project by the SA Health Commission and Harrison Health Research\(^1\). So as to differentiate between my own comments and interpretations, most of the explanatory text provided by the Health Commission is enclosed in shaded boxes in this chapter. The 1994 report was more comprehensive as 1998 survey results are mainly used for comparison with the 1994 SF-36 findings. Not all the data collected was required for this thesis therefore only some of the socio-demographic data has been used.\(^2\)

Socio-Demographic Profile Of Adult Carers

1994 and 1998

The 1994 Health Omnibus Survey identified 104 (3.4%) carers from a total of 3010 people in the sampled population who answered 'yes' to the question of whether they were a carer of a dependent person. In 1998 the Health Omnibus Survey identified 127 carers (4.2%) slightly more than in 1994, again from a total of 3010 people.\(^3\)

---

\(^1\) The Health Omnibus Survey analysis and report was prepared by staff of the Behavioural Epidemiology Branch of the SA Health Commission and Harrison Health Research. This was at my request as I had submitted a multiple question for inclusion in the survey. The original 1994 report is included in full in the Appendix. The 1994 and 1998 reports were re-formatted for comparative purposes and they have also been included in the Appendix as the graphs are clearer to read.

\(^2\) The data however will be used as part of a separate ongoing longitudinal study I am conducting through the Behavioural Epidemiology Unit. A four year follow-up of the 1998 SF-36 results are planned for this year 2002.

\(^3\) This was based on the definition at the time:
"A carer is responsible for the permanent care of that person on a long term basis" and,
"A dependent person is someone who has a chronic condition that is unlikely to improve".
If the respondent asked for clarification and more details of the type of dependent person, the interviewer could cite examples such as frail aged, dementia, stroke, brain damage, mentally ill, physically, or intellectually disabled.
The definition chosen in 1994 to identify carers is slightly different to that of the current formal Carers Association. My earlier version is not ideal but I purposely chose wording that would differentiate short term carers from those who did indeed have to look after someone with a chronic health condition on a permanent and ongoing basis. I am therefore confident that my figures are not over-inflated by including those caring for persons for periods like 6-12 months, as tends to happen in many surveys.

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were more female than male carers identified in both surveys i.e. in 1994, 61 females (57.2%) compared to 43 males (43.8%). In the non-carer population, the female to male ratio was more evenly balanced with 1467 females (50.5%) and 1438 males (49.4%). In 1998 the male-female gap was maintained in carers with 70 females (55%) compared to 57 males (45%). The female to male ratio of the non-carer population was within a similar range to the 1994 figures ie 1475 females (51.2%) and 1407 males (48.4%). (Refer Table 20.1)

<table>
<thead>
<tr>
<th>Table 20.1 THE SA 1994 and 1998 HEALTH OMNIBUS SURVEY Socio-demographic profile of carers compared with non-carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers '94</td>
</tr>
<tr>
<td>-------------</td>
</tr>
<tr>
<td>n=104</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>20-44</td>
</tr>
<tr>
<td>45-64</td>
</tr>
<tr>
<td>65+</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
</tr>
<tr>
<td>Married/De facto</td>
</tr>
<tr>
<td>Sep/Divorced</td>
</tr>
<tr>
<td>Never married</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td><strong>Educational Status</strong></td>
</tr>
<tr>
<td>Still at school</td>
</tr>
<tr>
<td>Left school &lt; 15 yrs</td>
</tr>
<tr>
<td>Left school &gt; 15 yrs</td>
</tr>
<tr>
<td>Trade/Cert/Dip.</td>
</tr>
<tr>
<td>Bachelor degree</td>
</tr>
<tr>
<td><strong>Country of Birth</strong></td>
</tr>
<tr>
<td>Australia</td>
</tr>
<tr>
<td>UK/Ireland</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><strong>Income</strong></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
</tr>
</tbody>
</table>

This yielded 4.7% of the population who identified themselves as "caring at home for a parent, partner, child other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness."
The overall results of the 1994 survey indicated carers were likely to be Australian, female, married/defacto and (34%) and left school before the age of 15 years. There were slightly more carers aged in the younger 20-44 age group (38%), while roughly a third of carers were in each the remaining two age groups 44-64 (32%) and 65+ (33%). Almost a half of the respondents (45.5%) were on the lowest household incomes (up to $20,000) with a half of those with an income under $12,000 / yr (23.2%).

In the 1998 Health Omnibus Survey people in the 44-64 age group were more likely to be carers (~36%), and as before, approximately a third of carers were in each of the remaining two age groups: 20-44 (33%) and 65+ (31%). Again carers were likely to be Australian, female, married/defacto, about a third (32.7%) had a Trade, Certificate or Diploma in and slightly less, 30% had left school before the age of 15 years. This time more carers were likely to have household incomes of $12,000-20,000 (28.7%), $30,000-40,000 (17.3%), and $20,000-30,000 (15.6%). In both 1994 and 1998 surveys, older carers were almost as likely to be carers as the younger age groups.

HEALTH STATUS OF CARERS 1994 AND 1998

Data and findings in this chapter are presented according to their relevance to the four of the five main questions under the third conceptual pillar of my research framework. The first two questions ask:

(1) **Do informal carers at the population level perceive their health is affected by their caregiving role?**

(2) **What proportion of these caregivers report they have health problems?**

**Perceived effects of caring role on the health of carer population**

In 1994 and 1998 the following questions were put to those survey respondents in the Health Omnibus who identified themselves as the carer of a dependent person. Carers were asked:

"Do you feel your caring role has affected your physical or emotional health or well being recently, or at any time in the past?" - Minor, moderate or major?"

This two-part question provides a rough guide only to the health status of carers surveyed in the population, as responses are limited by the coarseness of the questions...
and carer interpretations. However they are a useful point of comparison as I also used the same wording of this question in my carer questionnaire. Therefore the Health Omnibus data provides a simple benchmark for comparing my own data - from my Carer Questionnaire.

**COMPARISON OF FINDINGS FROM THE 1994 & 1998**

*(S.A. HEALTH OMNIBUS SURVEYS)*

**1994 Health Omnibus Survey**

In 1994 over half (52.8%) of the 104 carer respondents (3.4% of the sample population of 3010 persons) answered they felt their physical or emotional health was affected by their role as carer. Of those who answered yes, over a third (34.8%) stated the effect had been in either a moderate (21.5%) or major (13.3%) way. (See Table 20.2 below). I was surprised by these responses of carers in the SA population, so I decided to repeat the question in a Health Omnibus at a later date. It was to be 4 years before I could do that when the SF-36 was next included in the Health Omnibus Survey.

**Table 20.2: Effect of caring role on physical or emotional health of carer.**

*From the 1994 and 1998 Health Omnibus Surveys*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>48</td>
<td>69</td>
</tr>
<tr>
<td>Yes</td>
<td>55</td>
<td>58</td>
</tr>
<tr>
<td>Minor effect</td>
<td>19</td>
<td>32</td>
</tr>
<tr>
<td>Moderate effect</td>
<td>22</td>
<td>17</td>
</tr>
<tr>
<td>Major effect</td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>Moderate/Major Effect</td>
<td>36</td>
<td>26</td>
</tr>
<tr>
<td>Total</td>
<td>104</td>
<td>127</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CARERS</th>
<th>1994</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>1994</td>
<td>1998</td>
</tr>
<tr>
<td>No</td>
<td>48</td>
<td>69</td>
</tr>
<tr>
<td>46.4%</td>
<td>54.5%</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>55</td>
<td>58</td>
</tr>
<tr>
<td>52.8%</td>
<td>45.5%</td>
<td></td>
</tr>
<tr>
<td>Minor effect</td>
<td>19</td>
<td>32</td>
</tr>
<tr>
<td>18.8%</td>
<td>24.8%</td>
<td></td>
</tr>
<tr>
<td>Moderate effect</td>
<td>22</td>
<td>17</td>
</tr>
<tr>
<td>21.5%</td>
<td>13.7%</td>
<td></td>
</tr>
<tr>
<td>52.8%</td>
<td>45.5%</td>
<td></td>
</tr>
<tr>
<td>Major effect</td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>13.3%</td>
<td>7.0%</td>
<td></td>
</tr>
<tr>
<td>Moderate/Major Effect</td>
<td>36</td>
<td>26</td>
</tr>
<tr>
<td>38.8%</td>
<td>20.7%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>104</td>
<td>127</td>
</tr>
<tr>
<td>3.4%</td>
<td>4.2%</td>
<td></td>
</tr>
</tbody>
</table>

One problem in any survey when trying to identify carers is that people first have to recognise themselves as carers and nominate they are in the caring role. The dilemma can also be that some respondents may not perceive their health to be as good or as bad as it is.

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1998 Health Omnibus Survey
127 respondents (4.2% of the sample population\(^5\)) identified themselves as carers in the 1998 Health Omnibus Survey. They were asked the same question: "Do you feel your caring role has affected your physical or emotional health or well being recently, or at any time in the past?" - Minor, moderate or major?". Over a half, (54.5%) felt their health and well being had NOT been affected by their caring roles. This time less than half, (45.5%) answered 'Yes', while of those carers who felt their health had been affected, more in 1998 reported minor effects (24.8%) than moderate effects (13.7%) or major effects (7.0%) on their health and well being.

Comparing the earlier 1994 survey results with 1998 carer responses gives some idea of the prevalence of carers in a 4-year period and compares carer health status of the two populations. There was a slight increase in the number and proportion of carers identified in 1998 (ie from 104 carers (3.4%) in 1994 to 127 carers (4.2%) in 1998. Slightly fewer of the 1998 carers (45.5%) felt their health had been affected compared to 52.8% of the 1994 sample, nevertheless in both surveys around half of all the carers answered 'yes'. Fewer carers however, in 1998, reported moderate / major effects (20.7% or one fifth of the sample) compared to 38.3% of the 1994 sample. More of the 1998 carers (24.8%) reported minor effects compared to 18.8% of the 1994 population of carers.

Therefore in answer to the first two questions: Do informal carers at the population level perceive their health is affected by their caregiving role?" and What proportion of these carers appear to have health problems? the 1994 and 1998 Health Omnibus surveys indicated 45.5% - 52.8% of carers did feel their health was negatively affected. Whereas the 1994 survey suggested that over a third (38.8%) of those health effects were moderate or major, this trend was not sustained. By 1998 that proportion had dropped to one fifth of the carer sample reporting moderate or major effects (20.7%) and approximately one quarter reporting minor effects (24.8%). However this raises a further question. Of the 25% of carers who were experiencing minor effects in 1998, what proportion of them might progress to more serious health problems later? This in turn highlights the need for longitudinal studies to follow up the same group of carers in the population.

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\(^5\) Sample population for the 1998 survey was again 3010 persons.
MEASURABLE DIFFERENCES IN CARER HEALTH
AT THE POPULATION LEVEL

The next two questions of the third conceptual pillar ask:

(3) Can it be shown there are any measurable differences between the health of groups of informal caregivers and non-caregivers at the population level?

(4) If it can be shown that informal caregivers have a lower health status, what particular areas of their health and well being are affected?

To obtain measurable differences in carer health at the population level was a major challenge for me in 1994. At the time, I could find no studies that had utilized the SF-36 questionnaire with carers. From the literature the only health status measure which had been applied to an Australian population of carers was the Nottinghill Health Profile.

Health Status of Carers compared with
Non Carers & Population Norms

Accessing two well validated population health instruments, the Short Form-36 Questionnaire and General Health Questionnaire in the 1994 Health Omnibus, it was possible to 'fine tune' and measure carer responses and then compare the health of adult carers with non-carers in the survey. Data on carers' health was then compared with the total (adult) population.

The 1994, SF-36 scores for carers indicated there clearly were measurable differences between carers and non carers across nearly all of the 8 scales of the instrument. The scales ranged from the physical functioning end of the health spectrum to psycho-social functioning at the opposite end. For instance 8 scales of the SF-36 measure each person's:

---

6 This is a useful paper as it is one of the few studies on the health profile of carers conducted in South Australia in the southern region of Adelaide. 236 carers were identified and compared with a total sample population of 1765 adults.

7 The General Health Questionnaire is a more sensitive psychometric measure than the SF-36.
Reference used for the GHQ in 1993 was:

8 In the 1998 Health Omnibus Survey, a variation of this analysis occurred when the SF-36 was coupled with the Australian Quality of Life Questionnaire.
Chapter 21: Health & Socio-Demographic Status Of Adult Carers In The SA Population

- [PF] Physical Functioning
- [RP] Role-Physical
- [BP] Bodily Pain
- [GH] General Health Perception
- [VT] Vitality
- [SF] Social Functioning
- [RE] Role-Emotional
- [MH] Mental Health

More details about these dimensions, are outlined on the following pages.9

### SA Health Omnibus Surveys: Results and Interpretations

<table>
<thead>
<tr>
<th>1994 Results and Interpretation</th>
<th>1998 Results and Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>The response rate for the 1994 Health Omnibus survey was 72.4%. Overall, 3.4% (n=104) of the 3010 respondents reported that they were carers, given the definition outlined.</td>
<td>The response rate for the 1998 Health Omnibus survey was 70.2%. Overall, 4.2% (n=127) of the 3010 respondents reported that they were carers, given the definition outlined.</td>
</tr>
</tbody>
</table>

### SF-36 Data analysis

The 1994 mean scores of carers and non carers from each dimension are presented in Table 20.3.

### The SF-36 Health Status Measure

The SF-36 Health Status Measure is a generic measure of health status that has been validated for use in Australia10. It was constructed by Ware and others at The Health Institute in Boston, USA and consists of 36 questions which relate to physical and mental health. It is a subset of the RAND Corporation’s health insurance experiment which had over 100 questions.

The advantages of the SF-36 are that it is comprehensive, valid for use with adults of all ages, covers major health concepts and can be expanded if more detail is required. The SF-36 is scored such that the 36 questions make eight dimensions. Physical functioning, Role-physical, Bodily pain, General health, Vitality, Social functioning, Role-emotional and Mental health. The SF-36 can also produce two summary scales, - the Physical Component Summary scale (PCS) and the Mental Component Summary scale (MCS). The next page shows the descriptions of each of the dimensions11:

---

9 The SF-36 Health Status Measure, provided by Harrison Health Research Report: 'Findings from Autumn 1998 'Quality of Life' Health Omnibus Survey.


## The SF-36 Health Status Measure

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>The extent to which, on a typical day, a person is limited by their health in performing a range of physical activities, including bathing and dressing.</td>
</tr>
<tr>
<td>Role-physical</td>
<td>The effects of physical health on a person's performance of their work or other daily activities; ie whether limited in the kinds of work or other activities they were able to do, or reduced the time spent on those activities, or had difficulty in performing those activities due to physical health.</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>The severity of pain experienced and the extent to which it had interfered with normal activities.</td>
</tr>
<tr>
<td>General health</td>
<td>Combines self-assessed health status with indicators of current expectations and perceptions of health relative to the health of others.</td>
</tr>
<tr>
<td>Vitality</td>
<td>Energy level and level of fatigue.</td>
</tr>
<tr>
<td>Social functioning</td>
<td>The impact of health or emotional problems on the quality and quantity of a person's social activities with others.</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>The effects of emotional problems on a person's performance of their work or other daily activities; ie whether limited in the kinds of work or other activities they were able to do, or reduced the time spent on those activities, or had difficulty in performing those activities due to emotional problems.</td>
</tr>
<tr>
<td>Mental health</td>
<td>The amount of time a person experienced feelings of nervousness, anxiety, depression and happiness.</td>
</tr>
</tbody>
</table>

The SF-36 dimensions are scored on a scale from 0-100, where higher scores indicate better health status. For five of the dimensions (Physical functioning, Role-physical, Bodily pain, Social functioning, Role-emotional) the highest score of 100 indicates the absence of limitations or disabilities, while on the other three scales a score of 100 indicates a positive state of well being and a score in the mid range indicates that a person reports no limitation or disabilities.
Table 20.3: [1994] Mean SF-36 scores and differences for carers & non-carers adjusted for age, gender, SES (Occupation)

<table>
<thead>
<tr>
<th>SF-36 Scale</th>
<th>Carers (n=104)</th>
<th>Non-carers (n=2906)</th>
<th>Mean difference</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>82.8</td>
<td>85.0</td>
<td>-2.2</td>
<td>(-6.5, +2.1)</td>
</tr>
<tr>
<td>RP</td>
<td>76.0</td>
<td>79.9</td>
<td>-3.9</td>
<td>(-11.8, +4.0)</td>
</tr>
<tr>
<td>BP</td>
<td>72.6</td>
<td>77.0</td>
<td>-4.4</td>
<td>(-10.2, +1.4)</td>
</tr>
<tr>
<td>GH</td>
<td>69.6</td>
<td>73.1</td>
<td>-3.5</td>
<td>(-8.3, +1.4)</td>
</tr>
<tr>
<td>VT</td>
<td>60.8</td>
<td>63.8</td>
<td>-3.0</td>
<td>(-7.8, +1.8)</td>
</tr>
<tr>
<td>SF</td>
<td>81.7</td>
<td>88.4</td>
<td>-6.7</td>
<td>(-11.6, -1.8) *</td>
</tr>
<tr>
<td>RE</td>
<td>77.1</td>
<td>87.7</td>
<td>-10.6</td>
<td>(-17.2, -4.0) *</td>
</tr>
<tr>
<td>MH</td>
<td>73.5</td>
<td>78.8</td>
<td>-5.3</td>
<td>(-9.3, -1.3)</td>
</tr>
</tbody>
</table>

* Significant difference at 0.05 level

Carers' 1994 SF-36 scores were contrasted with non-carers and compared with the total population across these 8 scales. The areas where carer health and well being were significantly affected were at the psycho-social end of the spectrum, which are represented graphically in Figure 20.1 [1994].

Figure 20.1: [1994] Mean SF-36 scores for carers and non-carers, adjusted for age, gender and SES

The SA Health Commission report describes these results below.

"In 1994 data were first generated from a univariate analysis of SF-36 results. Analysis showed that "when compared against norms for the South Australian population, for
both gender and age, carers consistently scored lower than the non-carer population across three of the eight scales. Mean scale scores again showed that carers differed for 'Social Functioning', 'Role Limitations due to emotional problems', 'Mental Health'.

The Health Omnibus research group then conducted a multivariate analysis using the SF36. They reported: "Mean scores and differences in SF-36 and 95\% confidence intervals were corrected for age and gender". Carers again showed significantly lower scores "than the general population in the three scales" - Social Functioning, Role Emotional and General Mental Health", but this time also in GH, BP and PF scales [See Figure 20.2 below].

**Figure 20. 2: [1994] Mean SF-36 scores for carers and the total population**

![Graph showing mean SF-36 scores for carers and total population](image)

When carers' 1994 SF-36 scores were compared with the total population\textsuperscript{12}, carers scored lower than population norms across 6 of the 8 scales. Not only were scores significantly lower in the social, emotional and mental health scales, but also in Physical Functioning, Bodily Pain [BP] and General Health [GH]. All 6 scores were significant at the 0.05 level. (Refer Table 20. 4).

\textsuperscript{12} A re-analysis of the 1994 SF-36 scores occurred at the same time as the 1998 data was analysed.
Chapter 21: Health & Socio-Demographic Status Of Adult Carers In The SA Population

Table 20.4: [1994] Mean SF-36 scores and differences for carers and the general SA population

<table>
<thead>
<tr>
<th>SF-36 Scale</th>
<th>Total sample (n=3009)</th>
<th>Carers (n=104)</th>
<th>Mean difference</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>85.4</td>
<td>77.2</td>
<td>-8.2</td>
<td>-13.6,-2.8 *</td>
</tr>
<tr>
<td>RP</td>
<td>80.2</td>
<td>72.1</td>
<td>-8.1</td>
<td>-16.9,+0.7</td>
</tr>
<tr>
<td>BP</td>
<td>77.2</td>
<td>70.2</td>
<td>-7.0</td>
<td>-13.2,-0.8 *</td>
</tr>
<tr>
<td>GH</td>
<td>73.2</td>
<td>66.8</td>
<td>-6.4</td>
<td>-11.6,-1.2 *</td>
</tr>
<tr>
<td>VT</td>
<td>64.0</td>
<td>59.1</td>
<td>-4.9</td>
<td>-10.1,+0.3</td>
</tr>
<tr>
<td>SF</td>
<td>88.2</td>
<td>81.0</td>
<td>-7.2</td>
<td>-12.8,-1.6 *</td>
</tr>
<tr>
<td>RE</td>
<td>87.5</td>
<td>76.6</td>
<td>-10.9</td>
<td>-19.2,-2.6 *</td>
</tr>
<tr>
<td>MH</td>
<td>78.7</td>
<td>73.7</td>
<td>-5.0</td>
<td>-9.3,-0.7 *</td>
</tr>
</tbody>
</table>

Significant difference at 0.05 level

This trend continued when the SF-36 was repeated in the 1998 Health Omnibus Survey below. Again all carers' scores were below those of non-carers, but significant only in the dimensions of RE and MH (not Social Functioning in 1998). Carers' and non-carers' scores were less pronounced.

Health Omnibus Surveys: Results And Interpretation

CARERS COMPARED WITH NON-CARERS

Table 20.4 shows the mean scores and differences in SF-36 scores for respondents who were or were not carers, after adjusting for age, sex and occupational status. At the conventional p<.05 level, it is apparent that scores for carers are LOWER across all scales of the SF-36, compared with their non-carer counterparts. However, scores are statistically significant only for scales measuring:

- Social Functioning
- Role Limitations [Due To Emotional Problems]
- Mental Health

Table 20.5: [1998] Mean SF-36 scores and differences for carers and non-carers adjusted for age, gender and SES (occupation)

<table>
<thead>
<tr>
<th>SF-36 Scale</th>
<th>Carers (n=127)</th>
<th>Non-carers (n=2879)</th>
<th>Mean difference</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>80.9</td>
<td>83.1</td>
<td>-2.2</td>
<td>-6.2,+1.8</td>
</tr>
<tr>
<td>RP</td>
<td>75.4</td>
<td>80.0</td>
<td>-4.6</td>
<td>-11.9,+2.7</td>
</tr>
<tr>
<td>BP</td>
<td>73.8</td>
<td>76.6</td>
<td>-2.8</td>
<td>-9.5,+1.1</td>
</tr>
<tr>
<td>GH</td>
<td>72.9</td>
<td>73.9</td>
<td>-1.0</td>
<td>-5.4,+3.4</td>
</tr>
<tr>
<td>VT</td>
<td>61.1</td>
<td>64.5</td>
<td>-3.4</td>
<td>-7.6,+0.9</td>
</tr>
<tr>
<td>SF</td>
<td>83.8</td>
<td>88.1</td>
<td>-4.3</td>
<td>-8.8,+0.2</td>
</tr>
<tr>
<td>RE</td>
<td>81.9</td>
<td>88.1</td>
<td>-6.2</td>
<td>-12.4,-0.03 *</td>
</tr>
<tr>
<td>MH</td>
<td>76.2</td>
<td>80.2</td>
<td>-4.0</td>
<td>-7.6,-0.4 *</td>
</tr>
</tbody>
</table>

(3) Significant difference at 0.05 level

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**CARERS AND THE TOTAL POPULATION BY GENDER**

Next, comparing carer SF-36 scores by gender in the total population, showed in 1994 and 1998, that female carers had lower scores than male carers, and both male and female carers had lower scores than non-carer males and females in the total population.

---

Fig 20.3: [1998] Mean SF-36 scores for carers and non carers, adjusted for age, gender and SES

![Graph showing mean SF-36 scores](image)

Fig 20.4: [1994] Mean SF-36 scores for carers and the total population by gender

![Graph showing mean SF-36 scores by gender](image)
There were two exceptions with these trends for female scores. One was detected in the Vitality dimension where female non-carers had the next lowest scores. In 1994, female carers had lowest scores of nearly all groups, except in Role Physical, where male carers were showing lowest scores. The other was in the General Health (GH) dimension where male carers had the lowest score. For GH, female carers and the total population had similar scores.

Table 20.6: [1994] Mean SF-36 scores for carers and the general SA population by gender

<table>
<thead>
<tr>
<th></th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Males</strong> (n=1480)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>88.6</td>
<td>82.6</td>
<td>79.9</td>
<td>74.3</td>
<td>68.0</td>
<td>90.6</td>
<td>90.3</td>
<td>81.3</td>
</tr>
<tr>
<td>SD</td>
<td>19.3</td>
<td>32.5</td>
<td>24.4</td>
<td>21.0</td>
<td>20.1</td>
<td>19.1</td>
<td>25.5</td>
<td>16.5</td>
</tr>
<tr>
<td>Carers (n=43)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>82.3</td>
<td>69.0</td>
<td>74.8</td>
<td>68.7</td>
<td>66.0</td>
<td>86.6</td>
<td>81.7</td>
<td>77.0</td>
</tr>
<tr>
<td>SD</td>
<td>21.1</td>
<td>40.7</td>
<td>27.7</td>
<td>22.2</td>
<td>20.7</td>
<td>18.8</td>
<td>36.8</td>
<td>16.8</td>
</tr>
<tr>
<td><strong>Females</strong> (n=1530)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>82.4</td>
<td>77.9</td>
<td>74.6</td>
<td>72.2</td>
<td>60.1</td>
<td>86.0</td>
<td>84.7</td>
<td>76.2</td>
</tr>
<tr>
<td>SD</td>
<td>23.2</td>
<td>36.9</td>
<td>26.3</td>
<td>22.2</td>
<td>22.0</td>
<td>23.0</td>
<td>31.6</td>
<td>18.4</td>
</tr>
<tr>
<td>Carers (n=61)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>73.6</td>
<td>74.2</td>
<td>67.1</td>
<td>65.4</td>
<td>54.4</td>
<td>77.2</td>
<td>73.1</td>
<td>71.3</td>
</tr>
<tr>
<td>SD</td>
<td>25.6</td>
<td>38.0</td>
<td>26.9</td>
<td>23.4</td>
<td>23.3</td>
<td>27.9</td>
<td>38.5</td>
<td>20.7</td>
</tr>
</tbody>
</table>

Fig 20.5: [1998] Mean SF-36 scores for carers and the total population by gender
In 1998, the mean scores of carers and the total population by gender were slightly different. (Please note different legend in the 1998 graph.) Nevertheless a similar trend was seen in 1998 with males in the total population showing consistently higher scores than all others.

**COMPARING CARERS ACROSS THE AGE GROUPS**

*Comparing carer SF-36 scores across four adult age groups*

Further comparisons of mean SF-36 scores for carers and the general SA population were made across four adult age groups.

Fig 20.6: [1994] Mean SF-36 scores for carers according to age (years)

To summarize differences within these age groups, the mean SF-36 scores for carers according to age (years) have been combined in Figure 20.6.[1998]. This shows the anticipated contrast between carers aged 75+ with lower SF-36 scores for the physical scales of Physical Functioning and Role Physical. This contrasted with the higher scores for the younger 15-34 year olds and 35-54 age group in the same scales. What is interesting to note from 1994 however, is the reversal of SF-36 scoring for these age
groups at the psycho-social end of the spectrum in the Role Emotional and Mental Health scales.

Comparing all age groups, it was the 15-34 year olds who exhibited lowest scores in the Role Emotional, Mental Health and Vitality scales. The 55-74 age group maintained mid range SF-36 scores for most of the 8 scales except in General Health where they scored the lowest, just below the 75+ age group which had the highest scores overall. In 1998 these trends were not maintained, with the over 75 year olds having lowest scores for RP, SF, RE and MH. The 15-35 group 1998 scores by contrast to their 1994 scores were consistently high (which were double checked). What is more significant is to look at each age group of carers and compare them with the total population. Again the carers have consistently lower scores across the age groups than the total population. It was more marked in 1994 for the 15-34 year olds and the 55-74 age group which had in 1998 higher scores in RE and BP than the total population. There were only two scores amongst the wide range of SF-36 graphs, where carers showed better scores than the general population. In this instance the 75+ age group which in 1994 survey went against the trend and showed higher scores than the total population in all dimensions except MH, where they had lower scores.

Fig 20.7: [1998] Mean SF-36 scores for carers according to age (years) [AGES COMPARED]

![Graph showing mean SF-36 scores for carers according to age categories, comparing 15-34, 35-54, 55-74, and 75+ years.](image-url)
With the significant findings showing slightly lower MH scores, it was helpful in 1994 to have a point of comparison using the GHQ.

THE 1994 GENERAL HEALTH QUESTIONNAIRE (GHQ)

Findings of the second population health measure for carer health status used in 1994

When a follow up univariate analysis of the carer and non-carer populations was carried out using the 12-item General Health Questionnaire scores, it again showed the carers to have lower scores than the non-carer population. "Of the 104 carers, 21.8% showed a high/severe disturbance and a further 12.5% had a mild/moderate disturbance". It was also reported that, "There is a significant difference between carers and non-carers when the mild/moderate/high/severe groups are compared with those with no or low disturbance. The Carers are 1.5 times more likely to have a mild to severe disturbance on the GHQ score than non-carers (odds ratio = 1.5 (1.0 - 2.3), p=.045)."

A multivariate analysis showed that "after adjusting for age and gender using logistic modelling, the odds ratios increases to 1.6 (c.i. = 1.1,-2.5), and is significant (p=0.023)". Based on the 1994 GHQ scores, "carers show significant difference to non-carers and have lower scores than non-carers at the .02 sig. level". I emphasise however that these lower scores in carers do not indicate disturbance at clinical levels. In comparison to people with mental health problems of depression etc. carers in the 1994 survey had much lower scores. When compared with other groups in the population, carers' GHQ scores are closer to scores of persons with disability, hearing loss or conditions like psoriasis. These were interesting findings. The report from the SA Health Commission is re-stated in the box below:

**INTERPRETATION OF GHQ RESULTS 1994 HEALTH OMNIBUS SURVEY**

Whilst carers do not evidence differences in functioning in the final three scales of the magnitude of differences apparent for people with/without high scores on the 12-item GHQ (indicating a strong likelihood of psychiatric impairment), they (carers) do show differences in functioning similar to those of people with/without asthma or other chronic limiting conditions such as arthritis or diabetes.

Thus for most people who are carers, there is evidence of impairment in aspects of living related to emotional, social & mental health, rather than in domains related to physical functioning.

Refer [See Tables 20.8 - 20.11]
Chapter 21: Health & Socio-Demographic Status Of Adult Carers In The SA Population

Table 20.7: GHQ 1994 Omnibus - Weighted data

<table>
<thead>
<tr>
<th>GHQ by carer (Are you a carer of a dependent person?)</th>
<th>CARER</th>
<th>CARER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>Row Pct</td>
</tr>
<tr>
<td>GHQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.00</td>
<td>2163</td>
<td>68</td>
</tr>
<tr>
<td>LOW/NO DISTURBANCE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.00</td>
<td>337</td>
<td>13</td>
</tr>
<tr>
<td>MILD/MODERATE DIST.</td>
<td>96.3</td>
<td>3.7</td>
</tr>
<tr>
<td>HIGH/SEVERE DIST.</td>
<td>406</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>94.7</td>
<td>5.3</td>
</tr>
<tr>
<td>Column</td>
<td>2906</td>
<td>104</td>
</tr>
<tr>
<td>Total</td>
<td>96.6</td>
<td>3.4</td>
</tr>
</tbody>
</table>

Number of missing observations: 0

Data analysis of the SF-36 and GHQ was part of the 1994 Health Omnibus Survey and was provided by staff of the Behavioural Epidemiology Branch of the SA Health Commission.

Table 20.8: RGHQ (recoded GHQ score)

<table>
<thead>
<tr>
<th>RGHQ (recoded GHQ score) by carer (Are you a carer of a dependent person?)</th>
<th>CARER</th>
<th>CARER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>Row Pct</td>
</tr>
<tr>
<td>GHQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.00</td>
<td>2163</td>
<td>68</td>
</tr>
<tr>
<td>LOW/NO DISTURBANCE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.00</td>
<td>743</td>
<td>36</td>
</tr>
<tr>
<td>MILD TO SEVERE DIST.</td>
<td>95.4</td>
<td>4.6</td>
</tr>
<tr>
<td>Column</td>
<td>2906</td>
<td>104</td>
</tr>
<tr>
<td>Total</td>
<td>96.6</td>
<td>3.4</td>
</tr>
</tbody>
</table>

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Table 20.10: GHQ Chi-Square

<table>
<thead>
<tr>
<th>Chi-Square</th>
<th>Value</th>
<th>DF</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson</td>
<td>4.00734</td>
<td>1</td>
<td>0.04530</td>
</tr>
<tr>
<td>Continuity Correction</td>
<td>3.56358</td>
<td>1</td>
<td>0.05906</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>3.77847</td>
<td>1</td>
<td>0.05192</td>
</tr>
<tr>
<td>Mantel-Haenszel test for linear association</td>
<td>4.00601</td>
<td>1</td>
<td>0.04534</td>
</tr>
</tbody>
</table>

Minimum Expected Frequency = 26.838

Table 20.11: GHQ

<table>
<thead>
<tr>
<th>Statistic</th>
<th>Value</th>
<th>95% Confidence Bounds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relative risk estimate (RGHQ 1.0/RGHQ 2.0):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>case control</td>
<td>1.52172</td>
<td>1.00605</td>
</tr>
<tr>
<td>cohort (CARER .0 Risk)</td>
<td>1.01592</td>
<td>.99876</td>
</tr>
<tr>
<td>cohort (CARER .0 Risk)</td>
<td>.66761</td>
<td>.44884</td>
</tr>
</tbody>
</table>

Number of missing Observations: 0

Therefore by using the two population health measures [SF-36 and GHQ], the 1994 Health Omnibus Survey results revealed that carers in the wider population had noticeably lower scores on both the instruments. Both the GHQ and SF-36 are useful for detecting psychological distress. The SF, RE, MH dimensions (some authors also include 'vitality' dimension of SF-36), are the best measures of the mental component of health status. Although the RE scale is the most coarse of the SF-36 scales, Role Emotional defines substantial differences in mental health burden.13

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According to Ware, it is sometimes argued that differences in the psychological well being range of the MH (at the top) are not clinically and socially relevant, the 3 point difference on the MH scale, which has been shown to be roughly equivalent to the psychological distress caused by being fired or laid off one's job.
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COMPARING CARER SF-36 SCORES ACROSS CONDITIONS

Taking an even wider view of carer SF-36 scores and comparing them 'across conditions' with those in the population identified "with and without" chronic illness, it was interesting to note that carers share some similarities with individuals who have chronic conditions, at the psycho-social end of the spectrum. The graphs the follow illustrate how carer scores compare with persons who have conditions like arthritis, asthma and diabetes. The consistently low SF-36 scores of carers were quite unexpected and very surprising. The interpretation of such scores however is not straightforward as explained in the box below.

In 1994, carers actually had the lowest RE (Role Emotional) and MH(Mental Health) scores compared to scores of persons with asthma, diabetes and arthritis. Carers’ scores therefore were not only lower than the population norm, but in some dimensions also fell below the standard population score for persons with chronic medical or health conditions.
**Chapter 21: Health & Socio-Demographic Status Of Adult Carers In The SA Population**

Fig. 20.8 [1994] Mean SF-36 scores for carers & non carers, across conditions, adjusted for age, sex, SES

Fig. 20.9 [1998] Mean SF-36 scores -Carers and Non carers, across conditions, adjusted for age, sex & SES
As can be seen from the preceding figures, carers' social functioning was well below that of persons with diabetes and only marginally better than SF scores of persons with arthritis and asthma. Therefore it was found that carers have comparable mean difference in scores to those people with/without arthritis, asthma and diabetes. In another study (adapted from Garratt\textsuperscript{14}) people with suspected peptic ulcer had very similar SF-36 scores to carers.

**A COMPARISON OF HEALTH STATUS OF CARERS & NON CARERS: 1994 & 1998**

My final comparison for this population study was comparing health status between carers and non carers for each of the two surveys - 1994 and 1998. Despite some slightly improved scores for the 1998 carers, the scores clearly show carers below non carers in the population. (Refer Fig. 20.11 below).

The population based evidence is compelling indeed and it is planned for these findings to be contrasted with a future Health Omnibus Survey planned for 2002/3, again using the SF-36.

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Chapter 21: Health & Socio-Demographic Status of Adult Carers in the SA Population

QUALITY OF LIFE SCORES: 1998

Comparison of carers and non-carers

The "Health Related QoL Measure" was used in 1998, scores between carers and non-carers were very close. However using AQoL scores, does not show any significant differences between carers and non-carers. (Refer Table 20.10 and Figure 20.10 below).

Table 20.11: [1998] Mean AQoL scores and differences (95% CI) adjusted for age, gender & SES

<table>
<thead>
<tr>
<th>AQoL variable</th>
<th>Carers</th>
<th>Non-carers</th>
<th>Mean difference (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness</td>
<td>0.73</td>
<td>0.77</td>
<td>-0.04 (-0.1, +0.02)</td>
</tr>
<tr>
<td>Independent living</td>
<td>0.94</td>
<td>0.96</td>
<td>-0.02 (-0.04, +0.004)</td>
</tr>
<tr>
<td>Social relationships</td>
<td>0.91</td>
<td>0.93</td>
<td>-0.02 (-0.06, +0.002)</td>
</tr>
<tr>
<td>Physical senses</td>
<td>0.96</td>
<td>0.96</td>
<td>0.00 (-0.02, +0.01)</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>0.92</td>
<td>0.93</td>
<td>-0.01 (-0.03, +0.02)</td>
</tr>
<tr>
<td>Overall AQoL</td>
<td>0.68</td>
<td>0.72</td>
<td>-0.04 (-0.1, +0.003)</td>
</tr>
</tbody>
</table>

Figure 20.11: 1998 AQoL scores for carers and non-carers adjusted for age, sex and SES (Occupation)

The differences between quality of life scores for carers and non-carers were marginal, with carer scores similar, or slightly lower than non-carers. The only AQoL variable of interest...
appears to be the "illness" variable which of all the scores, showed a very small mean difference, but still not significant. It is possible that this is not the ideal instrument to show differences between carers and non carers. The HRQoL is most suited to "patients" or populations with conditions that are being measured for differences resulting from health interventions. Despite its validation it does not appear to be as sensitive as the SF-36 in assessing carer health status.

Conclusion.
Using population health status measures as part of the 1994 and 1998 Health Omnibus Surveys confirmed that carers had noticeably lower scores with both the health status measure SF-36, and on the GHQ, the latter used for detecting psychological distress.

The findings indicate that at the broader population level, there is a perceived negative health effect amongst half (45.5% - 52.8%), of the surveyed carers, with 20% - 30% of the carers indicating that caring had had a moderate or major effect on their health and well being. This was less pronounced in the repeat survey of 1998.

Combining the SF-36 in the South Australian Health Omnibus survey results of 1994 and 1998, showed that although carers do experience significant psycho-social problems associated with caregiving, their physical health status can also be affected. Physical health problems do not seem to be confined to the older age groups. Therefore there is potential for informal caregiving to impact on the physical, emotional and general health of carers. Although the emotional and mental health aspects of carer health were shown to be quite significant, the presence of physical health problems and needs in carers should also be considered.

From the results of the two Health Omnibus Surveys in South Australia and my own emprirical data from carers and GPs, I suggest that the difficult and restricted lifestyle of informal caring 'work' may actually prevent up to half of carers in the population from achieving their optimum health status. Due to their caring role, these carers may not be able to achieve improvements in their health status and risk a further decline in their physical or

---

mental health. Vulnerable carers, especially older women with pre-existing health problems, disability or who are themselves ageing may be at greater risk of physical or psychological health deterioration if their caring role continues. Although 50% of carers were not experiencing health problems at the time of each survey, there is still the possibility a proportion might start to show a lower health status as the caring role continues.

Below is an overview and summary of the main findings of the Health Omnibus surveys.

**SUMMARY OF SA HEALTH OMNIBUS SURVEYS: 1994 AND 1998**

**PREVALENCE OF INFORMAL CAREGIVING AND CARER HEALTH PERCEPTION**

- In the 1994 SA Health Omnibus Survey, 3.4%, or 104 out of 3010 persons, identified themselves as carers. More than half (52.8%) of these carers answered 'yes' - their physical or emotional health and well being was affected by their caring role. More than a third of the same group of carers (34.8%), reported their health had been affected in a moderate (21.5%) or major (13.3%) way.

- In 1994 less than half (46.4%) of all carers identified answered that their health was NOT affected by their caring role.

- In 1998 slightly more, 4.2% or 127 out of 3010 persons contacted in the SA Health Omnibus Survey, identified themselves as carers.

- This time however more than a half of carers answered 'no' - their physical or emotional health and well being was NOT affected by their caring role.

- Nevertheless, just under a half of the carers (45.5%) in 1998 answered 'yes' - they felt their health had been affected by their caring role. What is different in 1998, is that more carers reported their health had been affected in a minor way, (24.8%). Only 20% of carers in the 1998 survey reported their health and well being was affected in a moderate way (13.7%) or in a major way (7%). This was 10% less than were identified in 1994.

**CARER SOCIO-DEMOGRAPHIC PROFILE OF CARERS:**

**Gender**

- In 1994, 57% of carers were female and 43% male. In 1998, 55% of carers were female and 45% male, indicating a slight increase in male carers. [The non-carer M:F ratio remained stable at 49%: 51% respectively in both 1994 and 1998].

- Although it can be stated that more than a half of carers in both surveys were female, that should not detract from the fact that male carers are very well represented, slightly increasing in 1998 to nearly half of respondents. Late twentieth century informal caregiving therefore should not be assumed to be the province of women.

**Marital Status**

- The marital status of carers was consistent for both 1994 and 1998 surveys (76%-86%) with the majority (married/defacto) people identified as carers. However in the earlier survey of 1994, ~10% of carers were also separated/divorced or never married. By 1998 that figure had fallen to only 3.7% with the 'never married' group as carers. In 1998, 8.4% of the separated/divorced persons were carers, slightly less than in the 1994 survey (10.5%).
Chapter 21: Health & Socio-Demographic Status Of Adult Carers In The SA Population

Age

- Carers were evenly represented across the main age groups in 1994 with approximately a third of carers in the 45-64 and 65+ age groups. Slightly more carers (36.5%) were in the younger 20-44 age group in 1994. In the same year, the age distribution of non-carers was clearly differentiated with more than half of non carers (56.5%) aged 20-44 years; More than a quarter of non carers were aged 45-64 and only 17% aged 65+. The age profile of these non carers remained constant for the two surveys of 1994 and 1998.

- In 1998, slightly more carers (36%) were identified in the middle age range of 45-64 years, however when comparing carers between the 1994 and 1998 surveys, it is noteworthy that older carers were as likely to be carers as persons from younger age groups. In other words, the likelihood of being a carer did not diminish with age.

Educational status

- The educational status of carers revealed in 1994 that more carers had left school before they were 15 years (34%), than non carers (19%). In 1998 a similar trend persisted with (30.5%) of carers having left school before 15 years, in comparison to only 18% of non-carers identified as leaving school early, before 15 years.

- Looking at higher educational status in 1994, only 7% of carers had bachelor degrees, (and 9.8% of non-carers). In 1998 slightly more non-carers had bachelor degrees (12%), but only 8.5% of carers had achieved higher education. Findings suggest that carers tend to have left school earlier and have a lower educational status than non carers which is interesting in the light of the considerable responsibility, supervision and work load they carry in their informal caregiving role.

COMPARING CARERS WITH NON-CARERS AND THE GENERAL POPULATION USING THE THE SF-36 HEALTH STATUS MEASURE

The following is a summary of the health status of carers. The results strongly suggest that informal caring is associated with carer health departing from "a healthy standard".

- Carers' health fell below the population norms in 1994 and again in 1998.
- Carers' health status was consistently lower than non-carers' health in both 1994 & 1998.
- Carers show differences in scoring across all aspects of carers' health when measured on each of the 8 scales of the SF-36.
- Carers' Role Emotional and Mental Health scores remained at significantly low levels in 1994 and again in 1998 but when using the psychometric measure (GHQ) in 1998 carer scores were not at the clinical level. [Nevertheless, in 1994 it was suggested that carers are 1.5 times more likely to have a mild to severe disturbance on the GHQ score than non-carers.]
- Female Carers maintained a lower health status than their male carer counterparts in 1994 and again in 1998 using the SF-36 instrument.

CARERS COMPARED WITH NON CARERS

- In 1994 when carers were compared with non carers, there were statistically significant scores in 3 scales measuring social functioning and emotional aspects of carer health. (SF, RE and MH).
- When the survey was repeated in 1998, carers were compared with non-carers, carers again showed significant scores, this time on 2 scales of RE (Role emotional) and MH (Mental Health status). The social functioning scores were lower than those of non carers but were not at significantly low levels in 1998.
CARERS COMPARED WITH THE GENERAL POPULATION

- In a re-analysis of all data in 1998, the 1994 scores for carers compared with the general population carers scored lower than population norms across 6 of the 8 scales. All 6 scores, including both physical and mental health measures, were significant at the 0.05 level in Physical Functioning (PF), Bodily Pain (BP), General Health (GH), Social Functioning (SF), Role Emotional (RE) and Mental Health (MH). Carers' Role Physical and Vitality (RP and VT) scores remained lower than those of the general population, but were not at significant levels.

- When the SA Health Omnibus survey was repeated in 1998, and carer health status compared with health of the general population, carers scored lower than population norms across 3 of the 8 scales - this time in the physical dimensions of PF, RP and GH. This was the first time that carers's scores were significant in the RP (Role Physical) dimension.

- Scores for Physical Functioning (RF) remained similar for both 1994 and 1998 while the General Health (GH) scores for carers slightly higher than in the earlier 1994 survey.

COMPARING CARER SF-36 SCORES ACROSS CONDITIONS

- Comparing carers and persons in the general population with chronic conditions was perhaps the most revealing of all the survey results using the SF-36. In both 1994 and 1998, it showed that in terms of the mental health summary measures, carers' scores were similar to, sometimes lower than the psycho-social scores of persons with chronic illness. (The survey analysis allowed for any bias from carers having chronic illness themselves.)

- Carers had the same Social Functioning scores as asthmatics (40%).

- In the RE dimension (Role limitations due to emotional problems), carer scores (36%) were lower than those of persons with diabetes (39%)

- In the Mental Health dimension, carer scores (39%) were the same as those of diabetics.

- These results raise many more questions than can be addressed in my thesis but highlight the fact that many carers have an emotional health status and quality of life comparable to persons with/without a chronic illness. Ramifications of this finding will be featured again in the Discussion Chapter.

THE AUSTRALIAN QUALITY OF LIFE QUESTIONNAIRE

- When the AQoL questionnaire was used in 1998, carers scores were only very marginally lower than scores of non carers, but not at levels of significance. This suggested there was little difference between the quality of life of carers and non carers across the surveyed population in 1998.

- On closer examination of the AQoL instrument, which is designed for discerning effectiveness of intervention programs amongst populations of persons with known health problems, the poorly differentiated findings in relation to carers could also indicate that the HRQoL instrument is more suited to comparing populations with chronic illness. The results are therefore inconclusive.
SECTION IV
INFORMAL CAREGIVING, CARER HEALTH AND PUBLIC POLICY.

(The policy implications of the health needs of informal caregivers in Australia.)

Informal Caregiving, Carer Health and Public Policy
Is Informal Caregiving and Carer Health a Public Health Issue?
THE 4 PILLARS OF CONCEPTUAL FRAMEWORK
RESEARCH QUESTIONS

1. First conceptual pillar: CARER HEALTH @ INDIVIDUAL LEVEL
   Caregiving as a health issue for the INDIVIDUAL informal carer

   1st conceptual pillar is based on the notion of informal caregiving impacting on carer health.
   1.1 Does caring impact on the health of carers?
       ie. In what ways/ how is informal caregiving perceived as detrimental to health of family / informal carers? [Literature Review]
   1.2 What effect does caring have on the health, well being & lifestyle of informal carers?
      1.2.1 CARER PERCEPTIONS. What do carers themselves have to say about their experiences of caregiving roles and responsibilities.
       What are the needs and general effects of caring on carer health.
      1.2.2 GP OBSERVATIONS. What do local GPs say about carer health and related needs?

2. Second conceptual pillar GENERAL PRACTICE OBSERVATIONS: CARER/GP NEEDS
   GENERAL PRACTICE AS THE KEY TO CARER HEALTH ENHANCEMENT-

   2nd conceptual pillar is based on notion of GPs as the pivotal health professional with whom carers have most regular and ongoing contact.

   Before suggesting a broadening of the GP role in supporting the health / social needs of caregivers, I wanted to know:
   2.1 Do GPs understand informal caregiving, carer roles and responsibilities?
   2.2 What did GPs have to say about their supporting carers? Would GPs themselves be amenable to a more pro-active approach to informal caregiving in the future. [1994/5]
   2.3 What is happening in general practice in southern Adelaide re carer issues? I ask selected GPs from across the southern region.
   2.4 GP EXPERIENCES: What problems have GPs had in trying to assist carers?

3. Third conceptual pillar introduces: CARER HEALTH @ POPULATION LEVEL
   Informal family caregiving as a POPULATION_health issue [SF-36]

   The 3rd conceptual pillar focuses on informal caregivers as a group at risk of health problems across various populations.

   3.1 Do informal carers, across a population, perceive their caregiving role has affected their health?
   3.2 What proportion of surveyed caregivers report they have health problems?
   3.3 Can it be shown there are any measurable differences between the health status of caregivers and non-caregivers surveyed at the population level?
   3.4 If it can be shown informal caregivers have a lower health status than non carers and/or the general population, what areas of carer health and well being are most affected?

4. Fourth and final conceptual pillar examines CARER HEALTH & CARER POLICY
   & CAREGIVING AS PUBLIC HEALTH ISSUE - An overview and discussion

   4.1: Theoretical and Ethical Context for Policy-Development for carers.
      - Transformation of domestic needs of carers into public policy
      - Concept of Community Care. Where does General Practice fit in?
      - Carer Policy within an Ethical Justice Framework

   II. Australian public policy, carers' health and GPs
   4.1 How well does Australian public policy address carers' health?
   4.2 Are GPs adequately integrated into Government carer policy?
   4.3 Are carers integrated into General Practice policy? (RACGP)

III :Is informal caregiving and carer health to be viewed as a public health issue?
CHAPTER 22
INFORMAL CAREGIVING, CARER HEALTH AND PUBLIC POLICY

Introduction
The fourth pillar of my conceptual framework for this study [see opposite], examines informal caregiving and carer health in the context of policy development for carers in two domains - across the Commonwealth government and within general practice in Australia. This section illustrates challenges inherent in translating carers' personal health needs into actionable public policy and how well that has been done by policy-makers in the past decade or so. To discuss this I present an ethical context for policy development for carers based on the concepts of health, opportunity and justice for carers. I also examine the location of general practice within public policy in relation to the crucial role of GPs, in supporting carers and enhancing carer health. Lastly I combine all these elements to address the question as to whether caregiver health is a public health issue and how that might be translated into future public policy. Key issues are carried forward into the Discussion chapter.

From the findings of my research, and the extensive literature on health, welfare and social policy, I suggest that carer health needs have not been adequately translated into public policy. The dilemma is that carer health issues have been dealt with through existing carer support and carer respite programs - not through health policies. In fact carers' clinical health are not dealt with at all as they are beyond what can be provided for carers within the confines of current social policies like community care. What I believe is needed to maintain, protect and enhance carer health, is a specific and well integrated carer health policy -To my knowledge no such policy exists in Australia. For the purpose of discussing carer health in this section, I explore social and carer policy generally and refer to "community care" in particular.

To better understand the actual structure of carer policy as it exists at the moment in Australia I point out that our Commonwealth Government does not have one clearly written policy for carers, or specific carer legislation, as is the case in the United Kingdom with the Carers Recognition and Services Act of 1995, (see Appendix 15). Carer "policy" in Australia is piecemeal and has evolved over a period of fifteen years or so. It exists as a collection of six or eight key initiatives and strategies listed in the Box overleaf. Some are
about carers, like carer respite, others as part of broader government policies associated with community care, aged care, dementia, disability or welfare initiatives.

Government carer-related policies - Australia.

Examples of Australian government carer 'policies' represented by key initiatives, strategies and programs introduced between 1985 and 1999.

<table>
<thead>
<tr>
<th>Year</th>
<th>Initiative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985/86</td>
<td><strong>Home and Community Care Program [HACC]</strong></td>
</tr>
<tr>
<td>1992</td>
<td>The first initiatives by the C'wealth with a specific focus on carers were introduced. Included carer information, support and respite needs.</td>
</tr>
<tr>
<td>1992-97</td>
<td>The National Action Plan for Dementia Care - included carer support initiatives</td>
</tr>
<tr>
<td>1992</td>
<td>Community Options</td>
</tr>
<tr>
<td>1992</td>
<td>Commonwealth Community Care Packages [An in-home community based alternative to people with complex care needs who would otherwise require low level residential care.</td>
</tr>
<tr>
<td>1992</td>
<td><strong>The Carer Support Kit</strong> - a practical and comprehensive info kit to help carers with the issues and concerns they face in caring - linked to State and Territory Carer Associations.</td>
</tr>
<tr>
<td>1993</td>
<td>Disability Discrimination Act</td>
</tr>
<tr>
<td>1995</td>
<td>National Mental Health Strategy featured carers</td>
</tr>
<tr>
<td>1995/6</td>
<td><strong>Towards a National Agenda for Carers</strong></td>
</tr>
<tr>
<td>1996</td>
<td>National Carer Action Plan</td>
</tr>
<tr>
<td>1996 *</td>
<td><strong>National Respite for Carers Programme</strong> that had 3 components</td>
</tr>
<tr>
<td></td>
<td>* Carer Respite Centres [ first full year of operation was 97/98 ]</td>
</tr>
<tr>
<td></td>
<td>* Carer Resource Centres</td>
</tr>
<tr>
<td></td>
<td>* Respite Service Provision</td>
</tr>
<tr>
<td>1998-99</td>
<td>Staying at Home package for older Australians</td>
</tr>
<tr>
<td>1999</td>
<td>National Strategy for an Ageing Australia</td>
</tr>
</tbody>
</table>

Carers are identified at a national level within the context of a variety of policies including social security initiatives which provide carer pensions and benefits, taxation benefits and other disability payments. The Department of Veterans Affairs also developed carer support and respite programs and initiatives.

In this chapter I will not be presenting a detailed description of the many and varied 'policies' or programs as listed in the box above. This is because none of them adequately integrate General Practice with carer support or community care initiatives, nor do the policies provide the means for **clinical** support for carer health. So as to provide some
background, to those more successful and enduring carer initiatives, I have included in the Appendix, an excellent paper by Perring\(^1\) which summarises Commonwealth government support for carers. Perring was Director of the Carer Support Branch for a period during the mid 1990s - the time most relevant to my own research.

At the time of my commencing this study in 1994, carer 'policy' was vague and remained so until developments in the mid 1990s. Carers were only marginally recognised at the Federal level up until the early 1990s with the government philosophy about informal carers somewhat two-pronged, and at times, almost contradictory. On the one hand the Commonwealth Government had an overarching economic policy based on financial constraints within the health system shaping the health and social policies of government, directing more care to the informal sector. On the other hand through an ongoing bipartisan commitment to carer and community support, the federal government can boast an impressive array of carer support initiatives and services. This had occurred by the mid 1990s, mostly through work of the Carer Support Branch and the Home and Community Care Program.

Home based care and community support services which assist carers to maintain sick, disabled and frail persons at home are partly funded through the Commonwealth Home and Community Care Programme under the "HACC Act" of 1985\(^2\). This Act represents the only actual piece of formal legislation supporting the diverse area of community care throughout Australia\(^3\). A specific HACC Carers' Policy was released separately later and updated in 1996.\(^4\) The delay in developing a specific carer policy within HACC could be because the earlier carer initiatives were not shaped by carer problems in the first place. Rather carer programs emerged as part of, or as a consequence of broader government

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2. HACC is administered under the federal government's Department of Health and Aged Care, Community Care Branch and is a joint agreement between the Commonwealth Government, State and Territory governments.

3. Carers were very briefly mentioned in the HACC Act [See Appendix for part of the Schedule for the HACC Act] but there were no clear references to carer support and assistance. Various parts of Government legislation covering Australian Taxation and Social Services are the only other legislative aspects one could add here in terms of carer support outlined in the original Schedule.

4. However this did not apply to all carers per se - on those who were part of the HACC Program and therefore was not a comprehensive or across government document (See Appendix for copy of "HACC Carers Policy" - 1996.)

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policy frameworks responding to problems associated with aged care, dementia care, home based care and disability to name a few areas. Many of the earlier carer programs and initiatives between 1985-1995, can therefore be seen as unplanned sequellae of other government activities, rather than developed for carer and family issues in their own right. Therefore their design and delivery was not necessarily carer focused.

Assumptions
An example of the mismatch between carer needs and services delivered, was in the assumption of early community care initiatives of the 1980s. For example, it was assumed if the Govt provided enough help for the patient, in the form of community and home support services, you had helped the carer. In particular it was assumed that the provision of respite care would temporarily ease the strain on carers long enough for them to resume their caregiving role and keep on caring - for longer. The expectation was that by providing respite care and 'time-out' for carers to see to their own needs, it might contribute to an improvement in their health and well being, for the express purpose of keeping carers ‘functional’. A critical commentary on the initial HACC program in the same report suggested:

"...carers are unpaid health workers who serve as a cheap method of providing home care and as such will continue to be exploited receiving support only to the extent necessary to keep them functional."

From consultations with carer groups as part of early HACC reviews in the 1980s it was revealed by carers:

"...the HACC program did not directly benefit carers and it failed to service those carers most at risk". (1982:57 Evidence, p.S361)

That situation has since been reversed as HACC services are now directed at carers, but in the early 1980s policy-makers were slow to perceive the longer term significance of carers' personal health problems such as the stress and physical burden of caring. Carer support was certainly not provided for the benefit of the carers' health. Further, carers' domestic and family needs were translated into public social policies rather than health policies by

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5 This assumption underscored the HACC Act and subsequent initiatives and programs from the mid 1980s to the early 1990s. [Perring 2000 Brisbane 2nd International Carers Conference].
6 ibid
policy makers who were often restrained by administrative and ideological boundaries. Thus the first decade following the introduction of the Home and Community Care Program (HACC), services were directed at the needs of the person cared for and any efforts to address health issues of carers through policy initiatives involved indirect approaches through the provision of respite services to carers.

By the mid 1990s however, following HACC reviews, evaluations and extensive consultations with users and providers of HACC services, carers were finally placed on the government agenda and better funded for a range of national government initiatives in their own right. These included respite, information and carer support as well as social services benefits. Towards the end of the 1990s there was a period of consolidation with government support for more carer specific services. Most recently since the late 1990s, federal government carer initiatives have changed again with the introduction of Enhanced Primary Care initiatives. By 1999/2000 the government was moving towards primary care and community care, building on previous platforms of primary health care, coordinated care or community care.

An epistemological view of informal caregiving and community care.

It is important to briefly step back from this complex mosaic of government polices in Australia and take an epistemological view of informal caregiving and community care. That requires we recall how late twentieth century society conceptualized and moulded our reality of informal caregiving and how that has changed since the 1970s. As I described in earlier chapters of this thesis, there was a major transition from the conceptualisation of family or kinship caring (confined to the domestic and private realm of women and the home, with minimal financial or practical support), to a re-positioning of informal caregiving as "an area of public concern". The latter approach has since attracted considerable government funding and services for carers, including a range of initiatives to support home based care such as respite, dementia support and number of other social welfare benefits. To quote Anna Howe and Hilary Schofield in their paper:

8 The intricacies of why this happened are beyond the scope of my current thesis. It would be very interesting to fully investigate the political motivations that influenced these decisions.

9 Enhanced Primary Care evolved after release of the evaluation reports of Coordinated Care Trials (Round One) which recommended better integration of general practice with the care sectors.

Chapter 22: Informal Caregiving, Carer Health and Public Policy

"Carers now function in very different social and policy environments to those 20 years ago, and their role has been redefined several times over in policies and programs.

Howe and Scofield’s notion that caring has been reconceptualized is pertinent here. They write:

"... the provision of public support of carers has been defined as acceptable, or to apply Dobson’s rubric, the failure to support carers has been defined as unacceptable". This reconceptualization will continue into the future and approaches to support that develop over the next 20 years will also be different.11

Six years later as I edit this chapter in 2002, I can actually see that happening - again. The approach to carer support may be under threat from the influences of another period of transition, this time driven by aggressive market priorities, not care principles. I will address this in the discussion chapter.

PART I:
THEORETICAL AND ETHICAL CONTEXTS FOR CARER POLICY

Translating carer needs to public policy - The 4 catalysts

Understanding how and why carers were re-conceptualized to the point where informal caring became a public issue embedded in government policy is central to this chapter and this thesis. I therefore wish to briefly revisit the reconceptualisation and transformation of carers from their position of private obscurity to political and public prominence. The transformation of domestic needs of family and informal carers into public policy occurred through the influence of at least four sets of circumstances during the 1970s and 1980s, which I suggest, acted as important catalysts for new policy formation about carers. This summary is my interpretation of events as they occurred in Australia and the United Kingdom. [Steps of that transformation are summarised in Box on the following page].

During the past two decades there has been much comment and theorising about community care in terms of service users, carers and service providers, but scant reference to the providers of medical services within that same community! The concept of community care has been a bold social experiment in Australia and several other countries, mainly Britain. One would have to concede that community care has been partly successful in terms of outcomes for governments in reducing residential health care costs in a shrinking the welfare state. In some instances it may also have been in the best interests for those cared for persons living in a well supported home environment, and for some carers who know how to use the system. But for up to a third of carers with significant health

11 ibid. Howe and Scofield, 1996, p.16
problems associated with, or exacerbated by their caring role, community care has its limitations within the confines of such a social services policies.\(^{12}\)

### Steps in the transformation of domestic needs of family/informal carers into public (government) policy

By the early 1980s, the family was acknowledged by governments as integral to emerging community care strategies. Changes involved the transfer of aged care from formal institutions to the informal realms of the home and community. The assumption was that all individuals were able and willing to take on the caring responsibilities.\(^{13}\) This was the first catalyst which set in motion a series of events that would create "carers" as we know them today.

Although the driving force for such policies was cost containment of a burgeoning residential aged care sector, the trends of deinstitutionalisation of mentally ill and disabled persons had started during the 1970s. Interestingly, the impact of such policy on carers was not acknowledged in the same way by Government at that earlier juncture. There was nevertheless a flow-on effect to those family carers who took over care of their mentally ill and disabled relatives. Despite that carers were still conceptualised as 'family', coping with their troubles in the privacy of the home. In the 1970s, 'carers' did not exist as an identifiable and cohesive group, and had no public profile so their problems were not seen as a public issue. The only public forum for family members in caregiving roles was through consumer groups where carers were recognised - but always secondary to the consumer.

What was different in the 1980s and what I see as the second catalyst in the development of "carer aware governments", (as distinct from consumer focused), was the redefinition of family members as a generic group of 'carers' as I described in some detail in earlier chapters.

ie Informal care changed with the transformation of family, marital and social relationships into 'care' relationships. These caring roles with their inherent obligations and responsibilities were described as being beyond normal expectations of family life, referred to by Schofield as a transgression of customary expectations\(^{14}\).

As a result of their demanding caring roles and special lifestyle limitations, it was acknowledged by academics and governments that the lives of these carers were often significantly disrupted. Carers then took their place in public policy by virtue of that caring relationship. This led to public debate on issues of social justice for informal carers which in turn called for public policy intervention and support for carers in their own right. The debate however has been mostly confined within the orbits of social welfare and social policy, not health policy.

Once 'family' and 'kin' were re-defined as 'informal carers' and judged to have an identifiable and valuable role in society, they were then grouped according to whether they were primary or resident carers, and who they were caring for like the aged, the disabled etc. Once formally categorised, carers could be counted and this seems to have been the turning point and third catalyst for carers in the 1980s, both in Britain and Australia. Counting them immediately gave carers a profile and political currency. As Stone says, "counting something creates a community".\(^{15}\) In this instance counting carers also created a constituency, later to be formed into active carer advocacy groups in both countries. Carers no longer had to rely on the consumer movement to represent their needs.

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\(^{12}\) This is despite the provision of a wide range of government funded respite care services.


Chapter 22: Informal Caregiving, Carer Health and Public Policy

With Carer Associations formalised through government funding they at last had a platform for their own voices and a direct link to the government policy-makers. This was the fourth and most important catalyst in their transformation up to the year 2000.

By the mid 1990s carers were firmly on the Commonwealth Government agenda and active participants in the development of carer strategies as well as aged care policy, dementia support, disability services, palliative care, and mental health care. Most recently, 1999/2000, carers have contributed to improved integration of the Enhanced Primary Care Initiative.

This represents the dramatic shift of previously hidden domestic issues of family carers into the public arena where carer troubles could be addressed by publically funded services. Within two decades carers have become a political force in their own right. I now believe we are entering another phase where informal caregiving is re-conceptualised in terms of its impact on carer health both the individual and at the population level, thus transforming caring into a public health issue.

Complicating this is the reluctance of many carers to use respite and other support services even though they have been provided and offered. Unfortunately community care, as it has evolved as a policy framework, is inadequate for dealing with carer health issues because of its lack of attention to their clinical needs. For that reason I now take a theoretical look at the structure of community care policy.

The Concept of Community Care - A theoretical view

The concept of "community care" is complex and problematic from a policy perspective in terms of its ideological framework and application to carers. Community care in its

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16 In a review of respite services - to examine the models of respite care provided under the HACC and Commonwealth Respite for Carers (CRC) Programs, (1996:43), it was reported on carer health, that over one third of the carers said that their own health made it difficult to look after the person they were caring for. They rated their present health as 'fair to bad'. There was evidence to support the finding that carers health was worse than others of the same age in the community. They cited studies where carers reported higher rates of ill health and use of medication, more anxious, had depressive feelings and lower levels of life satisfaction than a comparison group (Herman, H et al, 1993).

In the same report (1996:54), it stated that a significantly higher proportion of these people [carers] said that they needed additional other (non-respite) services and they were less satisfied in general with respite services. These reasons did not appear to be related to either their health status nor the dependence of the people for whom they cared.

In the literature review included in the report (1996:Appendix 1, p 7) the authors gave earlier references to carers’ reluctance to use respite services. The implications for this review although not clearly stated, are that many carers remain reluctant to utilise these services which they find either in appropriate, inadequate, or their loved ones returned home in a worse state [ie disoriented], (1996: Appendix 2 page 4]. Nearly 14% of users reported they were not satisfied with respite services. (1996:66, Table 4.4.2).

broadest sense is multi-dimensional, incorporating health and social policies under a wider economic umbrella. Gardner (1992) presents a useful but rather simplistic model which places Australian health, social and housing policies around a core of community care, with these three major policies all enveloped by economic policy.

According to other commentators Palmer and Short some scholars deny the existence of health policy as a separate, legitimate field of study. Health policy is seen by them "simply as a small part of social policy". (That is not the case in Australia where social and health policies, although referred to under 'welfare', are kept so separate, that they are euphemistically referred to by bureaucrats as 'silos').

![Figure](image)

Figure
Australian Model of Relationship of Community Care to Social, Health, Housing and Economic policies

Outlining social and health policy from a British perspective, Gough et al located "health within the domain of social policy". These authors remind us that the central concern of social policy is "welfare" or "the general good" and this leads to attempts to define social need and consider the most appropriate ways of meeting people's health, personal social service and social security needs. To provide "good community care" for the informal home-based caregiver, relevant policy should be inclusive of all these elements: ie social policy, health policy, private and voluntary sectors - and housing where necessary.  

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19 For example to build or modify all houses so that they are suitable for home based care of the sick, aged and disabled.
Within the multi-dimensional and multi-disciplinary composition of community care I suggest that there is potential for considerable overlap between all the policy areas and a legitimate case for formal integration of, and links with General Practice, as the provider of community based medical care. A model that included GPs could look like the modified version below.

GPs already provide ongoing health support to families, are an important link between medical, health and community/social services and are the strongest link for patients and carers between the acute care and chronic health care sectors. GPs are closest to those individuals whose health is vulnerable and might be put 'at risk' by their caring role. As well as providing clinical health care, GPs also have an important preventive role in helping carers maintain good health. For GPs to function effectively in the interests of both carers, and those being cared for, they need to be included in the full range of carer, social, community care and other public policies, at both the planning and implementation stages. Again integration has been poorly facilitated in Australia. I will discuss this later in the chapter but first I shall explore community care and carer policies in an ethical context.

**Health, opportunity and justice for carers as an ethical context for policy development**

*Carer policy within an ethical framework*

With the introduction of Community Care, "the home" as a site of supported care of people with a disability, medical or aged related frailty has become the focal point at which there is a crossing of boundaries between private and public. But the home is not only the
boundary where there is a blurring of these sectors. The private household has now become, "...the preferred site for the exercise of public responsibility for many of the most vulnerable and dependent of citizens". It has also become the ideological battleground for social change towards normalisation, driven by social policy.

Two Australian writers, Shaver and Fine, claimed in the mid 1990s that "Informal caregiving in the home and community has now been recognised as a fundamental part of the system of social policy". Not surprisingly, the domain of "home based care" has provided the stage for informal caregivers as 'citizens', to exert their civic rights to claim entitlement, rather than having to rely on charity to support them in their caring role. This has occurred through the establishment of carer associations which provide the stage for carers to voice their needs.

Doyle, a British commentator discussing the implementation of Community Care policies in the UK, argues that "where the government encourages duties of citizenship and moral duties to others" (as with informal and family caregivers), "a minimum welfare state is contradictory to helping potential 'good citizens' (ie carers) to do what is expected of them". Carers are in effect helping reduce some of the government's financial health and social care burden, by taking on much of the personal burden themselves and accepting extra care responsibilities. Carers themselves however are also a vulnerable group by virtue of the impact that caring role may have on their health and well being. Mendus suggests that due to carers honouring their moral obligations (often of a 'given' rather than their 'chosen' role), they are constrained in their ability to lead an independent life. Thus the carers may become "the victims of their circumstances" rather than "the creators of their lives".

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21 ibid Shaver and Fine, 1996.


23 ibid Mendus (1993), Doyal (1991)
Doyal\textsuperscript{24} suggests that the aim of 'good community care' should be to provide specific types of goods and services as is necessary, "to achieve optimal levels of health and autonomy." To this end he has proposed a "Theory of Human Needs" which applies equally, if not more so, to carer policies. Doyal identifies health and autonomy as the most basic human needs which should be satisfied with goods and services, (like health or medical care and social services), if they as individuals (ie the carers) are to achieve optimal "social participation" in their life.\textsuperscript{25} There are some interesting parallels between Doyal and Maslow's Theory of Human Needs, featured earlier.

For the purpose of expanding the ethical context of this policy, I have extended Doyal's theoretical pathway by introducing a second ethical theory - the Theory of Health Care Needs, this time proposed by Daniel's.\textsuperscript{26} His notions include opportunity, a plan of life and distributive justice, and in contrast to Doyal's theory of human need, offer another dimension again to carer support. The impetus for Daniel's work (coming from a liberal individualist persuasion) is very different to that of Doyal who maintains a socialist view of civil life. Nevertheless, combining elements from both of their theories of need has helped me create a more comprehensive model for illustrating my own ideas that of a "cascade effect" of the caring role on carers' health and lives. (Refer Diagram opposite of Model of Carer Health Needs, Opportunity and Justice).

\textit{From An Ethic of Care to An Ethic of Justice in Carer Policies}

Like Mendus, Daniels moves from an ethic of care to an ethic of justice. Daniels' theory emphasises the moral importance of health care needs being met by noting their affects on opportunity. He postulates that health care is special and should be treated differently from other social goods. Which health care needs are more special than others are considered in terms of their improving the person's quality of life, their ability to restore or compensate for diminished function and capacity to follow one's life plans.\textsuperscript{27}

Doyal's and Daniel's separate ethical theories of need, with their focus on health and autonomy, are consistent with the theme of this thesis. From my own research, I find that


\textsuperscript{25} ibid


\textsuperscript{27} ibid
Carer Health, Opportunity & Justice

Intensive and prolonged caring can increase personal health & welfare needs of vulnerable carers

Informal Caring Role

Lack of integrated public policy without GP input to monitor and protect carer health

→ deterioration of carer's health

→ health status

→ functioning

reduced physical, emotional, social functioning, vitality and social participation

→ quality of life

→ autonomy & choice of life plans

→ lack of OPPORTUNITY for carer

Caring role is a potential discriminatory impediment to carer health, choice of life plans and opportunity

A public health issue + A public justice issue

Model of Carer Health Needs, Opportunity & Justice
© A. Stacey 1997

[Created out of N. Daniel's Theory of Health Care Needs, Gough's Theory of Human Needs and Doyal]
the unsupported caring role may be a potential discriminatory impediment to a carer's health, functioning, quality of life - and autonomy. These factors combined, act as an impediment to the carer's choice of life plans and opportunity in life. "The duties associated with that role (eg the caring role of informal caregivers) constrain their ability to lead the life of an independent free chooser." Mendus warns that when translating domestic needs of carers into public policy, it is especially important to be aware of the significant issue of choice for the carer. This is not only a problem for the individual carer. If sufficient numbers of carers are similarly 'encouraged' to assume that role and are affected with poor health and restricted in achieving life goals, it constitutes both a public health issue and a public justice issue.

One can therefore argue that the moral imperatives for carer policy are to facilitate levels of carer health and autonomy that allow the carer to have the quality of life which provides them opportunities to pursue their chosen life plans. To achieve and maintain an optimum level of health, carers need public policies that are inclusive of General Practice to provide well integrated primary medical (clinical) care on a long term basis.

In the next part of the chapter I return to some more examples on what has been happening with carers in Australia at the national level and how well public policy caters for carer health.

**HOW WELL DOES PUBLIC POLICY ADDRESS CARERS' HEALTH IN AUSTRALIA?**

*Indirect support for carer health*

The first question for Section III is "How well does Australian public (government) policy address carers' health? As I stated earlier in this chapter, my initial response is that carers' health is only supported indirectly by carer and public policy in the form of respite care services. Over recent years a concerted effort has been made by successive Commonwealth governments to provide the type of respite services that can relieve carers of some of their

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29 The expectation at government level was that all individuals were able and willing to take on the caring responsibilities. This became the prevailing assumption on which carer and community care (HACC) policies were based throughout the 1980s and early 1990s.
Chapter 22: Informal Caregiving, Carer Health and Public Policy

caring burden. The government also sponsored multi-disciplinary and intersectoral work on a National Agenda for Carers culminating in the National Action Plan for Carers.\(^{30}\)

Respite services and other initiatives for carers have been developed through a coalition of government funded social health and welfare services dating from the late 1980s through the 1990s to the present day, 2002.\(^{31}\) As described in Perring's paper, the federal and state governments together, established and funded home based respite and community care services that supported carers with in-home and residential respite care programs. To this end the Australian approach to carer support has been consistently holistic and strongly bipartisan across all political persuasions for well over a decade. This has been facilitated through a Carer Support Branch, located within the Commonwealth Department of Health and Aged Care. Indeed it was the work of motivated staff from that Carer Support Branch especially around the mid 1990s which facilitated the introduction of an impressive range of carer initiatives including the Carer Resource and Respite Centres as part of the National Respite Program for Carers in 1996.

There have been many other carer support strategies aligned to services for aged care, mental health, dementia and disability care. In addition there have been information packages for carers plus regional and rural carer support groups and services. In comparison to other developed countries, including the United Kingdom, Commonwealth nations or USA, informal carers in Australia probably have access to the most comprehensive social support anywhere in the world for which we can be justly proud.

**Poor direct support for carer health**

Even with this very impressive array of home care services and carer support programs for carers, I argue that Australian public policy does not directly address carer health. Strategies aimed at enhancing individual carer health have either not been included or have been ineffectually incorporated into other health initiatives of the government. Carer programs have not yet been refined, or clinically oriented to protect and enhance the health of carers because a clinical (medical) component is missing in nearly all of the 'policies'.

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\(^{30}\) Details of the National Agenda for Carers and National Action Plan for Carers are described in Perring's article [See Appendix 16.]

\(^{31}\) See box page 302 for summary list of the main carer support initiatives 1985-2002.

\(^{32}\) My research suggests that for many carers, their restricted lifestyle prevents them from achieving or maintaining normal health status. These lifestyle restrictions on informal caregivers may make health promotion or preventive health strategies, unsustainable or unsuitable for carers.
and programs created for carers to date. My observation is that carer 'policy' in all its various forms, does not provide specific strategies and guidelines for comprehensive health care for adult carers because carer policy in Australia, as in the UK, was developed and administered separately to health policy.

Despite the fact that Australian carer policy is administered under the umbrella of a succession of Federal Health Departments, very little was done to integrate carer initiatives and community care with primary care (primary medicine) up until the late 1990s. I have been unable to find any formal strategies or protocols in carer or community care 'policies' for the monitoring, maintenance or active management of carers' health at the clinical level throughout the caring episode or their caring 'career'. If and when medical intervention is required to assist the carer, there are no adequate guidelines for practitioners for protecting both parties of the caring relationship - the cared for person as well as the carer. There is inadequate research carried out to date, to know what are the preferred interventions for carers anyway.

There are two other aspects of being a carer that are poorly acknowledged in policy. Firstly, many carers have multiple responsibilities for more than one sick or disabled family member, caring simultaneously, sometimes living with them, other times commuting daily to the other person's home. Secondly for some carers it may be their second time around in the caring role, or even third 'tour of duty'. With each caring episode the carer is progressively older and more prone to health complications of their own. An annual health assessment is particularly important for at risk, ill, ageing or vulnerable individuals who are also carers. The points raised above are just some of the pressing issues associated with providing adequate health support to carers. They invite the next questions which are about who, (of the health professionals in regular contact with carers), might be responsible for conducting such clinical assessments, how the carer should best be followed up and how these services are to be remunerated.

This thesis is based on my argument that the general practitioner is well placed to take on the role of monitoring the health and social needs of carers and initiating clinical assessments. Currently for such an assessment to be carried out, the carer would need to become a patient in his or her own right. That is not unreasonable and it at least formalises

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33 An exception to this is the Enhanced Primary Care Initiatives.

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the action and provides remuneration for the consultation. Here the main issues are not monetary but rather the moral imperative of ensuring *medical responsibility* for the health of carers in the context of the carer's caring relationships, role and commitments. So why have medical and clinical strategies relating to carer health been absent from policies over past decades while the social and respite components of carer support been so well managed? I see to possible influences.

*Lack of strong medical interest and research on carer health issues*

Carer support has consistently lacked a clinical approach that incorporated a medical model of care for the carer. This could be because, until the mid to late 1990s, there was a lack of strong medical evidence that the informal caring role could be a direct 'risk' to the health of carers. Secondly models for the clinical management of carers with health problems (or counselling strategies for carers) do not exist in the formal health care system. Early carer support initiatives of the 1980s were based on service delivery programs developed around a social model of care, mostly through the HACC Program. And therein lies the dilemma. Carer policy has traditionally been constructed within the boundaries of social welfare and social health policy frameworks. Once the cycle of policy making was put into motion it was almost impossible to move policies beyond those frameworks. As Howe and Scofield commented, "the process of defining carers and caregiving in social policy has been a long and incremental process". The problem is, it has stayed locked into that same process.

Increased rhetoric in policy documents on the impact of caring on carer health and well being (ie stress, depression, injuries and burnout), did not detract from the assumption that carers could seek medical attention and help for their own health and become a patient in their own right. This certainly happens, but all too often, only at times of crisis when the effects of a carer's exhaustion or their own illness is already well advanced and untreated. (It is probably due to the competent care by observant family GPs and other health care professionals, that the health problems of carers are as well managed as they are). Nevertheless, this remains a hit and miss approach as it is at the discretion of each GP - and of course the carers themselves. To date there are no carer standardised guidelines or protocols available for the assessment and monitoring of carers' clinical health status by

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34 ibid Howe and Scofield (1996:13)
health professionals like general practitioners - beyond what is already practiced throughout our present universal health care system.

My concern is that the important role for general practice is not yet incorporated into carer programs and more significantly we do not have specific carer policies that are inclusive of GPs. Formally funded health strategies for carers and well integrated carer health policies are needed to encourage health professionals to observe and offer carers specifically designed clinical support and preventive health programs to circumvent deterioration of their health. So our first task is to review and modify those programs with the cooperation of representatives from General Practice. The second task is to place carers firmly within the framework of illness management, not only as *partners* in care, but also as *patients* in their own right who despite their caring role at home, also have to contend with chronic and disabling conditions of their own.

**The Relationship between Government and Carer Associations**

*Carer driven policy*

In discussing the process of policy development it cannot be assumed that the strategies and programs have been all government driven. Far from it. The government has increasingly drawn on advice from social researchers working with carers or from carers themselves, to guide decision-making on the preferred ways of supporting carers. As occurred with aged care policy under the influence of vocal and politically significant pensioner organisations, governments have become more consumer oriented and sensitive to older people's wishes to 'stay at home'. This of course suited the prevailing cost cutting approach of the governments of the day. One can see a similar process occurring in the 1990s with politically active carer and disability advocacy groups working in collaboration with government departments. The relationship that has grown between carer associations and government is an interesting and important one.

What made this partnership successful was the government's proactive role in supporting the carer associations, both state based associations and a national body. The aim was for these groups to stay in touch with carer members at grass roots level to facilitate carers becoming actively involved in the policy-making process. Although Australian carer associations are incorporated bodies with their own administration and governance, they are funded by the Commonwealth under the umbrella of the federal/state Home and
Chapter 22: Informal Caregiving, Carer Health and Public Policy

Community Care Program. During the 1990s I personally witnessed the transition of these independently run organisations as they expanded and became increasingly professionalised in their own right. Many are staffed by highly trained individuals with public sector experience who can negotiate their way through bureaucracy with ease.

It is my observation that due to the unique funding structure of carer associations in Australia however, these bodies now function, by default, as arms of both state and federal governments. This is not a criticism, but rather shows the prevailing philosophies of governments have filtered through these associations. The bonus for carers is that the associations, especially through the national body now located in Canberra, has direct links to Commonwealth Government ministers within portfolios of Aged and Community Care, Disability and Social Welfare - but to a much lesser extent with Health ministers. There are similar linkages between government and carer associations at state levels.

The needs based approach to policy making for carers by government has meant that much of the impetus for policy change has come from carers themselves through ongoing consultation processes in each state. It is interesting when one looks at the range of initiatives provided for carer support over the past ten years (1992-2002). There seems to be a parallel between how carer programs have emerged and been put into practice, and the way carers themselves prioritise their caregiving needs on an everyday basis. And therein lies the paradox. During consultations, carers in the 1990s have commented on how tired and weary they are and how they feel their health has been affected by their caring role. But their overwhelming preference has been for practical help in the home and relief from their nursing and supervisory duties. They have also wanted information on what services are available and financial benefits are open to them. Both Australian and British carer consultations have revealed very similar responses from carers in terms of what they ask for. Acting on this advice, channelled through the carer associations, Australian government has concentrated its policy efforts on respite, support and information for carers as requested by the carers.

_Carers put their own health last - is that reflected in policy too?_

What I find is most significant about this consultation and policy making process over the past decade, is that despite their obvious health problems, carers tend to give their own health needs a much lower priority than the care needs associated with the persons they are looking after at home. Many carers admit putting their own health last, ignoring it, even
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hiding personal health conditions from others, including their doctors. It appears they will protect that caring relationship at any cost - including their health. My empirical data from carers and GPs provides additional evidence of that occurring.

This self sacrificing behaviour has been reported not only in Australian research but also in British surveys conducted by the Carers National Association in the United Kingdom and other carer consultations through Kings Fund Centre projects for carer support\(^ {35} \). It was also highlighted in earlier research by Spackman\(^ {36} \) and could be a possible explanation for the lack of a clinical focus in carer support strategies. As much of the carer policy during the nineties has been carer driven, the emphasis has been firmly on the practical aspects of home help for carers, not on clinical aspects of carer health. Until two landmark carer surveys on health and well being by the British National Carers Association\(^ {37} \) and the Carers Association of Australia\(^ {38} \), all previous research that was driving carer policy in both countries was service oriented. Hence the good progress with carer support and respite services to date.

My other observation is that whereas carers know what they need to help them in their caring role, and are quite definite about issues like respite, education and home care/help, they do not seem to show the same clarity about what would help their own physical and emotional health needs beyond time out for themselves and the chance to regain and live their own lives. This is hampered by a lack of research exploring their clinical health needs within medical disciplines.

After ten years of lobbying governments for practical and financial support for carers, carer associations are now putting carer health issues on their own agendas for public action. The focus is turning more towards the health status of carers as an identifiable group at risk in the wider population. A parallel agenda item is for carer groups to work more closely with General Practice to develop improved ways of enhancing carer health through consultative processes. This could involve GPs and carers in the development of

\(^ {35} \) Naish, J. and Benaim, R. 1995, *Putting Carers onto the Agenda in General Practice*. Academic Department of General Practice and Primary Care, Medical Colleges of Bartholomew's and the London Hospitals of Queen Mary and Westfield College.

\(^ {36} \) Spackman, A. 1991, *The Health of Informal Carers, IHPS*, [Institute for Health Policy Studies], University of Southampton, UK.

\(^ {37} \) National Carers Association (1998)

\(^ {38} \) Carers Association of Australia (1999)
carer health policies, and more innovative and targeted practice methods to support carers' clinical health. Hence my interest is locating GPs within carer policy.

**LINKING CARERS AND GPS IN POLICY**

For nearly ten years, I have searched government documents for programs that not only facilitate the integration of carer support and community care with General Practice, but include strategies that actively bring carers and GPs together both for the *benefit of the carer as well as the patient*. Building relationships between carers and GPs for the express purpose of *benefiting individual carer health*, has not been well done, either by government or NGO policy-makers in Australia.

Policy which facilitates carer-GP partnerships for *the benefit of the patient* is more complex and needs to be described pre-Enhanced Primary Care before 1999, and post-EPC following the 1999/2000 federal budget. At the time I was conducting my research in the early 1990s, the only formal carer related activities involved GPs filling in and signing carer applications for carer pensions or other benefits like the Domiciliary Nursing Care Benefit for carers. GPs could also refer on patients to the Aged Care Assessment Teams should they believe a frail aged person required residential support. Beyond that, very few other government or general practice initiatives during the mid nineties integrated GPs with carer program or visa versa. Two or three Divisions of General Practice (in NSW and Victoria) developed short term service oriented projects with carer groups with limited success.³⁹

³⁹ After many interstate telephone calls and reviewing GPEP and NIS reports I finally found that the NSW Carers Association worked with a number of Sydney based Divisions of General Practice on a project called 'The Carers' Checklist 'Do Doctors Care'. The aim was to encourage GPs to refer carers to the Carers Association. It had limited success. [I note it did not acknowledge GP efforts or identify GP needs.]

In Victoria in 1995, the Northern Division of General Practice [Melbourne] conducted a brief needs assessment study of carers; The Mornington Peninsula Division of General Practice [Victoria] had a project on Caring for Carers in 1994-95 to improve the health status of carers and raise awareness of support systems for patients and carers and increase GP knowledge of carer problems and resources. However the project was not successful or accepted by GPs. [It did not acknowledge GP efforts or identify GP needs.]

Even as at 2002, there are no current Carer - GP or Carer-Division projects that I can locate in Australia. In SA I am personally working with the state Carers Association of SA to build strong links with GP Divisions, the RACGP and academic departments of General Practice. My working group has produced a Position Paper on Carers and GPs (based on my own research) with the long term aim of developing awareness raising initiatives for GPs and offering support to GPs on how to better access carer support services.
Some of the Coordinated Care Trials in South Australia and the ACT, identified the role and need of carers in the longer term management of people chronic illness in the community. The inclusion of carers was not consistent across all the trials by any means, as carers were not identified in the Trial hypothesis or Trial aims of the 'First Round'. This is reflected in the evaluation report of that first Trial which dedicates a few throw away comments about the important role of carers in one paragraph.

How well are carers integrated into General Practice Policy?

Within the discipline of General Practice, informal and family carers are acknowledged in some policies and position statements. As a profession, General Practice has undergone dramatic restructuring since 1992 through the Divisions Program and has been scrutinised by comprehensive peer review (culminating in reports on General Practice written in 1996 and 2000). For example the 1996 Commonwealth review was at the time the most comprehensive commentary on the past decade of general practice. In the chapter on "Integrating General Practice with other Health Services" the authors recognised the important role of carers and their relationship with GPs. The necessity to meet carer needs and provide carer support within Shared Care for Mental Health, the Aged, in Dementia Care and Palliative Care were highlighted in that review document.

In the section on Shared Care for the Aged in the 1996 report, it is acknowledged that:

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40 In SA the Care 21 trial the north of Adelaide, indicated they were carer aware in their report.
41 Refers to the Coordinated Care Trial evaluation report published 2000 [see below].
42 Carers were not part of the original aims or hypothesis for the first round of the Coordinated Care Trials. Some state projects included carers in the Trials, others did not so the evaluation of the Trials did not focus on carers. Only a few paragraphs were included in the evaluation report as a passing remark to the carers' role. [page 33], eg

"Within the context of the health and community services system, the role played by carers is a critical one. Being a carer can entail an enormous degree of physical, emotional and financial stress for the person who daily organises and provides care for the client. Coordinated care can provide direct assistance to carers to support them in their role. However, services that develop strategies aimed at preventing institutionalisation of clients need to consider the potential impact this may have on carers and provide the appropriate supports necessary to ensure that its consequences do not have a negative impact on carers." Commonwealth of Australia, 1996, General Practice in Australia: 1996" Commonwealth Department of Health and Family Services. What is of greater concern to me now is that the opportunity was not only missed in the first round of Trials but to my knowledge, when I last checked in February 2002, carers were still not adequately included in the second round of Trials currently being planned. This suggests a serious lack of integration between governments and programs.

43 Ibid
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"General Practice can provide optimal care by being more systematic in planning individuals' care by networking with other services and by providing support for carers. They also have important roles in coordinating multi-disciplinary services dealing with broader aspects of health care for the elderly".

There was the confirmation at the time that carers often feel GPs fail to recognise their stress, particularly in the area of dementia care.

From these earlier documents it is clear that general practice is placed in a supportive role to carers. In the early and mid 1990s there is some frustration evident that GPs perceived their own role to be unrecognised within major public policies like the HACC Program and were seeking a more formalised integration with other health service providers. This was already occurring through the development of joint protocols and guidelines, as part of shared care programs and Divisions of General Practice.

*From Rhetoric to Policy and Practice*

Viewing General Practice historically, GPs, as 'the family doctor', have had a long association with home based care and they remain one of the few medical professions funded through the Australian government's universal health care system to provide house calls to support acutely and chronically ill patients and their families. GP educators and policy makers working in the area of general practice have in recent years made efforts to include carers in their own College Training Curriculums and Position Statements. In doing so the College shows it has started to extend beyond its traditional boundaries of a primary medical care role, to embrace the wider primary health care paradigm of "social health".

*Royal Australian College of General Practitioners Policy*

During the 1990s the RACGP has prepared a number of policy documents as Position Statements in relation to carers, on programs like Home and Community Care. For example in the RACGP draft policy on "Carer Support in the HACC Program" (March 1994) the following statements were included for submission to the Community Care Branch of the Commonwealth Department of Human Services and Health:

"The College welcomed the formal acknowledgement of the importance of carers in the HACC Program....

"Their role will increasingly be important given the ageing of the population and in the increase in chronic illness as well as the trend to earlier discharge from hospital. Caring for a disabled or chronically ill person is often performed at considerable cost to the carer".

44 ibid
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It was also stated by the RACGP Position Statement that:

"General Practitioners have an important role to play in the care of people with chronic illness or disabilities in the community and are able to provide considerable support and assistance to carers."

Most significantly the College commented...

"It would be useful for acknowledgement of this role (of the GP) to be included in the Policy Statement as well as specific steps that would encourage the involvement of both GPs and carers in the drawing up of care plans."

This was suggested as a means of assisting "carers to receive greater recognition for their work" and that "it would be helpful for there to be protocols that specify the nature of their involvement." Other draft Position Statements in which the College has included specific references to carers related to the role of GPs in the provision of health care for Older Persons (October 1996), Women (May 1997), and for the delivery of Mental Health services (March 1997). In relation to the role of GPs in the provision of health care for Older Persons, the RACGP Position Statement highlighted the importance of support for carers and families. However carer issues were not included in the background section or objectives, nor was there any carer support strategy for older people proposed in the Statement. This is surprising in view of the fact that in the RACGP Training Curriculum under 'Aged Care', trainee GP Registrars are expected to be able to use strategies to promote discussion with older people and their carers.

The College policy position statement on women clearly recognised that, "women play a key role in managing the health of their family as parents and carers", and "the RACGP recommends that integral to the GP role are skills in communication with women patients and where appropriate, with their partners, relatives and other carers". As with the Older Persons policy, it would have considerably strengthened the policy if preventive strategies had been incorporated, and for GPs to act as advocates for women and older persons as carers. Surprisingly no mention was made at all about carers in the College Position Statements on HIV, Training, Prevention and Health Promotion in General Practice or Coordinated Care, the latter and chronic care issues having been recognised in the College's HACC Submission cited above. In the objectives of the Mental Health, and in the Training Program there were only references about GPs working with "families".

After a brief check of current College Policies on the RACGP website recently (Feb 2002) there appears to be little or no change regarding references to carers since my review in 1998.

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More recently, after 2000, with the introduction of Enhanced Primary Care Initiatives, which for the first time incorporated General Practitioners into community oriented government policy, there have been efforts to also link carers with GPs. But again this has been for the benefit of the patient rather than for the health and well being of the carer. Government documents during the 1990s included much rhetoric about the impact of caring on carers health and lives, but there was no funded programs for achieving GP integration with community care.

The Enhanced Primary Care Initiatives may be seen as the next catalyst for some incremental changes to better integrate general practice with primary and community care. For their part the RACGP has contributed excellent guidelines for GPs on Enhanced Primary Care and in the document recognised not only the role of carers but also the need to support their health needs. I have prepared edited excepts from those guidelines which highlight carers' vulnerability to health problems and the role of the GP to assess the health and social functioning of carers. (See box at end of this chapter) This is a most important step for the future enhancement of carer health in general practice. For example one of the most significant quotes is:

**Carer Responsibilities [Page 37]**

"The patient should be asked whether they are responsible for caring for another person and the effect that this has on their health and social functioning should be explored during the health assessment.

Although there is still room for improvement for the guidelines, I consider these quotes from the RACGP EPC Guidelines important templates for refining other general practice documents [on policy, practice and education], as well as updating all government and health professional documents where appropriate.

Introduction of Enhanced Primary Care means GPs as from 2002, can be remunerated for time given to care planning, discharge planning and case conferencing for patient care, in which carers are formally included. Despite these EPC initiatives, there is still no provision for payment of GPs time if they see carers on a one-to-one basis to discuss the carer's role and needs in caring for that same patient. Current EPC policy therefore retains some strategic restrictions to adequately addressing carer's general caring role needs within general practice. As a consequence the GPs needs are not met either.

Royal Australian College of General Practitioners, [2000] Enhanced Primary Care: RACGP Standards and Guidelines for the Enhanced Primary Care Medicare Benefits Schedule Items [Health Assessments, Care Planning, Case Conferencing].
Conclusion

In this chapter I that argue social policy has great strengths in providing carers with the impressive and comprehensive services and support we see today, but the weaknesses of developing carer policy within the constraints of social policy have a downside for some crucial aspects of carer health. In particular it makes incorporation of a clinical / medical model for carer support very difficult to integrate and fund.

Where the impetus for changing carer policy to better reflect carer health and medical needs will come from is uncertain. It will probably have to come from the carer associations, but this time in cooperation with GPs and other medical advisors who can contribute their clinical views. There is also a role for nursing input as well. More importantly there is a moral imperative on the part of governments to integrate carer health and medical needs with health policies more generally and with general practice in particular. My suggestion as a starting point is the drafting of carer health policy that can serve as a template for developing health care strategies at clinical and population levels building on the established social health approach of the 1990s.
"Social support and use of health and community services" [Page 17]

"Being a carer for another person can significantly affect physical and psychological health and substantially reduce opportunities to maintain social networks [Dept of Health and Aged Care 1999]. It is therefore, particularly important to ask the patient whether they are a carer and to evaluate the effect of this role on health and functioning."

"Equally where the patient is reliant on a family carer for day to day functioning, the health of the carer and the effect of the caring role on the carer's health status should also be considered. Strategies to improve patient independence can be of major benefit to both the patient and the carer."

Special health needs of older patients [Page 19]

"When assessing the support profile of the patient, it is equally important to identify the status of the carer [and/or caring network] in terms of the carer's ability to continue in that role."

Carer Profile [Page 20]

"One area of health care that is sometimes overlooked is the importance of the carer's role in supporting and assisting the patient. The maintenance of patient independence in the home may depend to a sig. degree on the presence or absence of a carer and the support the carer is able to give. The age and health status of the carer is pertinent to the health of the patient and therefore must also be considered when devising a management plan.

Understanding the ROLE of the carer and arranging for appropriate support services can improve quality of life and health outcomes for both carer and patient."

"Many older carers have age related health problems that affect their ability to adequately provide care. A number of carers are children and young people who look after parents or siblings [p. 21].

Health of carers [Page 20]

"The ROLE of caring can affect the health and wellbeing of carers. In 1999 the carers association of Aust undertook a questionnaire survey of carers, including aspects of self reported health and wellbeing. The survey looked at carer perceptions of the effect of being a carer on their physical and mental and emotional well being. Of the 1449 surveyed, 474 [33%] indicated that they had suffered at least one injury "...[see p. 21]

"Carers particularly older carers may themselves ave a medical condition which may be affected by their caring role"

Carer responsibilities [Page 37].

"Many patients are themselves carers for other(s). The physical and psychological health of the carer can be affected by the demands of care-giving" "The patient should be asked whether they are responsible for caring for another person and the effect that this has on their health and social functioning should be explored during the health assessment."
CHAPTER 23
IS INFORMAL CAREGIVING AN CARER HEALTH
A PUBLIC HEALTH ISSUE?

The bulk of what I have presented in this thesis can be brought to a meaningful conclusion under the banner of public health. Within this thesis I have featured two elements of public health, population studies and public policy as each relates to carer health. The discipline of public health of course offers a wide range of 'modalities' depending on one's ideological persuasion and social justice philosophy. They range from epidemiology, population health, preventive medicine, the social and behavioural sciences, to health promotion, intersectoral collaboration and community development. Under the rubric of public health one can therefore merge the science and politics of "preventing disease and promoting health of populations through organised community effort". This includes both clinical and social benefits to individuals and communities, mostly through preventive health services. In other words, public health strategies have the capacity to incorporate the public with the private domains and the individual with the collective. This is the breadth required if one is to adequately address carer issues in the future.

In the context of this chapter, the importance of public health relates to prevention and intervention of disease and illness in carers with the potential to limit their disabling potential if established. Starting with broader notion of public health as 'human welfare', I propose it is reasonable to discuss carer welfare in terms of utilizing public health knowledge and skills to identify carers, relieve their distress and enhance their health and life through ongoing monitoring and maintenance programs.

To develop a comprehensive model of care for carer health and well-being, I am suggesting that a shift in emphasis is required from community care to a public health

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2 For an issue to be considered of public health importance requiring sustained effort by formal political, public and health institutions within society, the traditional threats of infectious disease to whole populations or the occurrence of diseases across populations have taken second place to post modern problems. In most recent decades public health has aimed to limit the amount of chronic disease, illness and disability in the community. Focus on late twentieth century causes of disease, disability and illness include occupational and environmental hazards as well as a greater emphasis on behavioural / lifestyle or age related problems. [Notes adapted from 1998 course book: Public Health Ethics. Intensive course conducted by N. Hicks.]
3 ibid
Is Informal Caregiving And Carer Health A Public Health Issue?

paradigm. I am not suggesting a paradigm change away from community and primary health care, but the linking of the full range public health investigative and intervention skills to address the phenomenon of informal caregiving. A change in emphasis would enable interested parties to discuss the caring role in ways not usually considered within community care parameters.

Firstly, informal caregiving is associated with increased carer morbidity as described in detail in chapter 3. Personal restrictions and losses, chronic stress and emotional distress as well as heavy physical demands are associated with intense and protracted informal caregiving. There is now strong evidence that informal caregiving per se can be a risk factor for depressive symptoms in carers that in turn can lead to them developing ischaemic heart disease or even cancer. Lack of sleep and rest when carers are ill may leave carers vulnerable to certain stress related conditions and physical injury - and in extreme circumstances may put the cared for person at risk. Most recently research is suggesting caregiving as a risk factor in informal caregiver mortality. These challenges, combined with biological vulnerabilities of certain individuals who take on that role, can compromise neuro-endocrine, other physiological and psychological functioning of carers. Therefore it can be argued that direct medical based intervention is going to be necessary just to maintain the health and well being of many carers - especially at times of crisis.

Under a public health paradigm one considers, in addition, those health problems, such as emotional stress, anxiety, and depression, as well as physical injuries and disability suffered by carers, that may be avoidable (primary prevention). In addition, ill health, disability and other conditions that are not preventable in carers, can at least be monitored and managed so as to improve the quality of life of the carer (secondary prevention). An epidemiological insight providing another ‘eye’ on areas for prevention for carer health is the second benefit of a public health approach.

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4 Such a paradigm shift has been the subject of discussion for the past year or so in the latter part of my thesis preparation, at the state based Carers' Association. Its committees and working groups on policy and general practice, endeavour to share my research findings and put them to some practical use. This chapter includes elements of a discussion paper carer health based on public health principles that I developed with staff of the Carers Association of SA.


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In terms of prevention, I suggest there are two different aspects of public responsibility to consider - the social responsibility for overall carer welfare (through social welfare policies) and secondly through extended medical responsibility for carers' clinical health. As I described in the last chapter, a combining these two approaches create a carer health policy as part of a public health model that features maintenance / prevention strategies for carer health and well-being. Thus there are real benefits of a public health exercise in identifying and monitoring the health status of cohorts of informal carers. I am proposing we also consider the application of 'social epidemiology' to informal caregiving. This population approach takes more of an interest in the social determinants of health - and ill health and therefore it needs to focus on the social context of health related attitudes and lifestyles of carers.  

Informal Caregiving is not yet a mainstream Public Health Issue

Since social conditions such as caregiving can influence a person's susceptibility to disease, a proportion of carers may be at increased risk of psycho-social health and clinical problems. It is therefore important for carers to be identified as a group more at risk of general health and psycho-social problems than non carers. There is little doubt that carers are suffering distress due to their caregiving responsibilities and caring 'work'. Thus their welfare has been a matter of public concern, prompting governments to initiate increasingly costly social health and welfare support strategies over the past decade. But, thus far, informal caregiving has not been considered a public health issue' requiring specific or targeted public health programs in the same way as efforts are directed at disease control, drug, alcohol or occupational problems. Epidemiological monitoring of carers as a special group with special problems is not happening yet, and one wonders why. After all carers are suffering physical injury, stress and other conditions related to, or worsened by, their...
caring "work". Is it because as unpaid care workers they are excluded from routine epidemiological, population and demographic surveys? It seems if one is not paid, one does not exist within an 'occupational' framework. However a few lone voices representing carer associations in the United Kingdom and Australia have in recent years mooted the idea of recognising carers as 'workers' at risk and putting them on the public health agenda.

In her 1998 report for the Carers National Association, Melanie Henwood drew the following conclusion.

"While accepting that the relationship between caring and ill health may not be a simple causal one, the findings reported in this survey show there is significant physical and mental ill health among carers. Lack of attention to such needs at an early stage exposes carers to the risk of becoming increasingly unwell, and ultimately unable to continue their caring responsibility. The public health agenda must recognise that carers are a group potentially at risk."

When presenting her paper on this same report at the second international conference on caring in 2000, in Brisbane, Henwood emphasised that the "two health problems suffered by carers (physical injury and mental stress), were both acknowledged as 'preventable'." She added:

"Carers who experience stress and strain are at particular risk ... but as the evidence from the American caregiver health effects study... indicates, it (caring) can increase the risk of mortality." These negative health effects are avoidable. As such there needs to be recognition of caring as a major public health issue; carers are a population potentially at risk."

Similar findings on carer injury and poor health were revealed the following year in the Australian Carers Association survey of carers in 1999. My own research findings, the ABS surveys of Disability ageing and carers, the VicHealth longitudinal study of Schofield et al, plus the American caregiver health effects study, (all referred to in earlier chapters),
describe distressed and vulnerable carers at risk of declining health and loss of life opportunities due to restrictive lifestyles and preventable health complications associated with the caring role. I believe all these factors combine to more than qualify informal caregiving as a public health issue.

**Confusion in public health camps**

Public health as an institution however has been weakened by the emergence of at least two opposing academic factions belonging to disciplines driven by quite different ideological motivations during the closing decades of the twentieth century. Whether the arguments come from the traditional epidemiological, biomedical and behavioural based sciences or follow from a social health perspective, in my opinion there can only be one conclusion. There is merit in each paradigm and I unashamedly sit on the fence between the two. As a researcher on the topic of informal caregiving, and especially as a carer myself, I can see that we need the best of what both camps can offer. Only together can these public health approaches provide a complete 'picture' and a comprehensive strategy for enhancing carer health. One provides the hard data about the health status of carers so as to outline the map of informal caregiving (showing "what" and "who" is significant). For this we draw on epidemiology, demographics, biostatistics and population trends associated with caregiving mostly by family members. The other approach, using social health strategies and models of investigation, provides finer details about the territory within that map of informal caregiving - explaining "the why" of carer distress and "the how" of carer health decline. So if any good is to be forthcoming for carers in the twenty first century, either across communities or as individuals the two camps must work together. Daly et al puts this argument most eloquently.

"Social science research provides its own contribution to public health but in addition a *rapprochement* between epidemiology and the social sciences could lead to research strategies in which each discipline brings its special skills to bear on the same health problem."  

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13 For an well balanced and brief account of these public health movements in collision, refer to the Leading Article by: Holman, C.D.J. 1992, 'Something Old, Something New: Perspectives on Five 'New' Public Health Movements', *Health Promotion Journal of Australia*, vol. 2, no. 3, pp. 4-11.

The scope of public health to enhance carer health

The authors acknowledge areas of epidemiological research in which the social sciences could make an important contribution to devising better public health interventions. I suggest that informal caregiving is an area of social science research in which epidemiology could not only make an important contribution to devising public health policy initiatives, but is crucial to general practice oriented interventions for carers. In other words, an epidemiological and public health approach gives informal caregiving a credibility and relevance that community care cannot, especially when trying to incorporate informal caregiving into clinical (medical) models of care.

Beaglehole and Bonita, when discussing the definition and scope of public health, mention that it includes "medical care and rehabilitation, health promotion and underlying social, economic and cultural determinants of disease..." They point out that:

"... there is tremendous potential for merging the two disciplines, public health and medical care because both sets of activities are often under the direction of the same government department."

Despite almost a decade of rhetoric, this is only just starting to happen within our Commonwealth government, and I believe the success of 21st century public health will depend on the strengthening of this allegiance with general practice which remains uniquely community based.

In the meantime, post 2000, as the academics re-group themselves after this paradigmatic schism, it appears community care (and possibly primary health care) are being nudged slightly to one side by a greater emphasis on population centred health assessment, with more funding moving to centres for population health. I am hopeful that both groups aligned to public health will move on under a tolerant truce to form what Holman refered in

16 A good example of the General Practice Branch now incorporating a Population Health unit under the same departmental structure. (ie the Department of Health and Aged Care). Under government direction in previous years, Australian Divisions of General Practice have included strategic planning around public health principles since the mid 1990s to good effect especially with diabetes and asthma. Added to this is the establishment of the BEACH project which gives general practice a valuable statistical arm that can be applied to public health matters. However none of these initiatives yet differentiate or categorise persons who are informal and family caregivers for similar attention. This is regrettable considering how much time the GPs say they give to carers.
17 BEACH stands for Bettering the Evaluation And Care of Health - a continuous national study of general practice activity, which although service deliver oriented may have indirect input to public health planning and policy development within general practice.
1992 as, a 'total public health' approach.\(^1\) Holman offers two recommendations on this approach which still hold sway today as we discuss carer well being.

1. "Planning of public health programs should draw on the full complement of modalities, within the limits of their effectiveness and public acceptability. In other words, a comprehensive approach should be adopted, that represents an organised and fully integrated application of all effective knowledge and skills.

2. An objective of education and training of public health professionals of the future should be to equip them with a balanced and worldly appreciation of all five of the 'new' public health movements, their unique contributions, their strengths and weaknesses, their successes and failings.

Lastly, Beaglehole and Bonita, state that "an important task for public health practitioners is balancing effort devoted to controlling individual risk factors and dealing with the underlying social and economic causes of health." I therefore draw on both Holman and Beaglehole to present my concept of an enlightened and total approach to public health in this chapter, while emphasising other 'modalities' of epidemiology and population health.

**Fitting informal caregiving into the public health mould**

From a practical point of view I am also suggesting that informal caregiving as a public health issue might be considered on three levels that combine the A-B-C Model of carer needs I developed in 1995, with the Kings Fund Centre 1998 Carer Compass guidelines for Primary care (referred to in chapter 11).\(^2\) Combining these two approaches focuses on the carers' role where the carers are 'partners in care' (as unpaid care workers) and secondly on carers as patients - whose health needs, may require a different approach than non-carers.

**Carers As Partners In Care**

Demographic and health commentators in the 1990s have reported that successful public health strategies reducing mortality are paralleled with greater longevity. However longevity is associated with increasing non-fatal long term chronic illness and disability which means increased demand for home based informal carers. I am suggesting a slightly different way of looking at this consequence is in terms of DALYs - Disability Adjusted Life Years. Not only does the person with the illness or disability carry the burden (which can be calculated in DALYs), but in many instances the primary carer is


\(^{19}\) The Kings Fund Centre 1998 Carer Compass guidelines for Primary care (particularly relevant to General Practice) are based on the two themes of *Carers as Partners* and *Carers are Partners Too.*

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personally sharing the burden of the other person's long term care through the physical and emotional 'labour' associated with caring for that person at home. Here I am considering carers as partners in care in the context of carers who are in good health. But it cannot be assumed that all carers are healthy workers.

**Carers as Patients**

Another view of informal caregiving as a public health issue therefore needs to relate to carers as patients - carers as individuals with health problems and needs of their own. From my own studies, two thirds of carers are likely to be well, at any one time, but twenty to thirty per cent of carers are not. Where this latter group of carers are themselves infirm, frail or disabled, they are carrying the burden of their own illness and/or disability, plus shouldering the extra burden of disease/disability of the cared for person. As this is a double burden, I suggest we might interpret this as, "a double DALYS effect" on carers.

**Carers prevented from achieving optimum health status**

A third view of caring as a public health issue incorporates my argument that up to a third of carers may be prevented from achieving optimum health status through their restricted lifestyles associated with the caregiving role. Results from the population health (SF-36) surveys and findings from my own qualitative study with individual carers and GPs described in previous chapters, suggest a higher than expected level of morbidity in South Australian carers.

Finally it can be shown that the caring role can be a negative lifestyle factor. Not only are there too few health 'gains' achieved by carers, my own study suggests there are repeated social and health 'losses' inhibiting the carers even maintaining average health. This was illustrated very clearly by carer and GP responses. Sax referred to the health of family carers being as much bound to their caring role as other lifestyle factors. (I adapted these ideas into a diagram showing the carer cascade towards ill health and lack of opportunity in the previous chapter on policy). However a prevention / health promotion

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20 Health 'gains' were terms used by Gillian Parker, and also by Naish Parker, G. 2000, Disability and caring: The Cutting Edge. Presented at the 2nd International Conference, 'Share the knowledge'. Brisbane, March 2000. Hosted by the Carers Association of Australia.
Naish, J. and Benaim, R. 1995, Putting Carers onto the agenda in General Practice. Joint academic project through the Department of General Practice and Primary Care, Medical Colleges of St. Bartholomews and the London Hospitals of Queen Mary and Westfield College, Mile End Road, London, UK.

pathway that just focuses on lifestyle changes (for carers), is not enough as the British sociologist of medicine, Margaret Stacey in the late 1980s, warned public health educators:

'Health promotion... [is] not helped by exhortations to lifestyle changes. Health is better promoted by showing people ways in which they may be able to lessen the constraints that at present make healthy living impossible.'

Since the Declaration of Alma Ata, it has been common to describe public health as "society's efforts to engage people... in maintaining the conditions for their own health." Such a focus is crucial for practitioners when considering carers, as many informal family carers find healthy living impossible and are unable to maintain the conditions for their own health while they are in the caregiving role. It is hard enough for those well carers to maintain a healthy lifestyle with restrictions caused by their day time activities and night caring tasks. How much harder to maintain or control conditions if overburdened by their own illnesses/disabilities, with the added effort of trying to care for a heavily dependent adult or child at the same time.

Using health promotion strategies developed with non-carers to enhance carer health may be quite inappropriate when translated to the individual level, especially if carers are not offered any forms of relief, social support or respite. But therein lies another complication. Even if carers are offered home support or respite services some are just too tired to try, others do not want to stop for seemingly trivial activities for themselves. They don't see it as important for them in comparison to the health problems of the cared for person. Another explanation, evidenced from my own empirical work with carers and GPs, suggests that many carers' awareness of their own health problems may change. More significantly they may lose the capacity to respond to their own illnesses (for example to undergo or complete treatment) or be unsure how to cope best with their own disabilities caring under demanding circumstances.

Therefore policy makers and health educators devising public health intervention programs will need to factor in how to deal with these perceptual and behavioural barriers amid severe lifestyle restrictions experienced by carers. This chapter is not a prescriptive outline for developing such public health strategies for carers but does highlight the need to target carers in groups or as individuals, with carer sensitive and appropriate health strategies.

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Informal Caregiving and Public Health - Summary

In summary, if the scientific community is to take carer health and well being seriously, we need a broader conceptual framework than community care for thinking about why non-carers score a higher health status than carers. Establishing risk factors specific to informal caregiving is important for future health planning, the same way it is done for other 'occupations'. Therefore if we are to protect carer health, promote healthy living for carers and aim for the enhancement of carer health, we need ongoing research to better describe the the status of health of carers across populations. Epidemiological and other population studies that are inclusive of carers will enable us to identify and monitor patterns of disease, focus on functional problems and disability amongst a variety of carer cohorts, and establish health threats to carers (such as the complications and their own co-morbidity associated with prolonged stress). Alternatively we need to examine why some carers are healthier than others and what might be contributing to their health gains in comparison to continual health losses in others.

Once we have more explanations as to why certain health problems occur amongst carers, we are well on the way to establishing their determinants, and offering predictions of health effects on carers due to caregiving. As findings of population studies are translated into public health policies, more sensitive and appropriately targeted strategies for risk avoidance can be incorporated into and introduced through both the practice and public health arms of general practice.
SECTION V

DISCUSSION, IMPLICATIONS AND CONCLUSIONS
CHAPTER 24
DISCUSSION CHAPTER AND CONCLUSION

The four conceptual pillars that guided my research, (building on my study's original aims and objectives), structured the acquisition of evidence that enabled me to argue three main points.

Informal caregiving and carer health
The literature, carer experiences, GP observations and population studies, all indicate that informal caregiving does impact on the health of carers. Evidence from my own local study as well as state, national and international research, illustrates how informal caregiving negatively affects the lifestyle, health and well being of at least a third and sometimes up to a half of all carers. It is now clear that that 'carers' are an identifiable group with some common generic characteristics, are at risk of greater mortality, disability and morbidity. I have also been able to show that carers have a measurably lower health status than non carers in the population. Based on these facts I am suggesting that some carers, by virtue of their caring role and lifestyle restrictions, may be prevented from maintaining or achieving optimum health status.

Carers and General Practice
Secondly, in view of informal caregiving responsibilities and burdens having the potential to compromise social, physiological and psychological carer functioning, there is a good case for encouraging greater attention by GPs to the clinical care as well as the social support of carers. In my own study GPs were willing, but not always able, to be proactive on behalf of the family caregiver within the constraints of Medicare and the complexities of carer and community services experienced in 1995. GPs expressed frustration because they could not give more time and do more for carers. Despite that they vigorously defended the idea that supporting family carers was a legitimate role for family medical practitioners. The importance of the GPs's role in assisting family and informal caregivers has since been acknowledged and endorsed by organisations such as the RACGP.1

1 Were I completing my thesis two or three years ago, I would see the task of introducing a clinical (or medical) arm to carer policy as rather daunting. However the Federal Government's Primary Care Initiatives Program (introduced 1999), which was for the first time inclusive of General Practice, makes the task more achievable. Also adding a public health arm to informal caregiving that is inclusive of General Practice, may be easier now with the current Primary Care Initiatives Program in place. Although older carers are well recognised as having physical and general health decline and disability, my study shows that other younger age groups of carers are more vulnerable to the
My study, unlike most others, has recorded the GP voices, highlighting how much they are already doing for carers in their own practices and what they suggest could help them to make their work for carers more effective. Clearly if carers are to be adequately assisted within General Practice, some of the GPs’ own practice based needs must be acknowledged and addressed. These include improved communication of GPs with support agency staff - linked with and accountable to General Practice; involvement with and easier access to relevant “GP friendly” information on carer resources; carer awareness training for GPs at various stages of their post-graduate/continuing education; (Including better definitions and data on carer profiles and needs; and appropriate remuneration for GP time spent with carers, especially on a one-to-one basis).2

Carers, Policy and Public Health

Thirdly, I argue for greater co-operation of General Practice with State and Commonwealth governments and Carer Associations to participate in carer / community care policies, program development and strategic planning. My review of the development of government policy structures surrounding carers in the mid 1990s showed that GPs themselves were not well represented in key areas of government funded policy relating to carers.3 Future Enhanced Primary Care initiatives could deal with this problem.

Re-focusing on carer health from a population health perspective and re-conceptualizing informal (family) caregiving as a public health issue greatly extends existing social health (community care) structures. Incorporating a public health paradigm adds the final rung of my proposed four tiered approach to enhancement of carer health, a total care philosophy that combines social, clinical, population and policy strategies.4 I have suggested the introduction of a dedicated carer health policy and the development of future policy and program planning for carers within an ethical framework, considering for example, key conceptual elements of informal caregiving I outlined earlier in this thesis. Carer rights and responsibilities must be carefully balanced with those of the cared for persons (otherwise referred to as the patient or consumer).

emotional and psychological impact of informal caregiving. Many are also at risk of physical strains and injury from the heavy workloads of caring for disabled children and adults.

2 It is acknowledged some GP-carer consultations can be remunerated under routine Medicare Schedule items if the carer becomes a patient.

3 For example Home and Community Care Programs, Carer Respite and Carer Resource Centres or other social health / home care support initiatives. Even CareLink that was initially to be GP focused seems to have by-passed direct GP involvement. There have been too many good opportunities lost and this latest is another example of how GPs and the medical component of carer support have been missing through ten, if not fifteen years of policy development for carers.
A twentieth century picture of informal caregiving - what next?
The picture of carers and informal caregiving that has emerged from my research reflects late twentieth century society, health and political systems. However solutions to 1990s carer needs (and GP problems) described in this thesis, must also be amenable to twenty first century issues. Future political as well as demographic shifts, can be expected to continue to impact on the territory of family caregiving and in turn on carers and GPs. The benchmarks for decision-making, particularly within governments, are changing dramatically across all political persuasions, for example by the elevation of market language alongside civic language. The ethical values that have underpinned moral judgements on providing public welfare services (eg for carers), are at risk of being even more seriously eroded within public institutions than they are now. In the current climate where further public spending is said to be unsustainable, particularly in care of the aged, in the future we can expect governments to depend more on the "user-pays" approach to prop up carer support, community and home based care budgets.

The difficult part of the job has been done
Notwithstanding the turmoil of Australian health care and the evolving character of 21st Century General Practice, there are some positive aspects to consider and build on. For instance, the support structures put in place for informal caregiving over the past decade in Australia, are the toast of most overseas countries. One only has to talk with international representatives of carer organisations to appreciate that. In comparison to other OECD countries, family carers are well recognised within Australian state and Federal Governments and are generously funded in the public sphere, especially within welfare, disability, health and aged care. Combined with the philosophy and practice of our universal health care system, Australian carers are better off than most. Although I think carer support, respite and community care do not directly address health care or provide adequate preventive strategies for carers, in many ways the hardest part of supporting carers has been done. The difficult tasks of establishing the complex social support and welfare structures for carers have been achieved. This means is that in Australia (and probably the UK) the necessary structures are now there on which to build additional carer supports that will provide a holistic approach to care for carers. If informal caregiving is to be properly understood and a total care approach fully developed for family carers, a new intellectual territory of informal caregiving will need to evolve beyond service provision which has driven carer support to date. Both clinical (general practice-

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4 Although I have not featured it here, education and research would be integral to each tier of the strategies.
medical) and public health (especially epidemiological and demographic) information on carer health will need to be incorporated into future planning for carers.

**A new intellectual territory of informal caregiving - a new discipline**

During the 1960s and 1970s, when I observed interest grow around the private issues of death and dying, grief and bereavement. That awakening eventually stimulated a consciousness and response in professionals and laity which was to be the forerunner to modern palliative care. Many people are unprepared for dying (or caring for the dying), something so basic to human existence. They are also unprepared for the demands of informal care - another basic element of human life that is taken for granted. Twenty first century informal caregiving will become more complex and demanding on the informal carer - hence a total care / holistic model is required to protect carers. Such a model would require a review of carer education, perspectives of the cared for persons (the 'patients') and a wider representation of health care and welfare professionals.

**The human face of informal caregiving**

Finally I want to return to the human experience of informal caregiving as discussed in this thesis. What comes through time and again in the data is the psychological and social impact of caregiving on the carers. For many carers the emotional consequences are seriously debilitating and is easy to argue a direct relationship between caregiving and depression. I wish to avoid the blanket assumption that caregiving causes depression. My research suggests that what carers are mostly experiencing as psychological morbidity is protracted stress and distress and a range of other emotions like despair and sometimes even desperation. When I initially analysed my early data in 1995, I wrote the following comments in my interim research report:

"Much of the literature available on the health of carers has focused on these specific conditions, particularly of stress, anxiety and depression as evidence of psychological morbidity. However in relation to depression, Mohide (1990, p.452) provides some timely caution, drawing on the work of Fitting. He points out that, before too much emphasis is placed on "depression", the carer's moods may ..."reflect the demoralised state rather than major depression in that caregivers are unable to change the outcome of their relative's condition. This may lead caregivers to feel a sense of despair. Mohide also quotes Becker and Morris who have advocated that the research agenda should include the differentiation of clinical depression from depressive symptomology and despair among caregivers".

My current study supports a cautionary approach particularly as both carers and General Practitioners reported that despair, disappointment and sadness are a significant part of the caregiving experience. These findings should not be seen in isolation from the whole caregiving experience as this combination of factors can have a profound impact on carers. In addition, more attention should be paid to assessing

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and monitoring the existing health status of carers from early on in their "caring career". This is necessary to protect individuals who may become physically or emotionally vulnerable as the pressures of the caring role increase over the extended period of caring. The General Practitioner is the ideally placed to provide this type of health care and support.\(^6\)

I have mulled long and hard over Mohide's remarks and although his research was published in 1990 and focused on caregivers of persons with dementia, what he says in my opinion, is even more significant today.\(^6\) His notions of a carer's demoralised state and their sense of despair at not being able to change the outcome of their relative's condition is very important to consider. Whether the persons have dementia, cancer, disability, chronic illness, or are frail aged, they are not expected to return to normal health - more likely deteriorate. The carer has to live and cope with that. More recent studies on carers are revealing complex psycho-social impacts of caregiving on individuals that should not just be labelled or treated as 'depression'.

From my own Health Omnibus surveys in 1994 and 1998, using the SF-36 health measure, it is evident that the lower scores for carers using both the SF-36 (and GHQ) clearly indicated psychological distress, not clinical depression. There is a litany of such descriptors reported in studies about informal carers that not only incorporate notions of distress, demoralisation and despair. Carers also experience despondency, disappointment and as was very evident in this study, loss. Such powerful emotions often lead to reduced social and emotional functioning which was evident from my own research. However as described by General Practitioners in this study, the combination of factors like tiredness, lack of energy, unhappiness, unfulfilled roles and life goals can act as precursors to clinical depression. Most significant, as mentioned by GPs, was that the one additional factor which can push pre-depression into a clinical stage is deterioration of the cared for person's physical or mental condition. Here the important relationship is between the decline of their loved one's condition and the carer's own health status, (physical or emotional decline or both). Hence it follows that it is the timing of providing appropriate clinical and social support to carers which has most potential to assist the caregiver.\(^7\) At times of crisis in the carer's life, or marked deterioration of the sick or dependent person's condition it is vital to the carer's well being that the full armoury of health care and social supports are offered and that the carer is appropriately assessed, counselled\(^8\), supported

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7 Sometimes this assistance can be as simple as a listening ear and moral support.

8 Counselling carers is a pandoras box. Although I have not addressed it in this thesis it, counselling remains the area which will occupy much time and effort in years to come. We do not know who are
and monitored. Much of today's community care services aims to do this, but not all carers access community care, and as I argue, community care does not have a clinical arm.

A total care model for carer support model is possible in general practice but should not only be available when the carer is on the point of collapse. It needs to occur at regular intervals along the entire caregiving pathway. There are clearly discernable stages a carer progresses through, from the realisation and diagnosis of the sick or disabled person's condition, through to the carer's relinquishment of the caring role and for this I developed a chart describing six of those main stages of caring. (See Diagram "The 6 Stages of Caring" in the Appendix.) This chart has been based on information shared with me by the carers in my study and on extensive reviews of the literature. The carers have different priorities during each of those stages of their caring role and may need slightly modified approaches by health professionals to best assist them.

**Resolving problems in the long and short term**

Developing a new intellectual territory of informal caregiving and trying to redraw the map of caring is a long term challenge, particularly if employing policy and public health initiatives and aiming to incorporate carer health issues within teaching curriculums of health professionals (eg GPs, nurses and allied health). Enhancing carer health in that way, although very necessary, will take many years to implement and evaluate, but there are still today's carers to consider. A shorter term resolution to the urgent needs of carer health could involve GPs in the following ways. Firstly I suggest there is potential for increasing GP awareness training through their current Continuing Medical Education sessions as suggested by GPs in this study. With current emphasis in general practice on chronic and complex illness as well as continuity of care, the first aim could be to place informal caregiving firmly on the map of chronic illness to ensure that carers become part of routine chronic illness management - especially identifying carers with chronic illness themselves. This could be captioned: "Chronic Illness is chronic caring" as suggested by a GP from my own study. CME was underway, the RACGP GP Training Curriculum could be upgraded to include more specific information on carer related topics again highlighted by GP participants.

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9 Most state based Carer Associations if requested, could provide at short notice, helpful information and articulate speakers to highlight carer needs. We are soon to do this in South Australia with RACGP, Divisional and academic GPs.
Chapter 24: Discussion, and Conclusion

Thirdly GPs could be presently encouraged to use the RACGP Enhanced Primary Care Health Assessment protocols to target carer health in the course of their normal daily work. Accessing support services for carers can be facilitated through Carelink, state based Carer Resource Centres and regional Carer Respite Centres, already established. The added bonus is that GPs can be remunerated for some of their time with carers through specific EPC Medicare Schedule Item Numbers.

As I was completing the analysis of my carer and GP data, I also developed a teaching tool "The A.I.M. Model for Carer Health and Caring Role Assessment in General Practice" which could be trialed for GP education with carers.\(^\text{11}\) It is a simple conceptual model which aims to provide a focus on the caring role to encourage early carer support for carers as "partners in care", and a more proactive clinical health focus for initiating carer support for "carers as patients". [Diagrams and descriptions of the model are included in the Appendix]. I believe my A.I.M. Model is compatible with health care assessment protocols of the current Enhanced Primary Care Initiative. It is also designed to adapt to the six stages of caregiving, thus providing each General Practitioner with a way of providing more appropriate health maintenance as well as health enhancement for carers.

Conclusion

The impressive advances for carers achieved in the closing decades of the 20th century in which our Australian civic society and 'the State' have tried to alleviate carer need and provide support, may be short lived. Care principles and primary health care paradigms are starting to be overshadowed by market and user-pay priorities that threaten to erode the welfare safety nets previously provided by the State. This transition places carers, some already living on the edge of poverty and unable to pay for extra services that they need, in an even more tenuous position.

Early trends from other Commonwealth countries suggest the focus is moving from need to the evaluation of vulnerability and risk which could become the new rationing device for governments and public institutions protecting the shrinking public dollar. In the

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10 Topics on ageing, women's health and chronic illness already touch on carer issues but need further development. Other subject areas where carer support could be highlighted are palliative care, mental illness, managing intellectual and physical disability etc.

11 A Carer Assessment Tool was developed jointly by the Carers Association of South Australia and Royal District Nursing Service of SA for use by nurses and other health professionals but it is probably not suitable for use in General Practice because of its length. More importantly there is no provision for a clinical assessment of carer health.


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meantime more formal care is displaced to informal home and community domains and patient care is continually replaced by case management initiatives. Such deprofessionalising aspects of patient care are leaving responsibility with family and other informal carers to pick up the pieces when community care fails.\footnote{Kemshall, H. 2002, \textit{Risk, social policy and welfare}. Introducing Social Policy Series. Open University Press, Buckingham, UK, p.97.} The ethics of need are fast being replaced by the economics of risk. Therefore a moral focus on carer health maintenance and enhancement, combined with monitoring carer health across populations, provides an important counter strategy to community care beseiged by economic contingencies and instrumental judgements.

My research project initially focused on identifying carer health and social needs of individual carers then moved on to explore the risks to carer health across different populations. It therefore straddles that shifting focus from need to risk and provides public health imperatives for the continued support of informal carers under health policy - not just service oriented social and welfare policy. Enhancing carer health will not be achieved through social health or primary health care alone. Because of the special relationship between the carer, GP and the patient, (where it is trust that most characterises the relationships that bind them), it will be the clinical care and coordination available through General Practice that may provide the key to carer health enhancement. To work to that end both GPs, and carers, are going to need sustainable public funded 'safety nets' as well as reliable low cost / no cost private networks to buffer their needs along the way. The implications of my research for general practice are modest as they aim to formalise and remunerate what GPs are already doing for carers. I would like what I am proposing to assist General Practitioners as much as help carers. The ethics of supporting carer health and well being are clear. The stories and comments by carers and GPs in this thesis are testament to that.

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APPENDIX 1:

The 6 Stages of Caring
THE SIX STAGES OF CARING

Experiences reported by carers as the caring role changes over time

6 major time bound phases to caring were identified from qualitative data (Stacey research)

**Stage 1**
*At the time of diagnosis*
Confusion
A time of confusion and uncertainty for the family member or significant other in the patient's early acute phase;
Involves transition from family member/close friend to "carer";
It may not have been that person's choice to become the carer;
Becoming a carer may occur suddenly - or come on slowly.

**Stage 2**
The new carer
Unsure / Overwhelmed by new responsibilities
Starting out as carer - alone and uniformed, untrained;
Initial adjustment and transition stage;
Understanding the new role / learning to cope;
Searching for information, support, resources;
Many 'new' carers have a short term view.

**Stage 3**
Intermediate
Awareness and acceptance of role
Developing new patterns of coping as carer;
Developing new social / carer/community support networks;
Coping with destabilising changes to dependent's condition;
Progression of person's illness - changes in patient's functioning;
Looking at the longer term.

**Stage 4**
The experienced carer
Carer managing responsibilities and fine tuning role
Carer has learned from experience / Consolidating knowledge;
Has established routines and may try teamwork approach;
Increased tolerance to person's behaviour (or illness) but may be becoming tired - constant cycle of care;
Some carers ageing themselves or have existing illnesses made more difficult by ongoing caring role

**Stage 5**
The secondary carer
Handing over
Anguish when dependent leaves home care and goes into formal care, involves anxiety, guilt, fear for person's well being;
Loss of control for quality of care of the dependent person.

**Stage 6**
The retired carer
After the caring is over - Grief, loss and emptiness
Time to live for one person - for self;
Self renewal may require rehabilitation, reflection;
Time for carer to recover their strength, their life, their health;
Much knowledge and experience to share with others who are informal or family caregivers.

"Enhancing the Health Of Informal Caregivers. Implications for General Practice and Public Health".
Department of Public Health, Faculty of Medicine, University of Adelaide.
APPENDIX 2:

The Carer's Universe
"The Carers' Universe"

1. Zone of Informal Support
   - Family Home
   - Carer & Patient
   - Relatives, Friends & Neighbours

2. Primary & Community Services Zone

3. Secondary Services Zone

4. Tertiary Services Zone
HOME & CARE SERVICES ACCESSED & CO-ORDINATED BY INFORMAL CAREGIVERS

**The Carer's Universe**

**HOSPITAL**
- SPECIALIST UNITS accessed for father
- Pain, Radiotherapy, Oncology
- A & E, XRay, Fracture
- Urology, Geriatrics
  - [General Hospital & OPDs - for Mother who IS 2nd carer]

**HOSPICE**
- PALLIATIVE CARE TEAM*
  - Dedicated Beds
  - Trained Staff
  - Volunteers
  - AH Outreach
  - Stth Community Hospice Prog
  - Clergy
  - Private Nursing Agencies *
  - *Denotes those services which provide "hands-on" care that DIRECTLY assist carer with caring 'duties'
APPENDIX 3:

Qualitative Inquiry - how it differs from Quantitative Research
Qualitative Inquiry and how it differs from Quantitative Research

The following summary is a comparison of qualitative and quantitative philosophies and methodologies compiled from a number of authors, mostly published between 1984-1994. I organize their contributions under 12 main headings.

1. The metaphors
The most simplistic comparison between qualitative and quantitative research is to describe one that explores meaning through words as opposed to investigating 'the object' involving measurement and numbers. I have found two metaphors most appealing in contrasting these differences. Firstly, with qualitative research one illustrates the complexities and detail of a picture or painting inside a frame. The picture needs interpretation and understanding in the context of the person or situation and situation under discussion. In a qualitative study questions can be raised by the participants as well as the researcher requiring a research design that is holistic. Quantitative research by contrast, "represents the picture-frame surrounding it that picture. The frame is firm, clearly defined and easily measurable, but there is limited description. In this type of research the questions are set by the investigator and therefore the research design is essentially experimental. These are two separate dimensions of an analysis: ie participant generated constructions and evaluator generated constructions.

A second metaphor can be likened to the difference between understanding people, their experiences and the territory they live in, in contrast to knowing the boundaries and other parameters of the map of the same territory and people. Qualitative research methodology thus offers a 'warm' approach to the central problem of research and is concerned with interpersonal relationships, personal values, meanings, beliefs, thoughts and feelings. The aim is to obtain rich, real, deep and valid data. Qualitative inquiry is therefore interpretive, focusing on experience not behaviour, essence not appearance, quality not quantity. The following is a compilation of what many authors have written, some most eloquently.

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Gurray, C. 1989, Focus Group Methodology: an exploration of qualitative research. NSW Medical Education Project on Alcohol and Other Drugs.
2. The orientation: discovery vs verification
The qualitative philosophy is one of discovery, of phenomena, adopting research procedures that "are flexible and exploratory." As the study progresses the researcher "can add or change types and sources of data gathered" to create "a deeper understanding of what is being investigated."
A Quantitative approach means that "research procedures are oriented to verification of pre-determined hypotheses. Variables and procedures are defined and strictly adhered to. Flexibility is discouraged."

3. The researcher's position: insider vs outsider
Qualitative researchers are 'insiders' close to or part of the research. They talk to insiders and observe subjects who have experienced first hand, the activities or procedures under scrutiny. Leedy adds, "First hand experience provides the most meaningful data." Using a qualitative methodology the researcher is the instrument, "engaging the situation, exploring the human experience 'in the field' by aiming beneath manifest behaviour" to develop an understanding of a phenomenon or about those who experience it.
Quantitative researchers are essentially 'outsiders' investigating facts and arriving at an understanding through a detached and objective view.

4. The perspectives
Qualitative researchers "focus on context within which social facts are observed."
Quantitative researchers believe, according to Gurray, that social facts exist outside and independently of people's thoughts and feelings.

5. The research process: Inductive versus Deductive
The main difference between the two paradigms is that qualitative research is inductive, it proceeds from the ground up, moving from the specific to the general (or from the particular and concrete to abstract generalisations). Qualitative research is therefore theory generating. Quantitative studies on the other hand are deductive, moving from the general to the specific enabling researchers to test theories drawing and draw certain conclusions that follow on from the premises if they are true.

Another view is that instead of "forcing the data into a particular theoretical mould or explanatory framework" (which is the quantitative and theory driven approach to research,) "the qualitative researcher lets the data drive the concomitant interpretation and emerging theory (a data driven approach)." Further, says Denzin "if the goal is the exploration, discovery or seeking to understand the experience of others, the analyst must use an analytic method that keeps him / her more open and intimate with the text. If the goal is theory testing, an approach involving more structure and distance from the text is desirable."
Qualitative studies ultimately aim to describe and explain [at some level] "a pattern of relationships, which can be come only with a set of conceptually specified analytic categories [Mishler 1991]". Starting with them [ deductively] or getting gradually to them [inductively] are both legitimate and useful paths.

6. The focus: holistic or particularistic [variables]
Qualitative philosophy "is to gain as complete or holistic view of what is being studied. Thus researchers use a "wide array of data, documents, records, photos, observations, interviews, case histories and quantitative data." Denzin had also stated: "...qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand." Gurray adds, that qualitative paradigm attempts to complete an in-depth understanding of the subject matter.

The qualitative focus is particularistic - "to gain control of the events for investigation, to structure the situation, to identify and isolate specific variables for study with measurement devices to collect information on those variables.

7. The realities: dynamic or stable
The Qualitative paradigm considers the dynamic and changing nature of reality.
Quantitative researchers however focus on stable or unchanging facts or causes of behaviour. A stable reality enables the accumulation of facts and causes of behaviour. There is a general belief that facts do not change.

8. The conditions: naturalistic or controlled
Qualitative data are "collected within the context of their natural occurrence". This research permits variables that naturally influence the data to operate without interference."
Gurray writes, "Processes are investigated in situ. This allows for any variables that naturally influence events to continue to operate without interference." Qualitative research therefore " is committed to achieving a holistic perspective" and "should avoid the narrowness of single interpretations, approaches or perspectives", says Sarantokos. "Rather the research should be contextually grounded..." Quantitative research he explains, "preserves the sense of context and community...A holistic perspective is essential in qualitative research to present a more legitimate grounded and contextual view of the events or persons being described."

Quantitative researchers however seek "controlled conditions". The data is collected under controlled conditions "to rule out chance that variables other than those under study could account for relationships among the variables". Gurray states that Research is performed under controlled conditions to rule out influence of variables outside the investigation on observed effects."
According to Sarantokos "quantitative research often de-contextualizes the subjects of study. As such there is little sense of place, home, environment, or setting provided in the products of the research. There is limited attention to the social context in which events have occurred and been given meaning."
9. The data: subjective or objective [words or numbers]

Qualitative research "focuses on subjective data that exist within the minds of individuals". This is "typically expressed or reported through language." It is "essential to understand the meaning that persons attach to events in (their) environment." The researcher, using expressive language and voice, takes ideas and concepts and converts these to verbal form and textual data (words). In fact, Leedy says, "Qualitative methodology should consider words as the elements of the data".

The Quantitative paradigm focuses research "on objective data that exist apart from feelings and thoughts of individuals." "The data are expressed in numbers". Under the quantitative paradigm the investigator is concerned with measurement and numerical data (numbers).

10. The data analysis and interpretation

Qualitative research analysis is facilitated by a 3-stage process described by Miles & Huberman as data reduction, data display, and conclusion drawing or verifying conclusions.

Patton writes, "Each qualitative study is unique, and so the analytical approach used will be unique". "There are not ways of perfectly replicating the researcher's analytical thought processes." Denzin continues in the same vein, "In effect qualitative designs are not copyable, off the shelf patterns, but normally have to be custom built, revised and choreographed (Preissle 1991)". Denzin adds, "there is merit in loose inductively oriented designs and tight more deductively approached ones. The former work well when the terrain is unfamiliar and / or excessively complex, a single case is involved and the intent is exploratory and descriptive."

The task of the researcher is one of analysis and synthesis to fit pieces together to form a meaningful matrix. However according to Miles and Huberman, 'We have few agreed on cannons for qualitative data analysis in the sense of shared ground rules for drawing conclusions according to Patton. Qualitative analysis does not have the parsimonious statistical tests of quantitative analysis"; "There are no formulas for determining significance"; "There are no straight-forward tests for reliability and validity". Therefore "In qualitative analysis, "...the analyst makes judgements that provide clues for the reader as to the writer's belief about variation in the credibility of different findings: For instance when the patterns are clear or weak, or when they are strongly supported by the data."

Thick descriptions and interpretations - answering the 'why' questions.

The discipline and rigor of qualitative analysis depend on presenting solid descriptive data", quoted by Patton as 'thick description'.
This approach generates 'thick description' which 'goes beyond mere fact and surface appearances' says Patton, and Denzin. 'It presents detail, context, emotion and the webs of social relationships that join persons to one another'. Further, this thick description 'contains the necessary ingredients for thick interpretation, connecting individual cases to larger public issues.' These serve as the linkage between individual troubles and public concerns.'

11. The results: validity vs reliability
Qualitative research discusses valid results. It "concentrates on validity - data that are representative of a true and full picture of what the researcher is attempting to investigate." Gurray adds that qualitative research "emphasises validity so that the findings represent a true and full picture of the phenomenon under investigation."-1 Quantitative research "focuses heavily on reliability - data that are consistent or stable as indicated by the researcher's ability to replicate the findings".

Truth value or credibility of the conclusions involves," taking the data and interpretations to the sources from which they were drawn and asking people whether they believe (or) find the results plausible". This is in contrast to trying to establish its internal validity, which is the preferred approach used in quantitative research.

External validity, which refers to "generalizability of the findings and the representativeness of subjects, tests and testing situations" in quantitative research, is dealt with more in terms of the 'fittingness' when evaluating qualitative research. Research reliability in qualitative terms refers to the consistency, and auditability study that provides a decision trail; of the research process." Finally 'neutrality' or freedom from bias is important in the research process. "In qualitative research, confirmability can be achieved by establishing auditability, applicability and truth value which should be the standard by which neutrality is judged.

12. Limitations [particularistic & confirmatory]
Qualitative research therefore is difficult to refute or challenge because it is inappropriate for outsider to question what was a very personal experience (or a phenomenological experience.)
Quantitative research is verification oriented, particularistic & confirmatory. It is ill suited as an aid to decision-making and policy evaluation or to address social or educational relevance of research efforts."
APPENDIX 4:
Letters of Introduction
28 September 1994

TO WHOM THIS MAY CONCERN

I wish to introduce Miss Anne Stacey, who is a Master of Science (Qualifying) student with the School of Medicine, Flinders University of South Australia.

As part of her course Anne is conducting a research project on "Identifying the health and related social needs of carers, from the perspective of both carers and general practitioners."

Any assistance that you might be able give to Anne as part of her current project, would be appreciated.

Yours sincerely,

Chris Silagy  MBBS, (MED) FRACGP, FAFPHM
Professor and Head, Department of General Practice
23 June 1994

Mrs .................
Chairperson

Dear Mrs .............

Re: Qualitative Research Project of Anne Stacey
AUGUST FOCUS GROUPS

I am writing to ask if I might approach your organisation for assistance with the first stage of a research project I am undertaking as a M.Sc. Qualifying Student, at Flinders University of SA. It is:

"Identifying the health and related social needs of carers - From the perspective of both General Practitioners and Carers."

This research project aims to gain a greater understanding of the care giving role by exploring the experiences of carers, the associated responsibilities of being a carer, and their needs. It also seeks to investigate the perceived effects caring might have on the health and well being of carers. My longer term aim is to follow up the results of this study on the health of carers so as to develop potential strategies for addressing those needs, especially through general practice. (For more information please see the copy of my research proposal attached).
During the month of June, I am making contact with a wide cross section of organisations that offer carer support and/or self help groups for families and the carers of dependent people (adults and children). For example the carers of people with a physical or mental disability; frail aged; chronic debilitating illness, dementia, brain damage/injury or mental illness.

I wish to advise people of the study and invite their participation in Focus Groups planned for the end of August 1994. I am therefore formally requesting each organisation’s assistance in passing on my initial invitation to carers who might be willing to participate in this study. Would your organisation agree to approach two or three carers on my behalf, and to ask if they would allow me to contact them? A copy of the Information Sheet and Consent Form which I will be forwarding to each person who agrees to participate is enclosed.

Please let me know if your organisation requires any more information and any protocols I need to follow.

Correspondence can be sent to me at the address below:

Ms Anne Stacey  
C/o Department of General Practice  
Flinders School of Medicine  
Level 7  
Flinders Medical Centre  
BEDFORD PARK   SA  5042

My work telephone number, c/o Southern Division of General Practice is  
[or I can be contacted after hours]

Yours sincerely

ANNE F STACEY  
BN, AMRCNA, MRPIA

Msc/Corresp 3/6/94
APPENDIX 5:

Part of submission to ethics committee
- Re ethical / privacy issues

5a: Consent To Participation in Research Form
5b: Carer Information Sheet
5c: General Practitioner Information Sheet
ETHICAL / PRIVACY ISSUES

Part of Submission to Ethics Committee (Committee on Clinical Investigation) at Flinders Medical Centre, South Australia (5/5/94) for research project of Anne Stacey: "Identifying the needs of carers (health and related social needs): From the perspective of both the General Practitioners and Carers".

12. Ethical Considerations

12.1 Benefits anticipated from the study
There will be no direct benefits for individuals participating in this study, however carers may feel some benefit with the realisation that they are not alone in their circumstance. As informal caregivers they might see some potential benefits in a study that heightens the awareness of the family doctor (local GP).

12.2 Risks - incl. risk of causing physical disturbance, discomfort, anxiety or pain
There are unlikely to be any risks as described above to participants. There is unlikely to be any psycho-social harm or risks of harm to participants as described in the 1993 DEC Protocols for Social/Behavioural Research Ethics, [Attachment B: Ethical Considerations in Social/Behavioural Research page s 15 - 16]

12.3 Volunteers (source, honoraria)
There are no financial inducements to subjects to participate in this study. There is no formal funding for incidental expenses.

12.4 Protection of privacy and preservation of confidence
- All consent forms will be coded and each participant's questionnaire will be identifiable by number only.
- The researcher will be mindful at all times of her duty towards the individual subject of the researcher, respecting their personality, rights, wishes, beliefs, privacy consent and freedom.
  [1993 DEC Protocols for Social/Behavioural Research Ethics 7.6, page 5]
- The researcher recognises that the collection of this information should not intrude unreasonably upon the individual's personal affairs.
- The researcher also recognises that the collection of this information should not intrude upon the individual's relationship with their own medical practitioner or health care worker.
- All participants of the Focus Groups will be instructed to refrain from using full names that will identify themselves, members of their family or associated health professionals / health care workers. They will also be instructed that all group discussion is to be treated as strictly confidential information.
Participants will be advised prior to commencement of the research that they are free at any time to withdraw consent to further involvement in the research and to request that data already collected concerning them to be destroyed.


The researcher also acknowledges that individuals on whom personal information is held or collected must have access and the opportunity to amend inaccurate records.

[1993 DEC Protocols for Social/Behavioural Research Ethics. 9.5 page 7]

12.5 **Restriction of use of data**
Data collected in this study will only be used for the purposes specified. Access to this data will be restricted to only those people involved in the research project.

13. **Statement of compliance**

I wish to advise the Committee on Clinical Investigation that I have read and will adhere to the:


2. "NH&MRC Guidelines for the Protection of Privacy in the Conduct of Medical Research"


I will also be obtaining and citing a copy of Section 14 of the 1988 Privacy Act.

I undertake to adhere to those protocols in all aspects of the administration of my research project and will advise the Committee on any variation to my formal submission.

Anne F Stacey
CONSENT TO PARTICIPATION IN RESEARCH

I, Mr/Mrs/Ms/Dr................................................................., request and give consent 
(first or given names) (surname)
to my involvement in the research project "Identifying the Health and Related 
Social Needs of Carers - From the perspective of General Practitioners 
and Carers".

I acknowledge that the nature, purpose and contemplated effects of the research 
project, especially as far as they affect me, have been fully explained to my 
satisfaction by .......................................................... and my consent is given voluntarily. 
(first or given names) (surname)

I acknowledge that the detail(s) of the FOCUS GROUP and QUESTIONNAIRE has/have 
been explained to me, including the anticipated time involved for both activities and I 
consent to having my contribution to the focus group discussion taped.

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any 
direct benefit to me and that I may withdraw my consent at any stage without 
affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 21 years.

................................................................. Date: ....................
Signature of research volunteer:

.................................................................
Signature of Witness:

.................................................................
Printed name of Witness:

.................................................................
I, ................................................................., have described to .................................................................
the research project and the nature and effects of the Focus Group & Questionnaire. 
In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: ................................................................. Date: ....................

Status in Project: .................................................................
Dear Sir/Madam

You are invited to participate in the research project:

"Identifying the Health and Related Social Needs of Carers - From the perspective of General Practitioners and Carers".

I am conducting this research as part of my Master of Science (Qualifying Studies) through the Flinders University School of Medicine, the Department of General Practice at Flinders and with the support of the Southern Division of General Practice Inc. This project has also been discussed with several groups within the SA Faculty of the Royal Australian College of General Practitioners.

Aim of the study
The aim of this study is to explore the role and responsibilities of "carers" - people who care for dependent individuals in the home. This includes carers of the elderly, chronically ill, or people with physical or mental illness /disability. In particular, through this project it is hoped to gain an overview of the various needs of carers in the home/community.

Outcomes of the research
Although no direct personal benefits or risks are likely to arise for you or the person you are caring for, it is expected that this study will help clarify

(a) the roles and responsibilities of "carers"

(b) the most common and important needs of carers, especially when interacting with health care professionals like the local GP.

(c) how GPs (and other health care professionals), might be best able to support carers' health and related social needs.
Questionnaire and Personal Interview
If you agree to take part in this study you will be interviewed at home by the researcher (Anne Stacey) at your convenience during November / December 1994. The discussion will last one and a half to two hours depending on your availability on the day. To ensure that the information is recorded as accurately as possible, the discussion will be audio-taped.

You will also be required to fill out a Questionnaire which will assist the investigator to further clarify the needs and profile of carers from the southern region of Adelaide and the Fleurier Peninsula.

Confidentiality
All notes, audio-tapes, records and questionnaires containing personal information about participants from the Focus Group will remain confidential and no information which could lead to identification of any individual will be released.

Your right to withdraw at any time
Your involvement in this study is entirely voluntary. Should you decide to withdraw from the study, you may do this freely and without prejudice. 24 hours notice would be appreciated.

For further information
Should you require further details about the study, either before, during or after the study, you may contact Miss Anne Stacey, Ph: Work (08) 384-9533 or A.H: (08) 276-5278.

This study has been reviewed by the Clinical Investigations (Ethics) Committee at Flinders Medical Centre. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Secretary of this Committee, Ms Carol Hakof at FMC on 204-4507.

Yours sincerely

Anne F Stacey
B.N., A.M.R.C.N.A., M.P.R.I.A
M.Sc. (Qual) Student
School of Medicine, Flinders University of South Australia

Info Sheet- Ethics Subm'n
GENERAL PRACTITIONER INFORMATION SHEET

Date

Dear Doctor,

You are invited to participate in the research project:

"Identifying the Health and Related Social Needs of Carers - From the perspective of General Practitioners and Carers".

I am conducting this research as part of my Master of Science (Qualifying Studies) through the Flinders University School of Medicine, the Department of General Practice at Flinders and with the support of the Southern Division of General Practice Inc. This project has also been discussed with several groups within the SA Faculty of the Royal Australian College of General Practitioners.

Aim of the study
The aim of this study is to explore the role and responsibilities of "carers" - people who care for dependent individuals in the home. This includes carers of the elderly, chronically ill, or people with physical or mental illness /disability. In particular, through this project it is hoped to gain an overview of the various needs of carers in the home/community.

Expected benefits from research
The benefits that can be expected from this study will be to:

(a) clarify the roles and responsibilities of "carers"

(b) identify the most common and important needs of people, participating in an informal caregiver role, especially when interacting with GPs and other health care professionals.

(c) explore with you how General Practitioners (and other health care professionals), might be best able to support carers' health and related social needs.
Focus Group and Questionnaire
If you agree to take part in this study you will be required to participate in a
group discussion about these issues, involving 6-8 doctors. The discussion
group will be led by a professional facilitator and last one and a half to two
hours. To ensure that the information is recorded as accurately as possible, the
group discussion will be audio-taped. The meeting will be held locally in
southern Adelaide during July.

You will also be required to fill out a Questionnaire which will assist the
researchers to further clarify the needs and profile of carers from the southern
region of Adelaide and the Fleurier Peninsula.

Confidentiality
All notes, audio-tapes, records and questionnaires containing personal
information about participants from the Focus Group will remain confidential
and no information which could lead to identification of any individual will be
released.

Your right to withdraw at any time
Your involvement in this study is entirely voluntary. Should you decide to
withdraw from the study, you may do this freely and without prejudice. 24
hours notice would be appreciated.

For further information
Should you require further details about the study, either before, during or
after the study, you may contact Miss Anne Stacey, Ph: Work (08) 384-9533 or
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information about the conduct of the study or your rights as a participant, or
should you wish to make a confidential complaint, you may contact the
Executive Secretary of this Committee, Ms Carol Hakof at FMC on 204-4507.

Yours sincerely

Anne F Stacey
M.Sc. (Qual) Student
School of Medicine, Flinders University of South Australia

Consent Form - Ethics Subm'n
APPENDIX 6:

6a: Carer Discussion Schedule/Interview Guide
6b: GP Discussion Schedule/Interview Guide
FOCUS GROUP DISCUSSION SCHEDULE & INTERVIEW GUIDE FOR CARERS

Part I Exploring the role and experiences of the carer

(1) How long have you been a caregiver?
   What is the illness/disability of person you are caring for?

(2) What do you understand as the ROLE of a carer? - Describe the role

(3) Did you feel you had (or wanted) a CHOICE in becoming a carer?

(4) How do you feel about being the carer?

Part II Needs of the carer

(1) What are your needs as a carer?

(2) Where do you go for help with these needs?
   - Your very own personal needs
   - Need for assistance with the dependent person,
     Information needs / community resources
     Practical assistance in the home
   - Other needs?

Part III Carers and their GPs

(1) Do you think your local doctor sees you as the carer?
(2) Has your role and needs been discussed with your local doctor
(3) What support has been given by your GP? - how has it helped you
(4) How could your local doctor provide more help?
(5) What support do carers expect from their GPs?
(6) How often do you see your GP in a year/month?

Part IV The health and well being of the carer

(1) Does the carer feel his/her health or well being has been affected by that caregiving experience?

(2) In what ways has the carer has been affected by that caregiving role
   - Physical health, Emotional health
   - Ability to go out during the day / evening
   - Ability to live an independent life
   - Employment - recreation and relaxation, holidays
**DISCUSSION SCHEDULE and INTERVIEW GUIDE**
**FOR GENERAL PRACTITIONERS**

<table>
<thead>
<tr>
<th>Part I</th>
<th>Identifying the carer in General Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>What is your understanding of a &quot;carer&quot; or &quot;informal caregiver&quot;?</td>
</tr>
<tr>
<td>(2)</td>
<td>How does the GP perceive carers' roles and responsibilities?</td>
</tr>
<tr>
<td>(3)</td>
<td>How do you recognise carers in your own practice? What about parents of disabled or chronically sick children, or close friends and neighbours who are maintaining a mentally or physically ill person at home - are they also seen as carers?</td>
</tr>
<tr>
<td>(4)</td>
<td>Why do you think some people are not seen as &quot;carers&quot; in general practice? What makes it difficult for GPs? What assists GPs to recognise &quot;the carer&quot;?</td>
</tr>
<tr>
<td>(5)</td>
<td>Is it easier to identify carers in the surgery or when the GP visits the patient/family at home?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Part II</th>
<th>Needs of the carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>As GPs, what needs of carers are you aware of amongst your patients and their families? Can you give some examples of those needs?</td>
</tr>
<tr>
<td>(2)</td>
<td>Do you spend time talking with family members/carers about how they feel about being the carer, and what their needs are?</td>
</tr>
<tr>
<td>(3)</td>
<td>Can you give some examples of what GPs are already doing for carers?</td>
</tr>
<tr>
<td>(4)</td>
<td>Where could carers go for help with their non-medical (social) needs? i.e. does the GPs see this as their role or refer the carer elsewhere?</td>
</tr>
<tr>
<td>(5)</td>
<td>What 'outside', community services do GPs refer family members/carers to? What about HACC, local government,</td>
</tr>
<tr>
<td>(6)</td>
<td>Do GPs feel they have enough information about local community services, counselling, home support services, support groups?</td>
</tr>
<tr>
<td>(7)</td>
<td>What would assist GPs to have access to more useful information for carers?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Part III</th>
<th>Health of the carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>Have GPs noticed if the caring role has affected those carers with existing health problems or who are at risk? Can you give some examples?</td>
</tr>
<tr>
<td>(2)</td>
<td>Are GPs aware if the caring role has been a direct cause of health problems amongst people who are in a caring role? e.g. Have GPs noticed if when a carer is ill, requiring bed rest or hospitalisation, does that person have adequate care themselves?</td>
</tr>
<tr>
<td>(3)</td>
<td>How can/does the GP help</td>
</tr>
<tr>
<td>(4)</td>
<td>What other measures are GPs already taking to support the health needs of carers? Can you give some examples?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Part IV</th>
<th>GPs needs and suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>Can you suggest what would help GPs in meeting the needs of carers? Information, backup and other support, resources, short courses</td>
</tr>
<tr>
<td>(2)</td>
<td>What do as a GP want or need regarding issues of reimbursement /rebates for time spent with carers?</td>
</tr>
</tbody>
</table>
APPENDIX 7:

7a: Invitation to Participate - Carers
7b: Invitation to Participate - GPs
FOCUSING ON THE NEEDS OF CARERS

A research project about identifying the health and related social needs of carers - from the perspective of both Carers and GPs

The purpose of this study is to work with both informal carers and general practitioners to gain an overview of the broad health and social needs of informal caregivers.

This study aims to explore:
- the meaning and experiences of being a carer (informal caregiver);
- perceived effects a caregiving role might have on the health and well-being of carers;
- the needs (health and social support needs) of carers, and how primary care practitioners like GPs might be best able to support carers.

Carers invited to give their perspective

One component of the study is to conduct a number of focus groups and interviews with carers during March 1995. Masters qualifying student Anne Stacey from Flinders University, is currently making contact with a number of Carer organisations throughout the southern region to invite people who are carers to participate in the project.

If you would be interested in attending a Focus Group, and would like more information about this study, please contact Anne Stacey or fill in the form below and return it to the Southern Division of General Practice. Anne can be contacted at the Southern Division of General Practice, or after hours.

Telephone: 384-9533, [Fax: 382-0408] or phone a.h. 276-5278
Mobile Phone No: 015-792533

Anne Stacey, who is already known to many community groups in the southern region in her liaison role for the Southern Division of General Practice and FMC, is conducting this research project in association with the Flinders University School of Medicine, Department of General Practice, Royal Australian College of General Practitioners Research Unit (S. A.) and the Southern Division of General Practice.

Please fill in the form below and return it to the REPLY PAID envelope to: Department of General Practice, Flinders University of South Australia c/- The Southern Division of General Practice, Noarlunga Centre, SA 5168.

NEEDS OF CARERS RESEARCH PROJECT

Please indicate your preference with a ✓

☐ I am interested in participating a Focus Group for carers in March [1995]
or ☐ I would be prepared to participate in an interview during March 1995.

☐ Please send me more information about the Research Project: "Identifying the health and related social needs of carers".

Name: ____________________________________________
Address: __________________________________________
Phone No: ________________________________________
CARERS' PROJECT

It is acknowledged that General Practitioners already offer much support to family caregivers and other informal carers of chronically ill, frail aged or dependent people in the home and community. As well as identifying the carers' needs, what do GPs themselves want or need when trying to help caregivers?
You are invited to have your say...

Study seeks GP perspective on the health and needs of informal caregivers in the home

The purpose of this study is to work with both General Practitioners and carers to identify the broad health and related social needs of family caregivers and other informal carers, from the perspective of both GPs and Carers. The study aims to explore:

- the experiences of informal caregivers in the home;
- the effects a caregiving role might have on the health and well-being of carers;
- the needs of carers, and how primary care practitioners like GPs might be best able to support carers

GPs invited to participate during April

One component of the study is to conduct a number of interviews with groups of General Practitioners, and with individual GPs in April. The group moderator will be a GP. Project co-ordinator and MSC(Qual) student Anne Stacey, is currently making contact with metropolitan and country practices throughout the southern region to invite GP participation in the project. A questionnaire will also be sent to two hundred randomly selected GPs in the southern region.

If you or any of your colleagues would be interested in discussing issues regarding the needs of carers from the GP perspective, please contact Anne Stacey or return the form below.

Telephone: [ ] or phone a.h. [ ] Mobile Phone No: [ ]

This research project is conducted in association with: the Department of General Practice, Flinders University School of Medicine, Royal Australian College of General Practitioners Research Unit (SA) and the Southern Division of General Practice Inc.

Please fill in the form below and return / fax it (Fax: 382-0408) to Anne Stacey, Department of General Practice, Flinders University of South Australia, c/- The Southern Division of General Practice, Noarlunga Centre, SA 5168

Please indicate your preference with a ✓

☐ I am interested in participating in a General Practitioner FOCUS GROUP one evening during April 1995.

or ☐ I would be prepared to be INTERVIEWED (1/2 - 1 hour)

☐ Please send me more information about the Research Project: "Identifying the health and related social needs of carers".

Name: ........................................................................

Address: ........................................................................

Phone No: ........................................ Fax No: ........................................
APPENDIX 8:

Carer Questionnaire

[Sample]
CARER QUESTIONNAIRE

CARERS PROJECT

MARCH 1995

"Identifying the Health and Related Social Needs of Carers-
From the Perspective of both Carers and General Practitioners.

This research project is conducted by A. Stacey, MSc (Qualifying), Department of
General Practice, School of Medicine, Flinders University of South Australia, in
association with the Southern Division of General Practice Inc and the Research Unit
of the Royal Australian College of General Practitioners (S A).

PLEASE RETURN QUESTIONNAIRE IN THE REPLY PAID ENVELOPE TO A. STACEY
C/-
Department of General Practice, School of Medicine, Flinders University of South Australia,
Level 7, Flinders Medical Centre, Bedford Park, South Australia, 5042
Telephone: W:
or
Southern Division of General Practice, Noarlunga Centre, SA 5168
Telephone: W: or Mobile phone
FIRSTLY, A FEW DETAILS ABOUT YOURSELF

Please tick all the boxes that apply

Q. 1 Are you...? Male [ ] Female [ ]
Q. 2 What age group do you belong to?
   21-24 [ ] 35-44 [ ] 55-64 [ ] 75-84 [ ]
   25-34 [ ] 45-54 [ ] 65-74 [ ] 85+ [ ]
Q. 3 What is your marital status?
   Married [ ]
   Separated/Divorced [ ]
   Widowed [ ]
   Never Married [ ]
   Defacto [ ]
Q. 4 What is your employment status?
   Working: full time [ ]
   Working: part-time / casual [ ]
   Retired [ ]
   Home duties [ ]
   Unemployed [ ]
   Other [ ]
Q. 5 Which of these groups best describes the highest qualifications you have obtained?
   Left School before 15 [ ]
   Left School after age 15 [ ]
   Secondary School [ ]
   Trade qualifications/apprenticeship [ ]
   Certificate/Diploma [ ]
   Bachelor Degree or higher [ ]
Q. 6 What local government area do you live in? Postcode .................

(ANSWERING THE FOLLOWING QUESTION IS OPTIONAL)

Q. 7 What was your gross annual household income before tax?
   (Last Financial Year)
   Up to $12,000 [ ]
   $12,001 - $20,000 [ ]
   $20,001 - $30,000 [ ]
   $30,001 - $40,000 [ ]
   $40,001 - $50,000 [ ]
   $50,001 - $60,000 [ ]
   $60,000 - $80,000 [ ]
   $80,001 or more [ ]
Q. 1.1 What is your relationship with the dependent person you care for?

Please tick the appropriate box.

- I am their Husband
- I am their Father
- I am their Son
- I am their Brother
- I am their Wife
- I am their Mother
- I am their Daughter
- I am their Sister
- I am their Neighbour
- I am their Friend
- Other: I am their ...

Please briefly indicate if you are caring for any other dependant person(s)

Q. 1.2 What is the age group of the person you are caring for?

1-12   21-24   35-44   55-64   75-84
13-20   25-34   45-54   65-74   85+

Q. 1.3 What is the nature of illness(es) of disability of the person you are caring for?

More than one response is possible. Please tick all the boxes that apply.

- Elderly/Frail aged
- Mentally Ill
- Stroke
- Physically disabled
- Cancer
- Multiple disabilities
- Parkinsons disease
- Multiple Sclerosis
- Intellectually disabled or brain damaged
- Severe visual/sensory impairment
- Chronic heart/respiratory disease
- Chronic kidney disease
- Dementia / Alzheimer's Disease
- Rheumatoid arthritis or osteoarthritis
- Other illnesses/disabilities?

Q. 1.4 What personal care you are providing to the person?

Please tick all that apply.

- Bathing / Showering
- Co-ordinate/give medications
- Feeding
- Co-ordinate /give treatments
- Toiletering
- Written Communication
- Co-ordinate /give treatments
- Verbal Communication
- Helping with mobility
- Occupational Therapy
- Other types of care provided...

Q. 1.5 How long have you been caring for this person?

[ ] months
[ ] years

Q. 1.6 Approximately how many DAYS or HOURS per week do you care for this person?

[ ] days/week or [ ] hours/week
Q. 1.7 Who at present is helping you care for this person? 
*Please tick all that apply*

<table>
<thead>
<tr>
<th>No-one</th>
<th>[ ]</th>
<th>Dept. Community Welfare</th>
<th>[ ]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family/relative(s)</td>
<td>[ ]</td>
<td>Council Social Worker</td>
<td>[ ]</td>
</tr>
<tr>
<td>Home &amp; Community Care</td>
<td>[ ]</td>
<td>Doctor GP/specialist</td>
<td>[ ]</td>
</tr>
<tr>
<td>Domiciliary Care</td>
<td>[ ]</td>
<td>Neighbour</td>
<td>[ ]</td>
</tr>
<tr>
<td>District Nurse (RDNS)</td>
<td>[ ]</td>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

Is this help currently adequate for you? Yes [ ] No [ ]

If no, what problems have you had or are you encountering?

Is there any particular reason why you don't have assistance?

Q. 1.8 Do you feel you need more help to care for this person? Yes [ ] No [ ]

If yes, what kind of help would you like now, or in the future? 
*Please expand and give examples*

Q. 1.9 Do you live with the person you care for? Yes [ ] No [ ]

If no, how far away do you live? [Approx. distance only] ...

Q. 1.10 Do you have your own private transport? (e.g. a car) Yes [ ] No [ ]

If no, what means of transport do you use? ...

If no, how difficult is it for you to cope as a carer without your own private transport?

Q. 1.11 Do you feel you had a choice about whether or not to take on the caring role? Yes [ ] No [ ]

If no, how did that you feel about not having a choice?
Q. 1.12 At what stage of taking on a caregiving role did you realise you were "the carer"?

SECTION II
QUESTIONS RELATING TO GPS

Q. 2.1 It is acknowledged that the local GP is the most frequently consulted health care professional in the community.

How often did you see a GP in the last year
- for self [ ]
- for the person being cared for [ ]

Q. 2.2 Do both you and the person you are caring for consult the same GP?

I consult the same GP as the person I am caring for [ ]
I have a different GP to the person I am caring for [ ]

If it is the same GP, has this been of benefit to you as carer and why?

If it is a different GP, has this been of benefit to you as carer and why?

Q. 2.3 Has your local doctor (GP) recognised and supported you as "the carer", with special needs? Yes [ ] No [ ]

If 'No', how do you think you have been perceived?
[ eg as a parent, spouse, partner etc?]

Q. 2.4 Has the GP's receptionist recognised you as "the carer" with special needs? Yes [ ] No [ ]

Q. 2.5 In what ways has your local doctor been able help you as the carer, either recently or in the past?

Please briefly describe how you have been helped

Q. 2.6 Could you suggest how your local doctor might have been more helpful?
Q. 2.7 What general information and support has your GP offered you in your caring role?

**A. Information**
Finding and/or providing you with information about:

<table>
<thead>
<tr>
<th>Information Provided</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>the dependent person’s illness/disability (including diagnosis and outlook)</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>what to do in a medical emergency (concerning the person you are caring for)</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>contact for after hours medical care (for you or the person you are caring for)</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>respite services available for you</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>other services available for you or the dependent person</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>government benefits or special allowances and where to go to apply</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>where to obtain a Carer’s Kit</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>special adaptations for the home including where to go to find out where to get them.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Other information</td>
<td>.................................................................</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2.7.1 As a carer, what information from your GP have you considered to be the most important and helpful?

---

2.7.2 Who has provided you with the most helpful information in the past?

*Please tick the box that applies*

<table>
<thead>
<tr>
<th>Information Provider</th>
<th>[ ]</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>[ ]</td>
</tr>
<tr>
<td>Hospital doctors/specialists</td>
<td>[ ]</td>
</tr>
<tr>
<td>Community Health Nurse or worker</td>
<td>[ ]</td>
</tr>
<tr>
<td>District Nurse</td>
<td>[ ]</td>
</tr>
<tr>
<td>Hospital Nurse</td>
<td>[ ]</td>
</tr>
<tr>
<td>Social worker</td>
<td>[ ]</td>
</tr>
<tr>
<td>Local Council</td>
<td>[ ]</td>
</tr>
<tr>
<td>Carer Support Group</td>
<td>[ ]</td>
</tr>
<tr>
<td>Friend</td>
<td>[ ]</td>
</tr>
<tr>
<td>Relative Please specify</td>
<td>[ ]</td>
</tr>
<tr>
<td>Other</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Page 5
Q. 2.7 (Continued)

B. Referrals: Have you been referred to OTHER agencies by your GP:

Please tick all the boxes that apply

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Support Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Health Centre services</td>
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</tr>
<tr>
<td>Day Care Services</td>
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</tr>
<tr>
<td>District Nursing Services</td>
<td></td>
<td></td>
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<tr>
<td>Domiciliary Care Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial /Legal Advice or Services</td>
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<td></td>
</tr>
<tr>
<td>Meals on Wheels Services</td>
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<tr>
<td>Professional counselling services</td>
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<tr>
<td>Respite Care</td>
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<tr>
<td>Social Worker</td>
<td></td>
<td></td>
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<tr>
<td>Local Council Community Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Community services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(eg for practical home/domestic help or assistance with transport)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other

C. Support: Has your GP:

Yes | No
---|---
Offered you emotional support? |     |    |
Provided co-ordination of any of the services above? |     |    |
Reviewed your situation regularly? |     |    |

Q. 2.8 What other support has your GP provided that has helped you?

Q. 2.9 Please provide some examples of how GPs could help carers generally, or when the carer is ill and is needing care for him/her self?
Either in the consulting rooms or when making house calls.

Q. 2.10 Who do you usually go to when you need support and/or help?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members of your family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your local doctor (GP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Support Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A community worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q. 2.11 Who of the above do you prefer to go to when you need support and/or help?
### SECTION III
EFFECTS OF CARING ON YOUR HEALTH & WELL BEING

Q. 3.1 Is your own health?  
Excellent [ ]  
Very good [ ]  
Good [ ]  
Fair [ ]  
Poor [ ]

Do you have chronic illnesses, disabilities, etc.? Yes [ ] No [ ]

*If yes, please give brief details*

Q. 3.2 Do you feel your caring role has affected your physical or emotional health or well being recently, or at any time in the past?

*Please tick the appropriate boxes*

<table>
<thead>
<tr>
<th>Description</th>
<th>Yes [ ] No [ ]</th>
</tr>
</thead>
<tbody>
<tr>
<td>My caring role has not affected my health</td>
<td></td>
</tr>
<tr>
<td>My caring role has contributed to my health problems</td>
<td></td>
</tr>
<tr>
<td>i.e.</td>
<td></td>
</tr>
<tr>
<td>Has had a minor effect on my health</td>
<td></td>
</tr>
<tr>
<td>Has had a moderate effect on my health</td>
<td></td>
</tr>
<tr>
<td>Has had a major effect on my health</td>
<td></td>
</tr>
</tbody>
</table>

Please briefly describe how you feel your health has been affected.

Q. 3.3 Has your sleep often been interrupted because of the caring role and responsibilities? Yes [ ] No [ ]

*If yes, what effect do you feel this has had on your health and well being?*

Q. 3.4 Has this interfered with your normal daily activities? Yes [ ] No [ ]

*Please describe*

---

Page 7
Q. 3.5 What is the main effect your caring role has had on your ability to do each of the following?

Questions (a), (b) and (c) below have been adapted from the Carers Questionnaire, "Disability, Ageing & Carers", 1993 Aust. Bureau of Statistics, Catalogue No. 4432.0

(a) To go out during the day

<table>
<thead>
<tr>
<th>Effect</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>Minor change</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You can only go out when help is arranged</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You can only go out with the person you care for</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You are not usually able to go out in the day</td>
<td>[ ]</td>
<td></td>
</tr>
</tbody>
</table>

Please briefly describe the main difficulties involved in going out during the day.

(b) To go out during the evening

<table>
<thead>
<tr>
<th>Effect</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>Minor change</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You can only go out when help is arranged</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You can only go out with the person you care for</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You are not usually able to go out in the evening</td>
<td>[ ]</td>
<td></td>
</tr>
</tbody>
</table>

Please briefly describe the main difficulties involved in going out during the evening.

(c) To go on holidays

<table>
<thead>
<tr>
<th>Effect</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>Minor change</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You could take more holidays</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You cannot take as many holidays</td>
<td>[ ]</td>
<td></td>
</tr>
<tr>
<td>You cannot take holidays</td>
<td>[ ]</td>
<td></td>
</tr>
</tbody>
</table>

Please briefly describe any difficulties you have had in taking holidays.

Q. 3.6 How long is it since you had a holiday? ..................................................

Q. 3.7 Have you felt that not taking holidays in the past has affected your quality of life or health in any way?
Please explain briefly how this may have affected you?
Q. 3.8 Can you think of anything that might help to maintain or improve your own health and well being?

Q. 3.9 What are some positive and enjoyable aspects of your caring role for you?

Q. 3.10 What does 'being a carer' mean to you?

Q. 3.11 What are your responsibilities as the carer?

You are invited to add additional comments to these questions on the sheet of paper provided with this questionnaire.
Please indicate below if you agree with the following statements.

The statements below were adapted from the leaflet, "Carers' Needs. A 10 Point Plan for Carers", Kings Fund Centre, London.

You are invited to add your comments for each statement.

<table>
<thead>
<tr>
<th>STATEMENT 4.1</th>
<th>I would like recognition of my contribution as a carer and recognition of my own needs as an individual in my own right.</th>
<th>Yes [ ] No [ ]</th>
</tr>
</thead>
<tbody>
<tr>
<td>STATEMENT 4.2</td>
<td>I would like services tailored to my individual circumstances, needs and views, through discussions at the time help is being planned.</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>STATEMENT 4.3</td>
<td>I would like services which reflect an awareness of differing family, racial, cultural and religious backgrounds/values.</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>STATEMENT 4.4</td>
<td>I need opportunities for a break, both for short spells (eg during day) or night) and for longer periods (a week or more), to relax and have time to myself.</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td></td>
<td>I prefer: HOME-based respite [ ] SEPARATE respite care facility? [ ]</td>
<td></td>
</tr>
<tr>
<td>STATEMENT 4.5</td>
<td>I would like to explore alternatives to family care, both for the immediate and long term-future.</td>
<td>Yes [ ] No [ ]</td>
</tr>
</tbody>
</table>
STATEMENT 4.6
I need more practical help to lighten the tasks of caring, e.g. domestic help, home adaptations, incontinence services and help with transport. Yes [ ] No [ ]

STATEMENT 4.7
I need someone to talk to about my emotional needs, at the start of caring, during and after my caring task is over. Yes [ ] No [ ]

STATEMENT 4.8
I need information about available benefits and services for carers as well as how to cope with the condition of the person I care for. Yes [ ] No [ ]

Please add below your own statement about other needs you have as a carer.

MY STATEMENT
In addition I need:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Page 11
APPENDIX 9:

CARER QUESTIONNAIRE

RESULTS
### SECTION 1
**BACKGROUND INFORMATION ON THE CARING RELATIONSHIP**

**Q. 1.1**
What is your relationship with the dependent person you care for? 

<table>
<thead>
<tr>
<th>Relationship</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am her Husband</td>
<td>4</td>
</tr>
<tr>
<td>I am his Wife</td>
<td>10</td>
</tr>
<tr>
<td>I am his/her Father</td>
<td>0</td>
</tr>
<tr>
<td>I am his/her Mother</td>
<td>5</td>
</tr>
<tr>
<td>I am his/her Son</td>
<td>1</td>
</tr>
<tr>
<td>I am his/her Daughter</td>
<td>3</td>
</tr>
<tr>
<td>I am his/her Brother</td>
<td>0</td>
</tr>
<tr>
<td>I am his/her Sister</td>
<td>0</td>
</tr>
<tr>
<td>I am his/her Friend</td>
<td>0</td>
</tr>
<tr>
<td>I am his/her Neighbour</td>
<td>0</td>
</tr>
</tbody>
</table>

Please briefly indicate if you are caring for any other dependent person(s)

- C-9 Distant carer of frail mother-in-law
- C-23 My mother is in a hostel. I see her twice a week

**Q. 1.2**
What is the age group of the person you are caring for? 

<table>
<thead>
<tr>
<th>Age Group</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 12</td>
<td>0</td>
</tr>
<tr>
<td>13-20</td>
<td>11</td>
</tr>
<tr>
<td>21-24</td>
<td>0</td>
</tr>
<tr>
<td>25-34</td>
<td>4</td>
</tr>
<tr>
<td>35-44</td>
<td>1</td>
</tr>
<tr>
<td>45-54</td>
<td>0</td>
</tr>
<tr>
<td>55-64</td>
<td>2</td>
</tr>
<tr>
<td>65-74</td>
<td>6</td>
</tr>
<tr>
<td>75-84</td>
<td>6</td>
</tr>
<tr>
<td>85+</td>
<td>4</td>
</tr>
</tbody>
</table>

**Q. 1.3**
What is the nature of illness(es) of disability of the person you are caring for? 

<table>
<thead>
<tr>
<th>Illness/Disability</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple disabilities</td>
<td>2</td>
</tr>
<tr>
<td>Dementia / Alzheimer's Disease</td>
<td>9</td>
</tr>
<tr>
<td>Elderly/ Frail aged</td>
<td>7</td>
</tr>
<tr>
<td>Physically disabled</td>
<td>4</td>
</tr>
<tr>
<td>Intellectually disabled or brain damaged</td>
<td>6</td>
</tr>
<tr>
<td>Stroke</td>
<td>5</td>
</tr>
<tr>
<td>Parkinsons disease</td>
<td>2</td>
</tr>
<tr>
<td>Cancer</td>
<td>1</td>
</tr>
<tr>
<td>Chronic heart/respiratory disease</td>
<td>4</td>
</tr>
<tr>
<td>Chronic kidney disease</td>
<td>1</td>
</tr>
<tr>
<td>Severe visual/ sensory impairment</td>
<td>2</td>
</tr>
</tbody>
</table>
Q. 1.3 What is the nature of illness(es) of disability of the person you are caring for?

Other illnesses / disabilities listed by carers
Age/spinal/blood pressure complaints - husband
Colitis
Diverticulitis
Epilepsy/epileptic
Frail aged, physically disabled, brain damaged through meningitis/encephalitis and is often incontinent
Lymphoedema
Pagets disease
Parkinson's disease, also a history of heart ailments; Underwent heart surgery 5 years ago.
Incontinent, changed personality
Severe multiple disability - cerebral palsy - son
Severe visual/sensory impairment
Very little eye sight - incontinent, partially deaf.

Q. 1.4 What personal care you are providing to the person

Dressing / Undressing [16]
Co-ordinate/give medications [13]
Helping with mobility [12]
Bathing / Showering [11]
Feeding [10]
Toileting [10]
Help with Verbal Communication [9]
Co-ordinate / give treatments [4]
Occupational Therapy [2]
Help with correspondence [2]

Other comments from carers

C-3 Slowing speech, Cannot write.
C-5 Wheelchair [+ bed wetting]
C-6 Can't remember anything after just being told. OK to walk but shuffles a lot
C-7 Until recently son in shared care arrangement between home and 10 minutes away. My husband home. No speech. Can't sit unassisted, cannot stand or walk.
C-9 Support - prompting
C-11 Provide nursing care during and after seizures; Co-ordinating medical/social/ quality of life care
C-16 Household chores and meals etc.
C-17 Transport - appointments
C-20 Helping afternoons and evenings at nursing home
C-21 Full care during outings
C-22 Absolutely every ADL is provided by me for my daughter.
   I have 24 hour responsibility for daughter - but receive approx. 35 hours per week in home support.
C-23 24 hour supervision & providing care when required

-2-
Q. 1.5
How long have you been caring for this person? n=22

<table>
<thead>
<tr>
<th>Duration</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 12 months</td>
<td>0</td>
</tr>
<tr>
<td>2-3 years</td>
<td>7</td>
</tr>
<tr>
<td>4-7 years</td>
<td>7</td>
</tr>
<tr>
<td>8-10 years</td>
<td>2</td>
</tr>
<tr>
<td>14-19 years</td>
<td>3</td>
</tr>
<tr>
<td>28-29 years</td>
<td>2</td>
</tr>
</tbody>
</table>

C-1  2 yrs, 2 months
C-2  14 yrs
C-3  6 1/2 yrs
C-4  5 yrs
C-5  14 yrs
C-6  3 yrs
C-7  28 yrs
C-8  2 yrs [7 days / week]
C-9  8 yrs [7 days / week]
C-10 4 1/2 yrs [24 hours / week]
C-11 29 yrs [7 days / week]
C-12 27 months [7 days / week]
C-14 2 yrs 3 months
C-15 "years" 3 days/week [2 1/2 yrs mentioned in focus group]
C-16 7 days / week [5 years mentioned in focus group]
C-17 7 days / week [7 years mentioned in focus group]
C-18 7 days / week [14 hours / day] [6 yrs mentioned in focus group]
C-19 7 days / week [148 hrs / week] [2 1/2 years mentioned in FG]
C-20 10 yrs [7 days / week]
C-21 2 yrs [7 days / week]
C-22 4 yrs, 24 hrs a day
C-23 19 yrs [133 hrs / week]

Q. 1.6
Approx. how many DAYS or HOURS/ week do you care for this person? n=22

<table>
<thead>
<tr>
<th>Hours per week</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 24 hrs/wk</td>
<td>0</td>
</tr>
<tr>
<td>1-2 days/wk</td>
<td>1</td>
</tr>
<tr>
<td>3-5 days/wk</td>
<td>1</td>
</tr>
<tr>
<td>7 days/wk</td>
<td>13</td>
</tr>
</tbody>
</table>

Q. 1.7
Who at present is helping you care for this person? n=22

<table>
<thead>
<tr>
<th>Help</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domiciliary care</td>
<td>5</td>
</tr>
<tr>
<td>Doctor GP/specialist</td>
<td>5</td>
</tr>
<tr>
<td>No-one</td>
<td>2</td>
</tr>
<tr>
<td>Family/relative(s)</td>
<td>4</td>
</tr>
<tr>
<td>District Nurse (RDNS)</td>
<td>3</td>
</tr>
<tr>
<td>Home &amp; Community Care</td>
<td>4</td>
</tr>
<tr>
<td>Council Social Worker</td>
<td>2</td>
</tr>
<tr>
<td>Friend/Neighbour</td>
<td>0</td>
</tr>
</tbody>
</table>
Q. 1.7 [continued]

Who at present is helping you care for this person?

Other:
C-3  Dom care - fixing hand rails etc. Day Centre
C-15  Nursing home
C-16  Day therapy twice weekly
C-22  Support workers selected by me through community support scheme &... funding.
C-23  He attends school. .....Care worker 3 hours per week.

Is this help currently adequate for you?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>[8] C-3, C-8, C-9, C-14, C-15, C-16, C-17, C-23</td>
</tr>
<tr>
<td>No</td>
<td>[7] C-5, C-10, C-11, C-12, C-18, C19, C-21</td>
</tr>
</tbody>
</table>

If no, what problems have you had or are you encountering?

C-6  I can manage so far - help was available when requested
C-7  Services too restricted - always short on funds
C-9  No money available to pay for someone else to take my place
C-10 I have been trying to get help to put my wife to bed at night without success
C-11 Medical, social adequate suitable respite and services tailored to my son's needs.
C-12 Looking after house properly
C-18 The help is adequate if no other problems arise and I feel well.
C-19 Will soon need laundry help.
C-21 Many of these people were too busy to give me the assistance I felt I needed.
C-22 From 3 pm - 8.30am I am forced to remain at home to provide support to my daughter
C-23 I felt victimised when my husband left - have been very tired. Am coping well now.

Is there any particular reason why you don't have assistance?

Carer comments

C-5  Presently I am able to drive and deal with everything. Doctor's orders to make my husband do as much for himself as possible
C-10 Government funding.
C-12 People forgot to tell me
C-11 My son falls between service providers, not enough funding etc.
C-17 Had Dom Care & Day Care centre also a voluntary companion earlier when need was greater.
C-18 The lack of money the various Depts have.
C-22 Organisation refused to shift the $.. moneys (current cost) that supported my daughter in her community based home to provide support in her own home, when she returned to live with me.
C-23 I haven't been able to find a consistent carer. I wouldn't want someone different every time - I also haven't felt the need.

Q. 1.8 Do you feel you need more help to care for this person?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>[9] C-8, C-9, C-10, C-11, C-14, C-15, C-18, C-19, C-23</td>
</tr>
<tr>
<td>No</td>
<td>[3] C-12, C-16, C-17</td>
</tr>
</tbody>
</table>
Q. 1.8 [continued]
Do you feel you need more help to care for this person?
If yes, what kind of help would you like now, or in the future?

Carer comments:

- C-8 Respite care if I have to go to hospital.
- C-9 My son needs to be able to lead a full and satisfying lifestyle on his own.
- C-10 It's very difficult to put my wife in bed also prepare her for bed.
- C-11 Suitable work environment, suitable in-home respite, suitable service for my son's needs.
- C-14 I would like our children to offer help to both their parents.
- C-15 In the future I may need more help because my husband will get worse...
- C-17 To have someone take over for a few days in the year (trustworthy)
- C-19 More regular affordable respite and more financial assistance.
- C-21 I felt I needed more stress breaks. Some person to take over the caring temporarily just to relieve me more frequently.
- C-22 More S's so that I can develop an individual accommodation support option for her in her own home.
- C-23 It would be beneficial for him considering his future options, to be a little more used to being with and helped by others than myself exclusively.

MISC: As my husband and I get older we shall probably need more assistance, but at the moment he has a sitter once a week and goes to a day centre 1 and 1/2 days per week.

Q. 1.9
Do you live with the person you care for?

<table>
<thead>
<tr>
<th>Yes</th>
<th>C-1, C-2, C-3, C-4, C-5, C-6, C-8, C-9, C-10, C-11, C-12, C-14, C-16, C-17, C-18, C-19, C-22, C-23</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>C-15, C-20, C-21</td>
</tr>
</tbody>
</table>

Q. 1.10
Do you have your own private transport? (e.g. a car)

<table>
<thead>
<tr>
<th>Yes</th>
<th>C-1, C-2, C-3, C-4, C-5, C-7, C-9, C-10, C-11, C-12, C-14, C-17, C-18, C-19, C-20, C-22, C-23</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>C-6, C-8, C-15, C-16</td>
</tr>
</tbody>
</table>

Carer comments:

My own car is very old and unreliable and I do not use it to transport my daughter, because of the difficulties that will occur if the car breaks down. Carers need to have access to low interest subsidised loans so that new cars can be purchased that are safe, reliable, guaranteed and suitable for the needs of the carer of the person with disability. C-22

Q. 1.10
Do you have your own private transport? (e.g. a car)
If no, what means of transport do you use

- C-6 Taxi- Access Cabs
- C-8 Taxi or bus and tram
- C-15 Taxis from carers also Glenelg Community Centre
- C-16 Buses
Q. 1.10 [continued]
Do you have your own private transport? (e.g. a car) If no, how difficult is it for you to cope as a carer without your own private transport?
C-7 Need use of wagon which is difficult. Too heavy for me
C-8 Very inconvenient
C-15 Very difficult at times
C-16 Not bad. We do have Access Cabs when we go out.

Q. 1.11
Do you feel you had a CHOICE about whether or not to take on the caring role

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>C-6, C-11, C-18, C-19</td>
</tr>
<tr>
<td>No</td>
<td>C-1, C-4, C-5, C-7, C-8, C-9, C-10, C-14, C-15, C-17, C-20, C-21, C-23</td>
</tr>
</tbody>
</table>

If no, how do you feel about not having a choice?

C-2 One takes on the caring as a natural course of events when married.
C-7 At the time - no. Since then services haven't measured up
C-8 We have been married over 50 years and it just came naturally
C-9 At the time I did not feel anything.
C-10 I feel contented about it because there is only me to care for her.
C-14 I didn't and still don't want him to be in a nursing home permanently but didn't realize how hard and tiring it would be.
C-15 I felt it was my duty as wife, therefore, I felt I had no choice.
C-17 Just accepted it as a wife.
C-20 I wanted to care for him, but knew I would need help
C-21 It was a stifling feeling I felt I would not and could not cope, but I knew it was my duty to at least try.
C-22 Yes I had a choice of leaving my daughter in formal care. No, I couldn't morally leave her there because the organisation failed in their care to support her in a way that kept her well, safe and out of danger!!
C-23 It didn't worry me, he's my son.

Q. 1.12
At what stage of taking on a caregiving role did you realise you were "the carer"?

C-8 About 3 years ago.
C-9 Whilst my son was still in hospital.
C-10 At the start.
C-11 When my son was 8 months old and I found he had brain damage-then became a severe epileptic at 2 1/2 [years old].
C-14 When he came home after being in hospital 3 months.
C-15 Early stage when I knew my husband had multi infarct dementia.
C-16 About 12 mths ago when the 'Year of the Family' placed slight emphasis on that role.
C-17 2 1/2 years ago when I received a carer's pension
C-18 Since mother lost her ability to perform simple tasks (the last six years).
C-19 15 years ago when I cared for my late husband.
C-20 I never saw it that way. Of course if I hadn't loved my husband I imagine it would have been different.
C-21 Possibly at the stage when after a month of trying unsuccessfully to find a nursing home which would accept my wife as a fulltime patient. All had waiting lists.
C-22 From when my daughter became of school age (1970) and there were no options for her.
C-23 When my son was 15 years old.

-6-
Q. 2.1
It is acknowledged that the local GP is the most frequently consulted health care professional in the community.

How often did you see a GP in the last year?

<table>
<thead>
<tr>
<th>No. of times consulted GP in last year</th>
<th>For self</th>
<th>For the person being cared for</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 5 times/yr</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>6-10 times/yr</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11-15 times/yr</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>16-20 times/yr</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>21-25 times/yr</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>26-30 times/yr</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>30-40 times/yr</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>40-50 times/yr</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Mean No of visits by carers to their GPs =1.5 /year

CARERS: How many times has the carer seen the GP in the last year?

One carer commented: "First year at home at least weekly
4 carers saw their GP x 12 times last year
2 carers saw their GP x 3 times last year
2 carers saw their GP x 15 times last year
1 carer saw their GP x 2 times last year
>1/2 of carers saw their GPs 8 or more times last year
9 carers consulted their GPs between 12 - 20 times / year
19% of carers saw their GP x 4 times / year

DEPENDENTS: How many times has the carer seen the GP in the last year?

How many times did the carer see a GP in the last year?
3 dependents saw their GP x 6 times last year
2 dependents saw their GP x 8 times last year
4 dependents saw their GP x12 times last year
2 dependents saw their GP x15 times last year
18% of dependents saw their GP x 4 times / year
15 dependents saw their GPs 8 or more times last year
5 dependents saw their GPs 20 or more times last year
1/2 of dependents saw their GPs 10-30 times last year

Q. 2.2
Do both you and the person you are caring, consult the same GP?

<table>
<thead>
<tr>
<th>Yes:</th>
<th>No:</th>
</tr>
</thead>
<tbody>
<tr>
<td>[13]</td>
<td>[5 ]</td>
</tr>
</tbody>
</table>

[Several respondents answered both Yes and No.]
Q. 2.2
Do both you and the person you are caring, for consult the same GP?

If it is the SAME GP, has this been of benefit to you as carer and why?

C-8 I have known him for 23 years and am very comfortable talking over problems for us both.
C-9 GP has known the family since 1967. Continuity has been helpful.
C-10 The doctor is a caring person and is interested in us both.
C-12 Yes because he knows both of our positions in life.
C-14 We consult a husband and wife doctor team.
C-15 It helps because the GP knows my husband and myself and I can discuss the problems I have with my husband with GP. (But) He does not understand dementia.
C-17 We did have the same GP until 18 months ago and my husband changed to another. It did have benefits but I think I am happier separate.
C-18 I was hoping for it to be beneficial but was wrong. This GP is only interested in some physical symptoms.
C-19 Can combine visits to the doctor's surgery. The doctor can see the problems of the carer
C-20 Most beneficial as he understood the situation at home. Appointments at same place / time.
C-21 Yes it gave me more opportunity to discuss with the GP my wife’s health and how I could best help her and how I could cope with various situations myself. His advice and assistance proved very valuable.
C-23 I have been with my present GP since Dec 1994. I feel confident that she gets a better understanding of both of us when she knows us both.

If it is a DIFFERENT GP, has this been of benefit to you as carer and why?

C-11 My son’s GP seemed to see me as ‘stress related’ with problems that were quite separate medically. My own GP doesn’t “assume” that
C-16 It gives me my value as a separate person but my mother’s GP is understanding and supportive of me too.
C-17 Yes as I feel my GP can concentrate on my problems only,
C-22 No particular benefit just the way things evolved. My daughter’s GP is a former colleague and assumed her medical support at my request upon her de-institutionalization.

Q. 2.3
Has your local doctor (GP) recognised and supported you as "the carer", with special needs?

<table>
<thead>
<tr>
<th></th>
<th>C-2, C-3, C-4, C-5, C-6 C-8 C-10, C-12, C-15, C-16, C-17, C-19, C-20, C-21, C-22</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
</tbody>
</table>

If 'No', how do you think you have been perceived? [ eg as a parent, spouse, partner etc?]

C-7 Just there to solve all problems
C-9 As parent
C-11 Has no real idea of what ‘caring’ really does entail.
C-14 Spouse.
C-18 As an object.

Q. 2.4
Has the GP's receptionist recognised you as "the carer" with special needs?

<table>
<thead>
<tr>
<th></th>
<th>C-1, C-2, C-3, C-4, C-5, C-6, C-8, C-10, C-11, C-12, C-15, C-17, C-19</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
</tr>
</tbody>
</table>

-8-
Q. 2.4 [continued]
Has the GP's receptionist recognised you as "the carer" with special needs?

Comments:
C-16 GP doesn't have a receptionist at the surgery I attend. She's at the main surgery.
C-23 I haven't felt any lack of care though.

Q. 2.5
In what ways has your local doctor been able help you as the carer, either recently or in the past?

C-1 Directing us to persons who are able to help us
C-2 By advising with medication
C-3 Always at end of telephone and will make a house-call if required
C-4 Recommending appropriate support facilities
C-5 Home visits, referral to hospital, encourage me to go out more
C-6 Doctor calls to the house to examine husband, instead of us going to the clinic. [GP] also authorised pathology nurse to visit, to give him blood count each month, but all the assistance came after we initiated the question and actions.
C-7 If I know what I want will refer me on.
C-8 He helped me to receive the service of Community Options.
C-9 Helpful in enabling us to use local community transport service.
C-10 By helping me to get our entitlements.
C-11 In the past they used to come out to my son quickly during the night-now those services are not available.
C-12 He has gone out of his way to be available to talk to when needed.
C-14 Told me to have a week's respite when my blood pressure was up high
C-15 By being very kind when I have needed him and being able to talk to him about husband.
C-16 I think just by allowing me to pour out my worries and concerns, sometimes he does suggest things that are helpful.
C-17 Has always been available for support and very understanding and listens to me
C-19 By always being available. Doing house calls and referring to Specialists.
C-21 He has advised me as well as helped me to seek help from various local helpers eg. domiciliary care, district nurse, referred my wife to specialists at the hospital. Placed my wife in a private hospital to receive special care and to give me some respite from the constant pressure.
C-22 Not much (help) but then I take responsibility for myself and he knows this.
C-23 My son was acknowledged, accepted, not threatened. The GP has been quick to act when asked for help and is not judgemental. She is empathetic, helpful and approachable.

Q. 2.6
Could you suggest how your local doctor might have been more helpful?

C-1 To realize carers' needs and in my case help in letting husband understand that I need a break sometimes.
C-3 Quite satisfied
C-4 Has always been most supportive. Being aware and availing oneself of the support provided through community carers programs
C-5 If the carer is sick and cannot get medicine, surgery to get same and deliver it. - [PS Not needing this service up till now I don't know if our GP provides it.]
C-7 Talking - understanding
C-11 They could understand my situation more fully and respond accordingly.
C-12 No.
C-14 Told our children to be more supportive.
C-17 Could have had pamphlets and contact numbers of help and support groups.
C-18 By listening sometimes to my problems and not pointing out the difficulties he and also staff of private hospital has (when mother was admitted...)
Q. 2.6 [continued]
Could you suggest how your local doctor might have been more helpful?

C-20 My original GP did not listen to my concerns for my husband-I think he felt I was being a difficult wife. Perhaps if he had visited my husband at home and made more of an effort to talk to him he may have seen through my husband's camouflage.

C-21 Possibly by advising his receptionist to collect some information concerning local nursing homes and any patient vacancies that could be occurring in the near future. I only received this information when my wife was finally referred to the care of hospital. This was then far too late and I was almost a hospital case myself.

C-23 In the past I have often felt that we were dealt with as quickly as possible and not really considered to have much of an opinion or feelings.

Q. 2.7
What general information and support has your GP offered you in your caring role?

A. Information

General information and support offered to carer by the GP

<table>
<thead>
<tr>
<th>Category</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>the dependent person's illness/disability</td>
<td>2</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>what to do in a medical emergency (concerning the person you are caring for)</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>contact for after hours medical care (for you or the person you are caring for)</td>
<td>5</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>respite services available for you</td>
<td>9</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>other services available for you or the dependent person</td>
<td>7</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>government benefits or special allowances and where to go to apply</td>
<td>11</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>where to obtain a Carer's Kit</td>
<td>12</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>special adaptations for the home including where to go to find out where to get them</td>
<td>10</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

Other comments from carers

C-8 He or one of his partners has always been available
C-9 I had found out about most services that we could use whilst my son was still at .. Centre
C-16 I have received the information from FMC and Dom. Care and mum's GP.
C-17 This information was all supplied by Dom Care initially
C-18 The GP had decided 2 years ago to admit mother to a nursing home. As I disagreed the GP has been hostile ever since .
C-20 My first GP gave me no information. The lady who help me with house cleaning gave me a lot of information, she had nursed her mother. I took on a new GP a few years after my husband's diagnosis.
C-21 The GP was usually very helpful in most instances
C-22 Medical advice only.
C-23 I was in possession of this information before I met my GP.
Q. 2.7.1
As a carer, what INFORMATION from your GP have you considered to be the most important and helpful?

C-2 By his knowledge of my husband's affliction and he listens to our problems
C-3 To watch diet and exercise if able, and to take prescribed medication as instructed.
C-4 Providing contacts to the caring network.
C-5 He explains the illness and also tells me of any side effects from the medication
C-6 GP was not the person who gave advice on all groups who could help us
C-7 I usually seem to inform him.
C-8 What symptoms to look for and his referral to hospital or specialist when necessary.
C-10 I consider everything he has done for us is important.
C-14 Call an ambulance when he is very ill or a bad T.I.A.
C-15 I really think the Specialists at Daws Rd Hospital have given me most information about my husband.
C-17 How to care for myself by answering all questions in a straightforward manner.
C-18 None.
C-19 Referral to specialists who were unable to help.
C-21 His decision to refer my wife to specialists at hospital. They were able to seek government approval for my wife to enter a nursing home to receive far better care than I could give her. They too were able to find a vacancy for my wife to enter the ... Nursing Home because they had organised information re nursing homes.
C-22 Medical information that made the difference between life and death for my daughter.
C-23 Availability of counselling services; chance to have an appointment with a paediatrician interested in people with my son's diagnosis.

Q. 2.7.2 Who has provided you with the most helpful information in the past? n=22

Social worker [11]
Carer Support Group [10]
Hospital doctors/specialists [10]
GP [9]
Community Health Nurse/worker [4]
Local Council [4]
Friend [3]
ADARDS [3]
District Nurse [2]
Hospital Nurse [2]
Relative [daughter ] [2]

Q. 2.7.2 Who has provided you with the most helpful information in the past?

Other comments
C-1 GP - hospital, Doctors/specialists
C-2 GP & specialist, also family support
C-3 GP & specialist, district nurse
C-4 GP, social worker
C-5 GP, hospital, doctors, hospital sister, carers support group
C-6 Hospital social worker informed both carer support network and Alzheimers Assoc.
C-7 HACC program
C-10 ......Day Centre staff
C-15 Daughter
C-17 Day Care centre, Dom Care
C-19 ADARDS Carer eduction
C-22 My own network
C-23 Womens' resource centre, Telephone book
Q. 2.7.2
Who has provided you with the most helpful information in the past?

Specific comments: C-22
My own networks which consist of other carers, public servants at state & federal levels.
Re: Community Health Nurse/worker: ...they have a long way to go!
Re: Carer Support Group: Too group orientated. Too aged care focused.

Q. 2.7 (Continued)
B. Referrals: Have you been referred to OTHER agencies by your GP:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Support Group</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Community Health Centre services</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Day Care Services</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>District Nursing Services</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Domiciliary Care Services</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Financial/Legal Advice or Services</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Meals on Wheels Services</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Professional counselling services</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Respite Care</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Local Council Community Services</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Other Community services</td>
<td>1</td>
<td>8</td>
</tr>
</tbody>
</table>

(eg for practical home/domestic help or assistance with transport)

Carer Comments
C-14 I have told the doctors what help I have found out about and used
C-16 Not by my GP but by my mother's GP.

C. Support:

<table>
<thead>
<tr>
<th>Has your GP:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offered you emotional support?</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Provided co-ordination of any of the services above?</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Reviewed your situation regularly?</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Q. 2.8
What other support has your GP provided that has helped you?

C-14 Keeping a check on my blood pressure.
C-17 Always asks how I am coping first without me bringing the subject up and asks about problems.
C-18 None
C-19 Is understanding and supportive would give counselling if I asked.
C-20 In these last years whilst my husband was home my GP was very supportive. I could ring him any time to discuss a medical problem.
C-21 Placed my wife in a private hospital to give her some specialist care for a limited period and also to provide me with some respite.
C-22 I have just discovered a great doctor. Signs documents for carers pension, mobility allowance & DNBC [Domiciliary Nursing Care Benefit.] Emotional support by recognizing my (at times) frailty (emotional
C-23 Routine health checks. She has made herself available for discussion.
Q. 2.9
Please provide some examples of how GPs could help carers generally, or when the carer is ill and is needing care for him/her self?

Either in the consulting rooms or when making house calls.

C-1 By giving carer some time alone with them from time to time; to talk over their needs.
C-2 Listening to the carer; recognising that the carer has his/her own identity. Sometimes the carer can feel invisible.
C-3 Very good - explains how to keep carer healthy.
C-4 Being good listeners. Concluding consultation with comment: "Is there anything else?"
C-5 Easy access to surgery for wheelchairs. Have contact with carers support groups. More information displayed on where to get more help. Be able to provide medication when carer is sick and unable to get it at the chemist.
C-6 More pamphlets of information about various caring groups.
C-7 By becoming more informed as to what really happens in the home. Not just prescribing a bottle of pills and thinking that is the end. [GP doesn’t] Home calls would be a great help. Locums always start with - "You need someone who knows the patient".
C-8 By being more commutative about options.
C-9 In surgery-see carer at appointed time, eliminate long waiting time.
C-10 Could make a house call when I needed an injection for migraine instead of waiting hours for A.H. service-which means I would be unable to attend to my son’s urgent needs should he have a seizure.
C-11 I think GPs could listen to cause and try to understand mental illness which they do not seem to have a clue.
C-12 By being friendly and treating me as a person with a need.
C-13 By listening and avail time for empathy.
C-14 By recognising the carer’s stress and helping to arrange treatment or respite for the carer.
C-15 Ask the carer what help she has, then contact these people and advise them of what has happened and that more assistance will be needed. Dom care and Community Options were great support to me, but the doctor never contacted them.
C-16 Provide temporary care for patient while carer can shop or carry out business transactions. Call in a helper when carer is ill. Immediately notify correct authorities if a crisis is arising in the home.
C-17 As of today I have lost interest in other carers generally.
C-18 By empathy non-judgmental attitude. Concern for our ‘cared for’ and consideration of best available respite option.

Q. 2.10
Who do you usually go to when you need support and/or help?

<table>
<thead>
<tr>
<th></th>
<th>I go to:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[Many respondents gave more than one response]</td>
</tr>
<tr>
<td></td>
<td>n=22</td>
</tr>
<tr>
<td>Members of your family</td>
<td>C-1, C-4, C-6, C-11, C-12, C-14, C-15, C-16, C-19, C-21</td>
</tr>
<tr>
<td>Your local doctor (GP)</td>
<td>C-4, C-8, C-15, C-16, C-17, C-21, C-22</td>
</tr>
<tr>
<td>Carer Support Group</td>
<td>C-4, C-8, C-12, C-14, C-15, C-17, C-20</td>
</tr>
<tr>
<td>A community worker</td>
<td>C-4, C-6, C-8, C-12, C-17, C-20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I don’t go to:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=22</td>
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<tr>
<td>Members of your family</td>
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<tr>
<td>Your local doctor (GP)</td>
<td>C-6, C-18, C-22</td>
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<td>C-18, C-20, C-22</td>
</tr>
<tr>
<td>A community worker</td>
<td>C-18, C-20, C-22</td>
</tr>
</tbody>
</table>
Q. 2.10 [continued]
Who do you usually go to when you need support and/or help?

OTHERS:
C-1 [Family can assist] sometimes, but not always.
C-2 Carers' Project Group
C-3 Council Welfare officer
C-4 Alzheimer's Association + Family, GP, Community health worker
C-5 I do contact my son but he isn't really very forthcoming - unfortunately he doesn't think....
C-7 Battle on myself - it's usually out of office hours!
C-9 Community Living Project
C-10 Day Care Centre
C-12 Family
C-22 I manage my daughter (support) with funding
C-23 Carer support group, church, friends, clergy. Either depending on the help I think I need.

Q. 2.11
Who of the above do you prefer to go to when you need support and/or help?
C-8 Local doctor and Community Options.
C-9 Community living project.
C-10 Carer Support Group.
C-11 My cousin, we support each other-and a friend.
C-12 Family.
C-14 Daughter and son
C-15 My daughter who understands and has helped me since I have been a carer.
C-16 Local doctor.
C-17 Carer support or social worker.
C-18 So far I have managed by myself.
C-19 GP for advice, family for some help.
C-20 Community Options. The Carer Support Group. P.... was a wonderful back-up for me, extremely supportive.
C-21 Our family if not working. Secondly our local doctor
C-22 Emotional support comes from within. My friendship network of other single women caring for their adult children with severe and multiple disabilities.
C-23 Either - depending on the help I need
### Q. 3.1 Is your own health?

<table>
<thead>
<tr>
<th>Health Rating</th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
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</tr>
<tr>
<td>Very Good</td>
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</tr>
<tr>
<td>Good</td>
<td>6</td>
</tr>
<tr>
<td>Fair</td>
<td>8</td>
</tr>
<tr>
<td>Poor</td>
<td>3</td>
</tr>
<tr>
<td>Very Good/Good</td>
<td>11</td>
</tr>
<tr>
<td>Poor/Fair</td>
<td>11</td>
</tr>
</tbody>
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### Do you have chronic illnesses, disabilities, etc.? n=22

<table>
<thead>
<tr>
<th></th>
<th>n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>C-2, C-4, C-7, C-8, C-10, C-11, C-12, C-15, C-16, C-18, C-21, C-23</td>
</tr>
<tr>
<td>No</td>
<td>C-1, C-3, C-6, C-17</td>
</tr>
</tbody>
</table>

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### Do you have chronic illnesses, disabilities, etc.? Please give details.

<table>
<thead>
<tr>
<th>C-1</th>
<th>Osteoarthritis</th>
</tr>
</thead>
<tbody>
<tr>
<td>C-2</td>
<td>Osteoarthritis</td>
</tr>
<tr>
<td>C-4</td>
<td>Benign essential tremor</td>
</tr>
<tr>
<td>C-5</td>
<td>B/P control by tablets. Diabetes - tablets, glaucoma. Otherwise fine. I have a carotid body tumour which I'm told should be removed. Because of my husband’s needs and the fact that such an operation could cause one to have a stroke and I wouldn't be able to care for him if I did, I'm very very reluctant to have the op.</td>
</tr>
<tr>
<td>C-7</td>
<td>Heart and stress related - ie ulcer, partial mastectomy</td>
</tr>
<tr>
<td>C-8</td>
<td>I am at present attending a urologist for problems with blood in my urine.</td>
</tr>
<tr>
<td>C-9</td>
<td>I had a disc removed from my spine 5 years ago and have been in constant pain ever since.</td>
</tr>
<tr>
<td>C-10</td>
<td>Getting more frequent migraines through my back problems. I am limited to what I can do</td>
</tr>
<tr>
<td>C-11</td>
<td>Ulcers</td>
</tr>
<tr>
<td>C-12</td>
<td>Thyroid also bladder trouble and nerves.</td>
</tr>
<tr>
<td>C-13</td>
<td>I have high blood pressure (which for the first time in 5 years is normal).</td>
</tr>
<tr>
<td>C-14</td>
<td>An anxiety disorder</td>
</tr>
<tr>
<td>C-15</td>
<td>Allergies.</td>
</tr>
<tr>
<td>C-16</td>
<td>Arthritis right elbow, thumbs and right ankle. 20% back disability. Slight asthma, allergy.</td>
</tr>
<tr>
<td>C-17</td>
<td>Born with bronchial asthma, have been on cortisone daily for over 41 years, bones and immune system affected.</td>
</tr>
<tr>
<td>C-18</td>
<td>War disabilities; ulcerated stomach but under control. Loss of hearing through flying aircraft in war. Rheumatic pains</td>
</tr>
<tr>
<td>C-19</td>
<td>Emotional, mental issues. Physical very good but with a predisposition to chronic tension in my neck and shoulder which is debilitating when active.</td>
</tr>
<tr>
<td>C-20</td>
<td>Some osteo-arthritis-knees, neck.</td>
</tr>
</tbody>
</table>
Do you feel your caring role has affected your physical or emotional health or well being recently, or at any time in the past?

| My caring role has not affected my health | C-2, C-3, C-18 |
| My caring role has contributed to my health problems e.g. | [3] |
| Has had a minor effect on my health | C-4, C-5, C-6, C-7, C-10, C-11, C-12, C-14, C-16, C-17, C-19, C-21 |
| Has had a moderate effect on my health | [8] |
| Has had a major effect on my health | C-1, C-4, C-8, C-9, C-10, C-12, C-14, C-16, C-17, C-21 |

Moderate / Major effect combined [13]

3.2 (continued) Please briefly describe how you feel your health has been affected.

C-1 Back and muscle pains - tiredness, occasional depression
C-2 Lifting and moving - I find is difficult as I have arthritis and sometimes stress causes problems.
C-3 Tiredness, stress
C-4 Stress, depression
C-5 Occasional back/muscle strains, headaches, temperament, disability, irritability, frustration, guilt feelings.
C-6 Often very tired. Continuous weeding. Getting hiatus hernia through bending down to much, doing up shoes, putting on socks.
C-7 Severe tiredness, inability to control own life. Stress, depression. Continually at the call of carer / medical professional services. All geared to the male needs then female. When very tired - loss of memory
C-8 Stress and anxiety are 2 major concerns
C-9 Because of my known chronic disorders, I keep a rigid control on all known irritants, and take regular exercise. Sometimes I would just like to relax and let go.
C-10 With my wife needing total care it is very tiring, at times I feel exhausted.
C-11 After my surgery, caring for my son's physical needs during seizures, hurt my back more. Makes life more difficult because I can't do the physical things I used to alleviate the stress of caring for my son-ie, hiking, riding, gardening, driving, classes, etc
C-12 Stress is a major contributor
C-13 No ans
C-14 Affected by stress of coping and being very tired.
C-15 Mainly through the stress of having to run backwards and forwards to hospitals. Free time is curtailed to the afternoon. Taking Mum out is very stressful to me.
C-16 Blood pressure. Cholesterol raised. Stress have had to take anti-depressants and sleeping pills
C-17 Only emotionally whilst accepting a total behaviour change. Takes adjusting and attitudes of outsiders.
C-18 Because I am ageing the caring is becoming harder, which is very stressful.
C-19 My attitude, commitment and desire to care at home kept me going.
C-20 Weak back through lifting my wife frequently on my own.
C-21 The terrible isolation and feeling ALONE except my carer colleagues knows or understands what is really happening - AND the witnessing of service providers making a very fine living out of our misfortunes while we are living in poverty on $165.00 per week.
C-22 I am not sure if I can answer this. Other stresses have affected me also. I have been depressed, burnt out, terribly tired, but have also received the benefit of regular exercise with my son and absolutely no pressure to rush.
MISC Often feel debilitated and stressed. Upset sleeping conditions and habits.
MISC Moderate effect on my health.
Q. 3.3
Has your sleep often been interrupted because of the caring role and responsibilities?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13 C-1, C-7, C-10, C-11, C-12, C-14, C-15, C-16, C-17, C-19, C-20, C-22, C-23</td>
</tr>
<tr>
<td>No</td>
<td>6  C-2, C-3, C-4, C-5, C-6, C-18</td>
</tr>
</tbody>
</table>

If yes, what effect do you feel this has had on your health and well being?

C-8 Often feeling very tired
C-9 I have insomnia-possibly from stress-not from direct interruption.
C-10 Quite a bit.
C-11 I sleep lightly as my son’s seizures are nocturnal and necessitate jumping up when I first hear him convulsing. Sleep is constantly interrupted.
C-12 At times it makes me very tired.
C-15 When my husband was home full time I could not sleep and got quite ill. Now he spends 4 days in nursing and still have trouble sleeping because I worry all the time.
C-16 Detrimental of course. I do really need 8 hrs sleep straight. That causes stress and anxiety
C-17 Always tired.
C-19 Broken sleep and lack of sleep makes one tired and irritable.
C-20 A large effect.
C-21 Broken sleep due to the caring has created listlessness as well as sheer exhaustion which have influenced my health.
C-22 Tiredness in the morning which makes arising and taking part in the remainder of the day a depressing objective.
C-23 It happened when he was younger-that’s when I couldn’t cope well with other things in my life and became very depressed, often waking at 2-3am

Q. 3.4
Has this interfered with your normal daily activities?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15 C-1, C-2, C-10, C-11, C-12, C-14, C-15, C-16, C-17, C-18, C-19, C-20, C-21, C-22, C-23</td>
</tr>
<tr>
<td>No</td>
<td>2  C-4, C-9</td>
</tr>
</tbody>
</table>

Carer Comments

C-1 Broken sleep leaves me tired next day
C-2 I am limited to the time I can spend away from home. If I am to be gone for any length of time I have to have assistance
C-5 My husband spends a lot of time in the lavatory also is in many times so its difficult for me to ‘get there’. Breakfast a long process. Often doesn't eat his food.
C-6 Before his tablets were adjusted, he was having hallucinations - up sometimes 5 times between midnight and 5.30am. Now he sleeps right through the night. On bad nights I get up to check for him - he needs constant supervision next day.
C-7 Am never sure how I really am until near collapse - need the help of pills to sleep.
C-8 Being too tired to do as much as I would like to do.
C-10 I don’t seem to have the energy to do anything.
C-11 Makes me tired
C-12 Having to plan everything at specific times.
C-15 By being very tired all the time.
C-16 I find my energy level becomes effected.
C-17 Too tired to plan.
C-18 Hardship to stick to a set routine.
C-19 Tiredness causes depression and the feeling of never quite coping with everything.
C-20 One has to be alert and very patient with Alzheimers sufferers, so without sleep I was flat out being alert and patient
C-21 Has tended to slow down my activities and created confused thinking. My alertness is badly dulled.
C-22 I am losing my ability to continue the fight for Carers Rights and Constitution, and it is making me very sad.
C-23 I suppose I had little joy in life at that time, tending (to be) irritable and accident prone.
Q. 3.5
What is the main effect your caring role has had on your ability to do each of the following?

Questions (a), (b) and (c) below have been adapted from the Carers Questionnaire, "Disability, Ageing & Carers", 1993 Aust. Bureau of Statistics, Catalogue No. 4432.0

(a) **To go out during the day**

<table>
<thead>
<tr>
<th>Effect</th>
<th>Count</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Minor change</td>
<td>5</td>
<td>C-1, C-8, C-15, C-16, C-17</td>
</tr>
<tr>
<td>Can only go out when help is arranged</td>
<td>14</td>
<td>C-2, C-3, C-4, C-5, C-6, C-7, C-9, C-10, C-12, C-14, C-18, C-19, C-22, C-23</td>
</tr>
<tr>
<td>Can only go out with person you care for</td>
<td>5</td>
<td>C-3, C-10, C-14, C-15, C-23, C-10</td>
</tr>
<tr>
<td>Not usually able to go out in the day</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

[Some respondents answered more than once]

---

Please briefly describe the main difficulties involved in going out during the day.

- **C-1** Having to lift wheelchair into the car.
- **C-2** As said in question 3.4. My husband has one day a week at Day care which is good for both of us.
- **C-3** Day Centre provides me with Fridays off 9 am-4 pm.
- **C-4** Has to be planned so far in advance.
- **C-7** Husband doesn't want to go out, doesn't want to visit, go to cinema or theatre. I do go to art classes and leave him, although earlier this year he was suicidal and I couldn't leave him unattended. All the doctors we have even had have told me to go out - so I do.
- **C-8** Continually planning and watching clock.
- **C-9** Because my husband is blind I have to be here to get the three meals a day.
- **C-10** My son needs a structured routine and supports must be in place to enable me to be free.
- **C-11** I am able to go out when my wife is at the Day Centre. I must take my wife with me or I have to arrange for a sitter.
- **C-12** My ability to go out during the day revolves totally around my son's seizures and illnesses and varies as such.
- **C-14** Having to ensure somebody available to look after Dad.
- **C-15** Organising the Access Cab to the city and having to push the wheelchair.
- **C-16** When my husband is home Friday until late Sunday afternoon, I have to take him with me as he would not stay home on his own.
- **C-17** I can only go out after lunch, so full day activities are out of the question.
- **C-18** Usually have to organise my husband into an activity so I can relax while out.
- **C-19** The availability of a sitter to stay with the carer, and also the cost of same.
- **C-20** Arranging a sitter then making sure the sitter will be able to cope. Organise meals. Someone skilled and sensitive to my husband's needs.
- **C-21** The time factor was a problem. Helping my wife to shower and to dress herself. Assisting her in her walking and getting her in and out of the car in case she fell. Being near her at all times to give her help.
- **C-22** Reliable support workers who are able to take responsibility, be trusted to respect (1) my daughter's dignity and rights and vulnerability; (2) our home, and property and utilities within it. If I go out with my daughter it takes 2-3 hrs to get organised before we can go. We usually don't go!!
- **C-23** I can go out when son is at school but we usually spend weekends together.
Q. 3.5 (Continued)
What is the main effect your caring role has had on your ability to do each of the following?

(b) To go out during the evening

<table>
<thead>
<tr>
<th>Effect</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>[2] C-16, C-18</td>
</tr>
<tr>
<td>Minor change</td>
<td>[4] C-1, C-5, C-9, C-17</td>
</tr>
<tr>
<td>You can only go out when help is arranged</td>
<td>[9] C-2, C-4, C-11, C-12, C-17, C-18, C-19, C-20, C-23</td>
</tr>
<tr>
<td>You can only go out with the person you care for</td>
<td>[2] C-3, C-23</td>
</tr>
<tr>
<td>You are not usually able to go out in the evening</td>
<td>[10] C-6, C-8, C-10, C-11, C-14, C-15, C-19, C-20, C-21, C-23</td>
</tr>
</tbody>
</table>

Please briefly describe the main difficulties involved in going out during the evening.

C-1 Husband tends to feel vulnerable going out after dark. So we rarely go.
C-2 By late afternoon/evening my husband is very slow and unbalanced and is liable to fall.
C-3 Wheelchair access and lack of parking in close proximity. Impossible where no lift in building.
C-4 Has to be planned so far in advance.
C-5 I do go out in the evenings but always ask if its OK with him. He doesn't want to go out.
C-6 Both too tired.
C-7 Have lost all interest in going out in evening. Sleep too important.
C-8 Mainly our age and lack of transport.
C-10 For me to go out means that I have to arrange a person to sit with my wife.
C-11 The difficulty is getting a carer in; staying away overnight is out.
C-12 Extremely hard to arrange relief sitters.
C-14 We both need to go to bed by 9pm.
C-15 I do not care to go out in the evenings on my own, also feel too tired to do so.
C-16 Main difficulties—I'm usually too tired to enjoy myself.
C-17 Cannot plan too far ahead as never sure of my husband's needs or health condition.
C-19 The availability of a sitter etc.
C-21 Her poor eyesight and unstable walking made evening outings almost impossible. She would often "freeze" in the dark and it was only with great difficulty that I could get her to move on.
C-22 ... usually so stuffed I can't be bothered.
C-23 Finding a sitter, finding energy and motivation to arrange an evening out.

Q. 3.5 (Continued)
What was the main effect your caring role had on your ability to do each of the following?

(c) To go on holidays

<table>
<thead>
<tr>
<th>Effect</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change</td>
<td>[1] C-22</td>
</tr>
<tr>
<td>Minor change</td>
<td>[2] C-1, C-17</td>
</tr>
<tr>
<td>You could take more holidays</td>
<td>[2] C-8, C-19</td>
</tr>
<tr>
<td>You cannot take as many holidays</td>
<td>[5] C-4, C-9, C-10, C-17, C-19</td>
</tr>
<tr>
<td>You cannot take holidays</td>
<td>[10] C-3, C-5, C-11, C-12, C-14, C-15, C-16, C-18, C-20, C-21</td>
</tr>
</tbody>
</table>

Please briefly describe any difficulties you have had in taking holidays.

C-1 Finding suitable accommodation for husband - also a lot of places we used to go to are now unsuitable.
C-2 Holidays can only be taken when respite is arranged as my husband is unable to travel.
Please briefly describe any difficulties you have had in taking holidays. [continued]

C-3          Too much hassle trying to handle luggage with wheelchair.
C-4          Have to organise respite
C-5          Haven't had a holiday 1994 - husband didn't like hostel 1993 so feel reluctant to put him in another one. Also he now wears a urodynamic at night and I'm not sure whether he could cope with it in a hostel. Still one of these days I might test it out.
C-7          Am beginning to take more holidays with a lot of preparation. Until now had to take care also
C-8          To get someone to look after pets such as therapy dog and the garden
C-9          One parent stay at home whilst the other is on holiday
C-10         My wife cannot get on public transport as she is confined to a wheelchair.
C-11         My son must come or be cared for by a friend which is a worry and not really suitable.
C-12         Arranging respite care most places booked out till next year.
C-14         We are unable to take a holiday together. I have to go away by myself while my husband is in a nursing home. [6 months ago I had a 5 day bus trip]
C-15         Being on the pension we don't have many holidays. Occasionally my daughter takes me away for a few days, for a rest.
C-16         Mum needs me in the mornings. Breakfast, making bed, emptying commode, checking she's alright in the shower.
C-17         Holidays have to be planned to cope with my husband's abilities so not really what I would like to do.
C-18         After each stay in a private hospital mother's condition deteriorates.
C-19         Respite has to be arranged well in advance, and I do not like my mother to go into an institution, for this I worry about her
C-20         My husband is too confused to take away.
C-21         Unable to wash and dress herself. The stress of preparation for a holiday was just too much for her and brought on incontinence.
C-22         The flexibility of our funding arrangements enables me to use some of that funding to take a holiday which is how it would be if I were working full time.
C-23         It hasn't occurred to me to go on holiday without him.

Q. 3.6 How long is it since you had a holiday ?

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>C-22</td>
<td>C-15</td>
</tr>
<tr>
<td>2 weeks</td>
<td></td>
<td>1 yr</td>
</tr>
<tr>
<td>3 months</td>
<td>C-18</td>
<td></td>
</tr>
<tr>
<td>5 months</td>
<td>C-17</td>
<td></td>
</tr>
<tr>
<td>6 mths</td>
<td>C-10, C-11</td>
<td>2 1/4 yrs</td>
</tr>
<tr>
<td>7 months</td>
<td>C-8</td>
<td></td>
</tr>
<tr>
<td>8 months</td>
<td>C-19</td>
<td></td>
</tr>
<tr>
<td></td>
<td>27 mths [&gt;2 yrs]</td>
<td>C-12</td>
</tr>
</tbody>
</table>

Q. 3.7
Have you felt that not taking holidays in the past has affected your quality of life or health in any way? Please explain briefly how this may have affected you?

C-2          Sometimes, as the carer is inclined to feel tied down.
C-3          Miss the break away. Feel restrained
C-4          Yes adds to stress and depression.
C-5          I don't suppose not taking holidays has affected quality of life but I would love to travel far and wide. Thing is, I used to holiday with work colleagues abroad and my husband was quite happy for me to do so. I love going everywhere and meeting people whilst my husband says he's been there and done that. I can't bear staying at home, indoors all the time.
C-7          Yes. No time to recharge battery. Mentally as well as physically
C-8          Frustration. Loneliness.
C-9          I feel that everything is 'too difficult' and want to run away for some peace.
C-11         Yes, I would like to be able to go away without worrying about suitable respite or care. I can feel very stressed and tired, and would like some holidays on my own.
C-12         Yes lack of time to relax, worry about myself only.

-20-
Q. 3.7
Have you felt that not taking holidays in the past has affected your quality of life or health in any way? [Continued]

C-14  I need to plan future holiday, have something to look forward to. I plan to go to Norfolk Island in July.
C-15  One sees friends and family having holidays and it makes one feel very sad that the carer has just to keep on caring. Because of being the wife and is expected to do so.
C-16  Yes. I love travelling and find I get very jealous of other family members' freedom and also my great need for an unstressful change. I love travelling around by myself in a group.
C-17  Have had holidays with my husband. Have had 2 respite holidays on my own.
C-18  Being without constant responsibility few times during the year is relaxing as "a switching off" is beneficial.
C-19  I have not been able to have a holiday when I needed it. Holidays not long enough to completely rest
C-20  In recent years my helpers arranged to stay with husband whilst I had 2 nights at Goolwa with friends.
A complete break and rest would have restored my energy. However I would have had to have someone move in the house who know my husband, his routine and meals well. In my case just a lot more night relief would have made an enormous difference.
C-21  My daughter took over the caring for a week to give me a short respite - two years ago. The constant pressure of assisting, hurrying, organising, preparing, performing and worrying, certainly took it toll of my health and left me exhausted and irritable. While my stomach problems from my war years began to worry me again.
C-22  I usually get invitation to attend conferences. Give papers on Caring/ Disability and endeavour to have extra days at the beginning or at the end to have a bit of a break. Not the ideal however, as it is always necessary to discuss plans with others. Safe, reliable guaranteed suitable for the needs of the carer and the person with disability.
C-23  Not really-hard to know unless its happened! I suppose my expectations are lower. But I was the one to actually go on holidays. I had a week when he was at a camp [ 6 years ago ]

Q. 3.8
What might help to maintain or improve your own health and well being?

C-1  A little time on my own to rest.
C-2  At the moment all is well. I have a few outside activities which keep me in touch with other people, especially people in the same situation.
C-3  Turn back the clock 10 years.
C-5  The ways and means to go abroad and other places - impossible that my husband will want to go too. As my husband and I get older we shall probably need more assistance, but at the moment he has a sitter once a week and goes to a day centre one and 1/2 days per week. I continue to go to my hobby classes, and to my spiritual centre.
C-7  Time alone - seems impossible!
C-8  No. Since I have been included in Community Options Program I have felt much more relaxed.
C-9  To know that my son could live in his own home and be supported by others to maintain the lifestyle I have been able to create for him.
C-10  Getting the extra help I need.
C-11  Suitable services for my son, alleviating stress on myself; More understanding by other people and GP's in particular of my difficult role.
C-12  Access to respite needs to be improved on both long and short term.
C-15  If I could rely on staff at nursing home to do what I asked of them for my husband's best interests. Also to be able to have a short holiday more often.
C-17  Quality time to myself. To be myself and just not husband's carer. To be able to take a week off more often.
To be able to sleep without disturbances at night.

-21-
Q. 3.8 [continued]
What might help to maintain or improve your own health and well being?
C-18 To be considered by other as a person - not mother's carer
C-19 Regular short respite (once a fortnight) therefore less stress
C-20 Having weekly 1 or 2 nights sleepover and more when my husband was walking and yelling all night.
C-21 Yes, an absolute break away from the caring for at least a month. Some form of complete relaxation from all pressures on the mind and body. When my caring ceased, I noticed that my mind of its own accord, was constantly trying to shut out all memories of my caring period as though trying to mend itself, and I soon forgot many of the small things I did for my wife.
C-22 At least double the current pension or an adequate living wage with higher levels of funding, to provide adequate support for daughter. Individual funding managed by me which removes the necessity to continually telling people your plans.
C-23 Living in a community with other families and support workers and disabled people

Q. 3.9 What are some positive and enjoyable aspects of your caring role for you?
C-8 Just to be here when my husband needs me and to make his life as comfortable as possible
C-9 Shared achievements - goals realised; Shared enjoyment - knowing that I am good at my job; Working together to create a 'good life' for both of us
C-10 I am caring for someone I love and do not wish to be separated from
C-11 It's important to me to be able to feel I've done the best I can for him, even though he is considered very difficult. My son is fairly unrewarding, being non-appreciative mostly. However thanks to my personal commitment to his care he has exceeded all expectations of his specialist, and has a good quality of life. It is important to me to be able to feel I've done the best I can for him, even though his is considered very difficult.
It's important to me to be able to feel I've done the best I can for him, even though he is considered very difficult.
C-12 Being able to give back to my father some of the love and care that he gave me as a child. To extend his enjoyment in life as long as I can.
C-13 The people I have met at the various courses I have done; The wonderful friends I have met and knowing I am a much stronger person now than I was when I was not a carer; The courses I have done with carers club have given me the extra strength to carry on.
C-14 I love my mother and I do not want her to end up in a nursing home While I'm single and I've no intention of remarrying (too independent now) We get on very well. We used to go on holiday together, so I want to be there for her.
C-15 Have made new and interesting friends
Have learnt new skills.
Have become more positive person
Have learnt to enjoy whatever activity or outing I participate in
Am more patient and understanding with people in a similar situation
C-16 Being able to handle new situations and having time to enjoy my house, pet dog and garden
C-17 I am giving my mother home life in a family (instead of an Institution) for as long as I can manage to do this
C-18 I felt at peace within myself having him at home
C-19 My desire to help my wife seemed to grow stronger as I progressed with my caring. I devoted all to help her. Now that my total caring is our home is finished, I look back with pride and happiness on what I did to help my wife. I feel I could not have done more for her.
C-20 My daughter is safe and well and wakes up in her own room each day. That I am in total control of her support and people do things the way that I know is best for her.
C-21 I love my son, we get on really well. Through him I have gained much insight into myself I have been led to some wonderful people and experiences and have learnt to really know human worth. Also ignorance and fear. Its nice to reassure people
Q. 3.10
What does 'being a carer' mean to you?

C-8 The satisfaction of being able to do it.
C-9 Having to give up my paid work; Loss of freedom; Having to re-train my son in all social and domestic skills. I would love to potter in the kitchen on my own.
C-10 It means that I am caring for someone who needs me and that is very satisfying to me
C-11 It means giving my son the best kind of life I can. Its the most important (if hardly recognised) job one can do. I've cared for other family members in different circumstances - our family are very close and family values are very important to use, of which general "caring" is a huge part.
C-12 Giving of my time to improve the living standards for someone who otherwise would be placed in nursing home and become the patient, instead of "........." (father).
C-15 Exhaustion and always being there when my husband needs me. Being mentally tired all the time and coping with everything on one's own. Before everything was shared.
C-16 Just looking after Mum's needs and wants, although I grizzle sometimes I have to be her legs
C-17 Being responsible for the well being and care of my husband, finances, home, pets etc.
C-18 Living on a day-to-day basis without future plans
C-19 Assuming responsibility for someone else's welfare. Doing my best
C-20 It's being there for a person you love
C-21 To me it means a complete sacrifice of your own well being to help someone you love. If you love that person, your devotion and care will be absolute no matter what.
C-22 Isolation, depression loss of friends, little social life poverty, no sick leave, holiday pay, long service leave superannuation. Witnessing service providers and support workers maintain their lifestyle through government funded programmes while [carers are] receiving $165 for doing the same sort of work!!
C-23 Providing whatever may be needed to make up the person's deficit - and they invariably do the same for me

Q. 3.11
What are your responsibilities as the carer?

C-8 Visits to specialists. Medication supervision; Overseeing personal cleanliness; checking on appointments. Reminding about hair cuts, Doing laundry
C-9 Help my son to re-build his life using his present abilities; See that he (son) receives as much assistance from 'Service Providers' of all sorts as I can.
C-10 To do my job as a carer and see that the person I am caring for receives every attention
C-11 I have the absolute responsibility for my son's life and well-being. Trying to find and coordinate help and services, his lifestyle, his behavioural problems, his medical problems and health - working hard to give him as much independence as possible - mostly with an angry lack of co-operation. I can't give up on him though, even though I have been advised to at various times.
C-12 Supervising the life of my Father in his basic needs of life
C-15 Check at nursing home to see medications are given as ordered by specialist's. Everything, such as seeing bills are paid. All household chores, garden. After 2 years I feel so tired of it all.
C-16 To make sure Mum lives comfortably in her own home surrounded by her own things and her memories
C-17 To maintain my own health so that I can maintain a reasonable lifestyle for both of us
C-18 To clean, shop, wash, handle accounts, be a cook etc - The bonus - I am my own boss
C-19 24 hour constant care
C-20 A job where I felt overwhelmingly responsible for another person's life I had to try to get the best help and advice available. I had to organise our finances, make all decisions. I tried to keep our friends by explaining quite openly what was happening to my husband (with dementia), welcoming their visits and trying to stay bright and happy with them. I wanted my husband to feel safe and much loved. Also to give him some quality of life.
Q. 3.11 [continued]
What are your responsibilities as the carer?

C-21 To make sure that your patient is always happy, comfortable and contented and that he/she has not wants. Medication should be given in correct quantities and at the right time to ensure the patients as free from pain as possible and getting all the aid and rest that is needed.

C-22 24 hour, 7 day, 52 weeks each year. Involvement on various Board and Committees to ensure that things get done properly. But am rapidly becoming disenchanted by the attitudes of people in the various bureaucracies that are responsible for providing services to daughter and myself.

C-23 To provide shelter, food, love, warmth, education, exercise, different experiences of life and living - spiritual, physical, artistic etc. To nurture self-esteem and confidence, to accept and love someone for what they are and help them along their way, offering as much independence as they can manage.
Please indicate below if you agree with the following statements. The statements below were adapted from the leaflet, "Carers' Needs. A 10 Point Plan for Carers", Kings Fund Centre, London.

You are invited to add your comments for each statement.

**STATEMENT 4.1**

*I would like recognition of my contribution as a carer and recognition of my own needs as an individual in my own right.*

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C-2 Carers often feel their individuality is lost and is only acknowledged when it has been brought to notice.

C-7 This only happens when it fits in with the care/service providers' needs.

C-21 Despite feeling that I wished I could have done more to help my wife in her need with humiliation, I do feel proud of what I did to help her and that some form of recognition is appropriate.

C-22 Only in terms of an adequate living wage and proper funding: forget the flowers and kisses!

C-23 I would say most parents are in the same boat. But first that has to be recognised and then compatible people brought together.

**STATEMENT 4.2**

*I would like services tailored to my individual circumstances, needs and views, through discussions at the time help is being planned.*

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C-2 When my husband tried to commit suicide early in 1994 it was a great help and comfort to have the support of the Carers Support Group who rang me every day when he was in hospital.

C-7 There always seems to be more time put into "why a thing can't be done", than how it could be done.

C-9 I would like this to be a reality, not just written in guidelines. I would like services tailored to my needs by eliminating to need for 6 monthly or yearly assessments. Our needs are not going to miraculously disappear, in fact as I become more tired they will increase.

Over the years I have experienced being told of wonderful schemes to assist brain injured people only to find that by the time the various levels of controlling people have been put into place there is not enough money left to give the much needed support at the "coal face".

C-18 Domiciliary Care Services personel are very helpful always.

C-21 In my opinion this was done by those in the medical and nursing professions and I was very grateful for their advice and help.

C-23 I would be unhappy to leave my son with different people all the time. His difficulties are such that consistency is required to eliminate the likelihood of causing further problems. [He needs routine and consistancy].

-25-
STATEMENT 4.3

I would like services which reflect an awareness of differing family, racial, cultural and religious backgrounds/values.

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C-7 All families have a reason why and how something is done. Not just for racial/cultural and religious reasons. It seems that to do a thing one way because it works isn't good enough.

C-18 See 3.8 - I would like to be considered as an individual

C-21 To a degree, yes, but not paramount. The all important thing is total care.

C-22 Absolutely

STATEMENT 4.4

I need opportunities for a break, both for short spells (eg during day) or night and for longer periods (a week or more), to relax and have time to myself.

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C-2 Separate respite is of benefit in my case as it gives my husband an opportunity to meet other people.

C-3 Separate respite care facility

C-4 Need to experience both home respite and separate respite

C-5 Separate respite care facility

C-6 A need for both [home based and separate respite]

C-7 Both have their value. Depends on the stage the caree is at.

C-15 I prefer a separate respite care facility.

C-18 I would love to go away for two or three days once a year. Home based respite is less disturbing and confusing for the caree.

C-19 This is less disturbing and confusing for the caree.

C-21 Yes. I feel respite from the pressures of caring is very important to the carer.

C-22 Home based respite - Or would need personally selected support worker support in their home

[I prefer Home based respite - Never separate respite care facility - until a good quality support system is available...!]

C-23 I have to admit both of us would probably benefit from this type of growth experience.

STATEMENT 4.4

I Prefer Home-Based respite:

C-8, C-9, C-10, C-11, C-12, C-16, C-17, C-18, C-19, C-20, C-22

I Prefer SEPARATE respite care facility:

C-2, C-3, C-5, C-15, C-21, C-23

-26-
**STATEMENT 4.5**

I would like to explore alternatives to family care, both for the immediate and long term-future.

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C-3 In emergency it would be nice to know alternatives were available.
C-5 Haven't needed this yet, but hope it will be available when we do.
C-7 There doesn't seem the opportunity to try these services. It is all or nothing & if it doesn't work its nothing.
C-9 I am exploring this alternative but so far without success.
C-18 I never think of long term future and prefer to cross that bridge when I come to it.
C-21 This would be an excellent idea as the carer is often trapped into situations that they cannot avoid and becomes the victim of circumstances, whether he or she likes it or not.
Admittedly most people are normally willing to do their share of caring when called on to do so, but to be trapped is stifling.
C-23 I have a vision of a caring community within the community. i.e. a small estate set up.

**STATEMENT 4.6**

I need more practical help to lighten the tasks of caring, e.g. domestic help, home adaptations, incontinence services and help with transport.

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C-2 We are fortunate in SA as there are many services to help the carer, although sometimes this data is not shown. The carer has to find out for himself / herself
C-3 Able to cope at present
C-4 Incontinence - no problem at this time
C-5 Most essential needs.
C-7 Domestic help - that is, proper domestic help, not the Dom.Care kind of a lick and a promise. This doesn't necessarily need to be free- just experienced so that you don't have to go by the trial and error method which is too stressful.
C-18 Not at present
C-20 In nursing home
C-21 I agree. Many of these aids are exceedingly helpful to any frustrated carer.
C-22 Assistance in the form of low interest, subsidised loans for a suitable vehicle, and to cover the extra costs of disability. e.g. phone, ETSA, water, etc.

**STATEMENT 4.7**

I need someone to talk to about my emotional needs, at the start of caring, during and after my caring task is over.

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STATEMENT 4.7 [continued]

I need someone to talk to about my emotional needs, at the start of caring, during and after my caring task is over.

C-3 Carers Support Network has always been helpful.
C-4 Mostly provided by Alzheimer's Association counsellor, family - most supportive.
C-5 To have someone ring and ask if one is feeling OK. It's an awful feeling to be alone and wonder who would know that help is needed, if one fell and couldn't get up.
C-7 It is very hard to find someone who is non-judgemental. Being human + a carer is not on.
C-20 Not now. In the beginning the GP ignored emotional feelings. I worked hard to try and get him to see our needs. Community Options and social worker and Dom Care were very supportive.
C-21 Yes. It would help to settle all the turmoil and frustration which certainly cloud a carer's emotional mind. Talking to others about your problems would surely help to release some of the pressures.
C-22 But not a paid professional - it would just be another person making a fine living out of our misfortunes.
C-23 I would have benefited from this early on. I didn't trust anyone well enough, that only came three years ago. Also the listeners were professional, not family and friends.

STATEMENT 4.8

I need information about available benefits and services for carers as well as how to cope with the condition of the person I care for.

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C-2 This [information] is sometimes not forthcoming, although things are improving. Support groups etc are being explained more to carers/carees.
C-3 Receive pamphlets and up to date research data from Parkinson's Society.
C-4 Participated in Alzheimer's Carers' Training Course.
C-5 Information needs to be displayed at the doctor's surgery.
C-6 At first information was not forthcoming about all facilities. It took many months to gain knowledge from other people on what was available.
C-7 Battling one's way through government red tape is an art in itself.
C-18 I am always eager to learn.
C-21 Very essential. Due to my ignorance on this information I suffered badly at first as a carer. Full information of all available benefits and services are very necessary early in one's caring period.

From Carers' Questionnaire

Carers own statements about their needs

Please add below your own statement about other needs you have as a carer.

Administration costs too high - funds could go to carers
C-3 Possibility of too many agencies overlapping reaching the same conclusion. Administration costs eat up most funds allotted which could be used for benefit of carers, such as a carers allowance, for carers save State/Federal Govt thousands of dollars. Carers who qualify receive $26 per week which is a joke for the care given.
C-7 It seems to be perceived that if you're being paid to do the job it is harder than if you are doing it for nothing! Now the intense needs of my son are becoming less, my husband's are becoming more and I feel trapped. It looks like I will just have to battle on.

C-8 I feel I need some personal space at times but don't know how to accomplish this without hurting his feelings.

C-9 I would like services tailored to my needs by eliminating the need for six monthly or yearly assessments of our requirements. Over the years I have experienced being told of wonderful schemes to assist brain injured people only to find that by the time the various levels of controlling people have been put into place there is not enough money left to give the much needed support at the "coal face".

C-10 I feel that the best thing I ever did and which gave me access to more information to what my needs were also how to care for a person with Dementia and most of all what my entitlements were and what to do to get them. It was by taking the Alzheimers' Carers Courses at Glenside it was the best thing I ever did. It taught me a lot about caring and what help I could expect to get and left me with no illusions as to what a big job I was taking on.

C-11 More financial assistance. A large worry for us carers is the increasing level of poverty we find ourselves in, and trying to maintain a reasonable standard of living, our car etc, whilst on a pension. That in no way equates with the level of care we give in respect to outside service providers and what they earn.

C-17 To be recognised as my own person I attend aerobics and [special interest hobby] class weekly where no-one knows my home life so I am just myself. To overcome the frustration of people saying how well he looks/sounds.... they only see him [for] short periods and don't know what it is like not to have an intelligent conversation / discussion, and to listen to the same statement/question six times in an hour.

C-18 Being a carer means doing a job (as any other) to one's best abilities. If only outsiders would realise a carer is a person with knowledge and interests in other fields (so to speak). And sometimes there is a need for a shoulder to cry on. For me there is none.

C-19 I agree with the above statements. The full time carer needs a 5 day week, in order to continue caring without a further decline in health. Someone to step in and say "go and do what you want to do for a while." Someone to take the responsibility for a while: or someone to take the caree (i.e. the person being cared for), for an outing.

Recognition of my knowledge

C-20 As a carer not all health professionals acknowledge my knowledge, skills and understanding of what was happening and in some cases tried to take over

Importance of friends and family

C-21 I need the occasional company of relatives or close friends just to help share the caring burden for short periods. I also feel constant encouragement and friendly backing from others involved would be most beneficial to the carer to give him/her the impetus and fortitude to continue with the formidable task of caring.

Time out to enjoy caring role

C-23 Time out to enjoy the caring role would be great, the services provided get to do the good parts, I get to do the grotty. I suppose the thing I have missed the most is just the time to enjoy my son - that builds up resentment which in itself is destructive. Unless you are continually whinging, which is counter-productive, no one thinks about how hard it might be.
Carers added the following comments

C-8 I write this on behalf of other carers because all care workers are not as thoughtful as the ones I have. It has come to my notice that carers of people using oxygen are not told of safety procedures. Some carers are not able to get equipment they need. Some carers do not get enough respite. Some doctors could be more understanding and communicate. These are my observations from attending carers groups and not enough carers know that this support is available.

C-10 I feel that the best thing I ever did and which gave me access to more information as to what my needs were also how to care for a person with dementia, and most of all what my entitlements were and what to do to get them.

It was by taking the 'Alzheimer's Carers course at Glenside it was the best thing I ever did. It taught me a lot about caring and what help I could expect to get and left me with no illusions as to what a big job I was taking on.

Courses and training for carers

C-15 I feel that all carers need all the help they can possibly get to be able to keep on caring. I also feel that people caring for brain damaged people are such wonderful people because they have so much to cope with as one cannot converse with them and it is such a lonely life for a wife especially.

I urge all carers to do all the courses that are available because I had the choice of sitting home crying or getting out and doing every course. Some I did twice and the wonderful help I got I shall be ever grateful to ...[staff] from the Carer Support Network.

C-17 My role as carer has changed many times over the years. My husband has had a triple bypass 7 years ago, followed by a major stroke ten months later and a cancer op, 1 year later. During this time I waited on him entirely, put up with his anger and moods as I thought it was my duty.

Just over two years ago he had a heart attack and another major stroke also a brain op to remove a clot. I had a breakdown and with the help of a psychologist and then a social worker from Dom. Care have recovered.

My husband was very high care and dependent in this period and spent 3 full days a week in Day Care, but slowly recovered to a good degree of independence. He had another stroke and miraculously it has changed him into a "nice guy" so my role at present is the easiest I have had in 7 years.

C-19 Carers should have recognition of their work and every physical and moral support possible. Caring should be classified as an occupation with rates of pay and time off. (Imagine the Duty Statement??).

All carers should have the benefit of training courses to help them cope with whatever condition the caree suffers.

Support groups are a great help in providing education and understanding.

Family education should be provided so that families can understand the carer's problems and assist and appreciate domiciliary care and support is essential

C-20 My hardest time was having my husband diagnosed.

My GP at the time said he couldn't do anything unless my husband asked for help. During this time he (husband) was driving through red lights, turning without warning etc. He was also getting our finances in a mess, making wrong investments and losing our savings.

I managed to get him to his specialist and let him know my concern about my husband. The specialist told him his heart was OK now and then said "your wife seems to think you have a brain problem but you're pretty good aren't you? " This made life much more difficult at home. The doctor didn't see through my husband's camouflage and pick up on his little set sentences which covered so many situations. I had told the Doctor but he didn't listen. The GP I had in these last years treated me well and usually listened. In the last year or so that I had my husband home, a geriatrician [through Dom Care] came out to my home - I found him extremely supportive and he was a great help to me. My
Social Worker and Community Options Worker. They would talk to me and then communicate with one another to try and help me through my various problems.

When ...'s group was formed (the Carer Support Network), she became very much part of my support, communicating with the others.

In the early days I felt the GP didn't really have much knowledge of the disease (Alzheimer's). His main concern seemed to be to give drugs to try to stop my husband pacing. Pacing wasn't a great concern to me but the drug side effects were. Drugs have often caused adverse reactions with my husband.

Once years back, the GP came to me when I was ill one night, and he did ring for help - but he rang a nursing agency. This does not work, a stranger coming in was more stress on me as my husband was frightened and she had no idea how to handle him, even though she had worked at ....hospital.

Phoning Community Options who knew my husband would have been better.

I feel one of the important things to do is not to hide the patient away. I told the neighbour and friends about my husband's problem. They seemed to appreciate my honesty and became very supportive. They were always friendly and understanding towards my husband.

C-16 I am on a Disability Support Pension because of a debilitating anxiety disorder which always manifests itself to the maximum when I am very stressed and tired which is under control with help from my Doctor.

Although I finished school at the Intermediate Certificate I worked as a shorthand typist / receptionist in various offices and then became a billing machine (ledger) operator at ..... for 11 years plus many of her various office procedures which resulted because of my various skills.

C-21 My full caring for my wife took place approx. during the 2 years [ 1989 - 1991]. She was placed in the ... Nursing Home in 1991. As the 2 years progressed she became less able to help herself until she became almost total care and too much for me to cope with at the age of 80 years.

C-23 It actually never occurred to me to ask a GP for some of this information mentioned on previous pages. Schools, social workers and IDSC have been my main sources. For multiple reasons, I though I could do it alone ... and only sought help when he was 15, due to other things in my life not working out. I don't know which came first and certainly did not recognise that my mental or physical health was threatened, though I realise I would have been better able, had I had someone I could have talked to/with. I reached that stage on my own, having met a co-worker who had been helped by psycho-therapy. Things are improving all the time now.

My needs differ from those of people caring for the frail elderly. My son's health has been generally good and I have had little cause to contact a GP very often. He remains strong as I get older! Which is why I wrote the attached [below]

C-23 What do I need? As my son loses his childish cuteness and exhibits behaviour less and less socially acceptable for his age, I mostly need a different residential possibility. A community within a community, living with other families who have people with disabilities and others, who may see themselves in a supportive role. It would actually be far safer than living in isolation with its accompanying difficulties, as sharing & diffusing responsibilities of care would be very possible in that situation. Our people would also be freer to visit, go for walks etc. Within a protected environment, where they were known.

As it is, they rely on parents or other carers to take them out - this reduces their independence. Information & agencies are all very well, but coping with "challenging behaviour" (wonderful term) isn't necessarily conducive to being able to push for assistance and then, having too many 'carers', too much change & breaks in routine tend to exacerbate rather than ameliorate the situation.

I have been lucky this far & have found wonderful school staff who have been very willing to extend themselves - but they're a known quantity. How will it be when he leaves? I'd say I need back up, security for my son & somewhere where I can use the skills I've developed (with his help!) to assist others in our daily lives.
APPENDIX 10:

General Practitioner Questionnaire

[Sample]
Dear Doctor,

This questionnaire is part of a project about understanding informal caregiving in the home. A carer may be one of your patients or the relative or close friend of one or your patients.

GPs are already providing much support for family members and other caregivers but what are your experiences as GPs trying to meet those needs?
10 April, 1995

Dear Doctor,

This questionnaire is part of a project about understanding informal caregiving in the home and meeting the needs of people who provide that care. A carer may be one of your patients or the relative or close friend of one or your patients.

GPs are already providing much support for family members and other caregivers, but what are your experiences, views and needs as you try to help these people?

Your contribution to this questionnaire would be greatly appreciated as this information will help to clarify the needs of both carers - and GPs.

It is estimated this questionnaire will take between 20 - 30 minutes to complete. Please return it within 14 days.

Results will be published in local GP newsletters mid-late 1995.

Thank you for your time.

Anne F Stacey
MSc (Qualifying Studies)
Department of General Practice
School of Medicine, Flinders University of SA
C/o Southern Division of General Practice, Noarlunga Centre, SA

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A DESCRIPTION OF CARERS

Carers or informal caregivers, (unpaid) are people of all ages who take on the responsibility for the care of a dependent adult or child in the home, on a long term basis. E.g. they care for the frail aged, chronically ill or the physically, mentally and intellectually disabled.

These primary carers may be:
- a family member [daughter/son, in-laws, and other relatives]
- a spouse
- a parent [including step-mother, step-father]
- caring friends / neighbours / individuals
SECTION 1.
IDENTIFYING CARERS AND THEIR NEEDS IN GENERAL PRACTICE

Q. 1.1 a) How familiar are you with the term "carer" (i.e. informal caregiver)?

Please circle the number that best represents your response

Not at all familiar 1 2 3 4 5 Very familiar

b) If you are not familiar with the term "carer", how would you describe that person is in an informal caregiving role?

e.g. As a spouse, relative, parent, friend, neighbour?

Q. 1.2 What is your understanding of the role and responsibilities of a person who is an informal carer to a dependant person (adult or child) in the home?

Q. 1.3 How often have you identified, in your notes, the person who is the patient's carer at home?

Never 1 2 3 4 5 Often

How often have you identified, in your notes, patients who also have the role of informal caregiver to a dependant person?

Never 1 2 3 4 5 Always

Q. 1.4 Who are these family members and other carers looking after in the home?

More than one response is possible. Please tick all the appropriate boxes.

Carers are looking after people in the following categories
Cancer [ ] Rheumatoid or osteo-arthritis [ ]
Frail aged [ ] Severe visual/sensory impairment [ ]
Dementia [ ] Mentally/Intellectually disabled [ ]
Stroke [ ] Multiple Sclerosis [ ]
HIV/AIDS [ ] Parkinson's disease [ ]
Multiple disabilities [ ] Physically handicapped [ ]
Chronic renal disease[ ] respiratory disease [ ] heart disease [ ]
Other

Please list which of the above groups are the most common in your practice?
Q. 1.5. Have you identified carers as people with special needs (emotional, physical or social support needs?)

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What needs in particular have you observed? Please explain briefly.

Q. 1.6. Have you talked to family members/carers about their caring role?

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Q. 1.7. What have been some of the issues and problems that bother family caregivers, which they have raised with you?

Please expand

Q. 1.8. Have you made special times (either in the surgery or during house calls) to talk to family members/carers about their own needs? [In addition to the needs of the patient?]

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Comment

Q. 1.9. Have you found it helpful to seek information about the problems of individual carers from any other professionals or family members? (e.g. other GPs, district nurses, social workers...)

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<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Often</th>
</tr>
</thead>
</table>

Comment
### SECTION II. EFFECTS OF CARING ON CARER’S HEALTH & WELL BEING

**Q. 2.1** How often have you observed that the health and well being of persons in a caring role can be affected negatively?

*Please circle the number that best represents your response*

<table>
<thead>
<tr>
<th>Effect on General health</th>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existing health problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Exhaustion</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Physical injuries (eg lifting disabled person etc)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q. 2.2 How often have you observed that persons in a caring role exhibit each of the following?</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Please circle the number that best represents your response</em></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Effect</th>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor compliance with drug regimes (for self)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Poor compliance with other treatments (for self)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Reluctance to seek medical attention for self</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Reluctance to undergo surgery (which would mean being away from dependent)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Discharging self from hospital early</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

**Q. 2.3** Have you observed any other effects/impacts of caregiving on the health of carers, especially those who have pre-existing illnesses/conditions?
Q. 2.4 What have you observed to be the positive effects of caregiving on people who are carers?
Please list below

Q. 2.5 Have you talked to family members/carers about how their caring role might impact on their own health and well being?
Never 1 2 3 4 5 Always

SECTION III. SUPPORT FOR CARERS BY GPs

Q. 3.1 What general support do you already offer family caregivers and other carers?

A. EMOTIONAL SUPPORT
Never 1 2 3 4 5 Always
Comment

B. INFORMATION. - Have you provided family members and other informal carers with information about the following? :-

Please tick the categories that apply in each of the sections below

<table>
<thead>
<tr>
<th>NotApplicable</th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always, if appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(a) the dependent person's illness/disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) what to do for after hours medical care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(c) what to do in a medical emergency</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d) home services available for carers or for the dependent person</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e) home care appliances (including where to go for them)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(f) Carer Support Groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(g) Carer Support Kit (Carers Assoc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(h) government benefits or special allowances for carers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
C. REFERRALS:

Have you directly referred family caregivers or other carers to the following agencies / health care professionals for assistance?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Alzheimers' Association</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) Allied health professionals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) Community Health Centres</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) Community Options Prog. (HACC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6) Community Services Inc. (HACC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6) Counselling services (in general)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(7) Carer Support Groups (HACC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8) Day Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(9) District Nursing Services (HACC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10) Domiciliary Care Services (HACC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(11) Financial / Legal Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(12) Home Assist (HACC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(13) Inhome Emergency Respite Services (RESTHAVEN)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(14) Meals on Wheels Services (HACC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(15) Neurological Resource Centre</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16) Respite care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(17) Social Workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(18) Stroke SA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(19) Local Govt. Community Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(i.e. c/o local Councils - for home/domestic help or assistance with transport)

(20) Other agencies or services?

Q. 3.2 Have you experienced problems with accessing any of these services in the past? Yes [ ] No [ ]

If yes, please expand with examples

Q. 3.3 Would it have helped you assist family members and other carers, if you had had more information made available to you about local community and social services? In-part [ ] Yes [ ] No [ ]
If yes, in what form would you prefer that information?  
Please tick all that apply

Directories [ ]  
Pamphlets [ ]  
Data base on computer [ ]  
Telephone hotline [ ]

Other ideas? Please list.

Q. 3.4 Are you familiar with a range of community services in your local area that would be of assistance to carers in your practice?

In-part [ ] Yes [ ]  No [ ]
Please list a few community services you are familiar with

Q. 3.5 Do you know how to contact the local Carer Support Groups in your area?

Yes [ ]  No [ ]

Q. 3.6 Are other staff in your practice expected to be familiar with community or social services and Carer Support Groups in your local area?

(Ineg receptionist, practice nurse)

In-part [ ] Yes [ ]  No [ ]

Comment

Q. 3.7 Many family caregivers and other carers would welcome more help from their GP with accessing community and social support services. Is this a reasonable expectation?

Yes [ ]  No [ ]
Please expand

Q. 3.8 Are there any particular frustrations or barriers that you as a GP experience when trying to help and support people who are carers?

Yes [ ]  No [ ]
If yes, please expand
Q. 3.9 What do you believe have been the causes of those frustrations/barriers?

Q. 3.10 Have you helped carers by:

<table>
<thead>
<tr>
<th>Providing</th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) after hours support</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>(b) emergency support</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>(c) home visits to follow up or review the situation</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Arranging GP phone numbers for carer enquiries-
| (d) Office Hours                  | [ ]   | [ ]       | [ ]   | [ ]    |
| (e) After Hours                   | [ ]   | [ ]       | [ ]   | [ ]    |

Other support have you provided family caregivers and other carers:

SECTION IV.
FUTURE SUPPORT FOR CARERS IN GENERAL PRACTICE

Q. 4.1 Do you see it as a role of the General Practitioner to provide support and other assistance to family caregivers and other carers?  

Yes [ ]  No [ ]

Please expand

Q. 4.2 If the carer became ill, how could the GP offer additional assistance?  
(eg with prescriptions, emergency respite while the carer is needing rest)

Q. 4.3 Some family members and other carers have been unable to get adequate information about the condition of the person they are caring for. (i.e. so they can better understand the diagnosis, prognosis and treatments necessary to care for that person)
Please suggest how GPs (or others) could provide more helpful information in the future?

Q. 4.4 Some family members and other carers have perceived a lack of recognition by health care professionals of the carer’s role and responsibilities.

Please suggest what would help GPs to better recognise people who are carers in the future?

Q. 4.5 Which other individuals / professionals do you think could assist GPs to identify and support carers?

Please tick all that apply

- Carer Support Groups
- Council Social Workers
- Church workers
- District Nurse
- Pharmacists
- Others...

Q. 4.6 If you are aware that the carer is the patient of another GP, what is your approach to offering the carer support or medical care?

Comments

Q. 4.7 If appropriate remuneration could be arranged, would you prefer to visit and talk to carers in the surgery or in their own homes?

- In the surgery
- In their home
- Both

8
Lastly, we just need a few questions about yourself.

*Please tick appropriate boxes below:*

Q. 1  **Is your practice?**
- Solo [ ]
- 2 person [ ]
- 3-5 person [ ]
- 5-8 person [ ]
- Over 8 person [ ]

*Other, please explain* .................................................................

Q. 2  **Are you in general practice:**
- Full time [ ]
- Part time [ ]

Q. 3  **What is your age** ..........................................

Q. 4  **How many years have you spent in general practice since graduating?** ... yrs

Q. 5  **Are you?**
- Male [ ]
- Female [ ]

Q. 6  **Postcode of main practice location** ..............................

Q. 7  **Do you hold any additional qualifications?**
    a)  No [ ]
    b)  Yes [ ]  *Please circle*

   i)  FRACGP
   ii)  Other: Please specify .................................

Q. 8  **What societies/organisations do you belong to?**

*Please circle all that apply*

- a)  AMA
- b)  RACGP
- c)  Division of General Practice
- d)  Other: Please specify .................................

Q. 9  **Are/were you an FMP Trainee?**
- Yes [ ]
- No [ ]

Q. 10 **Are you vocationally registered**
- Yes [ ]
- No [ ]

Q. 11 **What percentage of your patients would be of non-English Speaking background?**

*Please specify the most common cultural group.* ..........................

(Excluding white Anglo-Saxon)
You are welcome to provide any additional comments.

In particular, what do you as a GP feel you need when trying to help caregivers?

THANK YOU FOR YOUR TIME.

PLEASE RETURN QUESTIONNAIRE IN THE REPLY PAID ENVELOPE

Enquiries: To Anne Stacey Mobile
C/o Department of General Practice, Flinders University of South Australia,
Level 7, Flinders Medical Centre, Bedford Park, South Australia, 5042

Telephone:

or C/o Southern Division of General Practice, Noarlunga Centre, SA 5168

Telephone:
APPENDIX 11:

GENERAL PRACTITIONER QUESTIONNAIRE
RESULTS
13 Original GPs
12 Survey GPs [Survey GPs presented in italics] Combined total (n) = 25

Q. 1.1
a) How familiar are you with the term "carer" (ie informal caregiver)?

<table>
<thead>
<tr>
<th>GP level of familiarity with the term carer</th>
<th>Number of responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Not at all familiar</td>
<td>1</td>
<td>D-12</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>D-10, D-11, D-13</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>D-14, D-21, D-22</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>D-3, D-4</td>
</tr>
<tr>
<td>5 Very familiar</td>
<td>7</td>
<td>D-1, D-2, D-5, D-6, D-7, D-8, D-9, D-15, D-16, D-17, D-18, D-19, D-20, D-23, D-24, D-25</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>D-14, D-21, D-22</td>
</tr>
</tbody>
</table>

b) If you are not familiar with the term "carer", how would you describe that person in an informal caregiving role? [e.g. As a spouse, relative, parent, friend, neighbour?]

GP's responses:
- "relative"
- "all of the above"

Q.1.2
What is your understanding of the role and responsibilities of a person who is an informal carer to a dependant person (adult or child) in the home?

D-1 to D-5: No equiv Q.
D-6 Provide physical + emotional support as needed
D-7 [1] Provide care, support, assistance in activities of daily living
      [2] Provide emotional support and company
      [3] Supervise medication, medical treatment etc.
D-8 To provide a reliable, friendly support/aid to a dependent to meet daily living requirements to meet and to communicate any difficulties in meeting those requirements to any appropriate person /body.
D-9 This is usually quite intense in a physical or bodily sense [like a nurse] but often involves psychological support too
D-10 Physical care and/or overall responsibility for all aspects of patient's well being
D-11 Informal carer is helpful if available
D-12 Similar to a parent of a young child
D-13 Support, nurture, attention to daily living needs

Survey GPs
D-14 No support / looks after dependent person
D-15 Responsible for the day to day care of the dependent, ie dressing, feeding, toileting, medicating, entertaining etc.
D-16 Unpaid nurse
D-17 Supervision of all daily needs including medications and also administration of all cares for dependent person
D-18 To be responsible for the dependent's needs being met - either in person or by someone else
D-19 24 hour care / supervision, help with ADL's, watch for safety
D-20 Responsible for looking after the persons. Usually a relative
D-21 Aid in Daily living activities / Having to deal with financial aspects of person's life / Emotional support to person.
D-22 To look after that person is whatever areas he or she needs help
D-23 To help the dependent person do the things they would normally be able to do themselves. To offer sympathetic support and TLC.
D-24 Seems to be full time job - with significant responsibilities for health and social well being of dependent person.
D-25 Responsible for all day to day activities of living and organising all affairs - dressing, feeding, giving medication, taking to appointments, helping with mobility, helping with toileting and bathing etc. Often total social network - provides company and stimulation.

**Q. 1.3**
(a) How often have you identified, in your notes, the person who is the patient’s carer at home?

<table>
<thead>
<tr>
<th>GP's frequency of identifying carer</th>
<th>Number of responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Never</td>
<td>3 D-6, D-12</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1 D-15</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>1 D-13</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 D-14, D-16, D-20, D-21, D-22</td>
<td></td>
</tr>
<tr>
<td>3 Times</td>
<td>1 D-10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 D-24</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>4 D-5, D-7, D-8, D-9,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 D-18, D-19, D-23, D-25</td>
<td></td>
</tr>
<tr>
<td>5 Often</td>
<td>5 D-1, D-2, D-3, D-4, D-11,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 D-17</td>
<td></td>
</tr>
</tbody>
</table>

(b) How often have you identified, in your notes, patients who also have the role of informal caregiver to a dependant person?

<table>
<thead>
<tr>
<th>GP's frequency of identifying carer</th>
<th>Number of responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Never</td>
<td>2 D-6, D-12</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>2 D-15, D-21</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>1 D-13</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 D-16, D-22</td>
<td></td>
</tr>
<tr>
<td>3 Times</td>
<td>4 1 D-11</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 D-14, D-18, D-23, D-24</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>6 D-2, D-3, D-5, D-7, D-8, D-9,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 D-17, D-19, D-25</td>
<td></td>
</tr>
<tr>
<td>5 Often</td>
<td>3 D-1, D-4, D-10</td>
<td></td>
</tr>
</tbody>
</table>

**Q. 1.4**
Who are the family members and other carers looking after in the home?

(i) Carers are looking after people in the following categories of dependent persons

<table>
<thead>
<tr>
<th>Condition of dependent person</th>
<th>Number of responses</th>
<th>n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mentally/Intellectually disabled</td>
<td>13</td>
<td>Rheumatoid or osteo-arthritis 7</td>
</tr>
<tr>
<td>Dementia</td>
<td>13</td>
<td>Chronic Heart disease 6</td>
</tr>
<tr>
<td>Frail aged</td>
<td>12</td>
<td>Chronic renal disease 5</td>
</tr>
<tr>
<td>Stroke</td>
<td>11</td>
<td>Chronic Respiratory disease 5</td>
</tr>
<tr>
<td>Multiple disabilities</td>
<td>11</td>
<td>Severe visual/sensory impairment 5</td>
</tr>
<tr>
<td>Cancer</td>
<td>10</td>
<td>Multiple Sclerosis 4</td>
</tr>
<tr>
<td>Physically disabled/handicapped</td>
<td>9</td>
<td>HIV/AIDS 2</td>
</tr>
<tr>
<td>Parkinsons disease</td>
<td>9</td>
<td>Other debilitating or disabling conditions requiring long term care at home? Cancer, chronic neurological illness, muscular dystrophy</td>
</tr>
</tbody>
</table>

GP Comments:
Q. 1.4 [continued]
Who are the family members and other carers looking after in the home?

Which of the above groups is the most common in your practice?

- D-1 Acquired brain injury, frail aged
- D-2 No answer
- D-3 Frail aged
- D-4 Frail aged
- D-5 Frail aged
- D-6 Dementia/frail aged/visual
- D-7 Mental illness, frail aged, dementia, MS, stroke, visual, arthritis
- D-9 Frail aged, arthritis
- D-10 Frail aged, stroke, dementia, cancer
- D-11 Frail aged/dementia
- D-12 Young Schizophrenics
- D-12 Frail aged/dementia

Survey GPs

- D-14 Multiple disabilities
- D-15 Frail aged, Parkinson's
- D-16 Wife / husband
- D-17 Cancer, frail aged, dementia, O/A
- D-18 Frail aged, dementia, stroke, psychological, cerebral palsy
- D-19 Frail aged, dementia, stroke, OA, sensory impairment, cancer
- D-20 No answer
- D-21 Cancer
- D-22 Cancer, frail aged, dementia, arthritis
- D-23 Cancer, dementia
- D-24 Frail aged, dementia, stroke, cancer
- D-25 Dementia, stroke, respiratory & heart disease, frail aged, mentally disabled, rheumatoid / osteo

Q. 1.5
Have you identified carers as people with special needs (emotional, physical or social support needs)?

<table>
<thead>
<tr>
<th>GP's frequency of identifying carer</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Never</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>D-2, D-21,</td>
</tr>
<tr>
<td>3 Sometimes</td>
<td>D-5, D-16, D-22</td>
</tr>
<tr>
<td>4</td>
<td>D-8, D-9, D-11, D-14, D-15, D-19, D-23, D-24</td>
</tr>
<tr>
<td>5 Often</td>
<td>D-1, D-2, D-3, D-4, D-6, D-7, D-10, D-12, D-13, D-17, D-18, D-25</td>
</tr>
</tbody>
</table>

Q. 1.5 GP Comments: What needs in particular have you observed?

- D-1 Need for "guilt-free" time away from the caring role
- Lack of acknowledgement of their caregiving role
- Lack of longer term respite care available -especially at short notice
- D-2 Decline in own health, Social [needs] usually not brought up
- D-3 Respite, Listening ear, Need support and a break
- D-4 Respite, Sleep
- D-5 Respite care
- D-6 No answer
- D-7 Respite breaks, Stress counselling, Psychiatric illness
D-8  Very often the need to supply emotional and psychological support to those caring for terminally ill, severe mental illness. A very often need to organise respite for carer
D-9  Usually need emotional support, but also need social support (such as 'time out') and financial support, + other support re Counselling and therapy as needed
D-10 Agency, + other support re Counselling and therapy as needed
D-11 Emotional support
D-12 Support, caring for themselves, "time out"
D-13 No answer

Survey GP's
D-14 Mothers of disabled children
D-15 Need for respite
D-16 Respite from the emotional stress
D-17 No answer
D-18 Time out from caring - short term, + long term for holidays
D-19 Someone to talk to, to clarify how to meet the carers' needs
D-20 Respite, support / information
D-21 Need for emotional support themselves; Need for rest / for the recognition of their work
D-22 Need for respite / information
D-23 Emotional support + consideration; Recognition; Respite support
D-24 To be able to take care of themselves; Need for emotional support / time out
D-25 To be able to talk to someone about the difficulties; To be able to recruit outside services

Q. 1.6 Have you talked to family members / carers about their caring role ?

<table>
<thead>
<tr>
<th>GP's frequency of talking to carer about caring role</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>D-1 Never</td>
<td>0</td>
</tr>
<tr>
<td>D-2 Often</td>
<td>2</td>
</tr>
<tr>
<td>D-3 Often</td>
<td>2</td>
</tr>
<tr>
<td>D-4 Often</td>
<td>5</td>
</tr>
<tr>
<td>D-5 Often</td>
<td>5</td>
</tr>
<tr>
<td>D-6 Often</td>
<td>8</td>
</tr>
<tr>
<td>D-7 Often</td>
<td>3</td>
</tr>
</tbody>
</table>

n=25

Q. 1.7 What have been some of the issues and problems that bother family caregivers, which they have raised with you ?

D-1 Fear of what will happen to their loved one if their own health deteriorates.
D-2 Lack of 'time out', restrictions on their own independent activities and recreational limitations.
D-3 Sense of hopelessness that they will ever be able to relinquish caregiving role and also guilt when this is reality
D-4 No answer
D-5 Tiredness; lethargy, burn out, Anger
D-6 The future, what to expect, placement; Recent changes in the 'cared for' what they mean.
D-7 Concern re care of dependent if they (carer) are not longer able to.
D-8 Getting tired; Worrying about the person
D-9 Worrying about how the person will be looked after if they are unable to do so.
D-10 Lack of respite facilities; Lack of information from hospital specialists
D-11 Concern re care of dependent if they (carer) are not longer able to.
D-12 The need to discuss changes in dependent's condition and expectations.
D-13 The need to discuss strategies they, the carer, have improvised in an emergency or to meet a need
D-14 The need to have a break, and the guilt associated with this
D-15 Needing a break from caring, usually short but regular - ? daily - occasionally longer holidays
D-16 Worries own health may fail
Q. 1.7 [continued]

D-10 Need for respite + support in the home. Financial issues / Own health [stress, insomnia etc]
D-11 Insufficient respite and relief, when will it end!
D-12 Guilt, anger with "the patient". Respite care
D-13 Isolation. Loneliness, lack of support

Survey GPs
D-14 Lack of support / difficulty with accessing services to help; Lack of respite care
D-15 What will happen to dependent when they are no longer able to care for them
Need for a break
D-16 Respite
D-17 Stress management, grief; Behaviour problems; Aggression
D-18 The feelings of the dependent person if the carer is not 'perfect', have time out etc; Tiredness
D-19 Need for information;
Need for some professional support; Access to respite
D-20 Conflict in needs - the person they care for and their own; Lack of respite
D-21 Demands of person;
Anger / sense of injustice; Not enough time for themselves
D-22 Lack of other supports;
Hopelessness of some situations
D-23 Their own health (as lack of it); Being left to do all the work by other family members
D-24 Overwhelming demands; Lack of respite
D-25 Physical demands - very tiring and heavy work often
Isolation - difficulty in getting time away from carer role
Guilt and anger at their predicament
Co-ordinating services to make it 'easier'
Knowing what is available
Deciding when it is time to give up and hand over the role

Q. 1.8 Have you made special times (either in the surgery or during house calls) to talk to family members/carers about their own needs?

<table>
<thead>
<tr>
<th>GP's frequency of making times to talk to carer about own needs</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Never</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>3 'times'</td>
<td>8</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>5 Often</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>D-3, D-4, D-5, D-9, D-10, D-13</td>
</tr>
<tr>
<td>D-17, D-24, D-25</td>
</tr>
<tr>
<td>D-1, D-11, D-12, D-13</td>
</tr>
<tr>
<td>D-14, D-18</td>
</tr>
</tbody>
</table>

GP Comments
D-8 I have arranged group meetings in home with several carers, and health care workers, all present at once
D-9 I could do more. Carers often reluctant
D-12 Not in separate visits, but often as part of visit to patient

Survey GPs
D-18 Usually takes longer than the 'patient'
D-23 Only if a patient of the practice
D-25 I do talk to carers quite a bit - usually lack time I see the patient and check that all is OK and sometimes I see them at the surgery to talk in great detail
Q. 1.9 Have you found it helpful to seek information about the problems of individual carers from any other professionals or family members? (e.g. other GPs, district nurses, social workers...)

<table>
<thead>
<tr>
<th>GP's frequency of seeking help about carers from others</th>
<th>Number of responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Never</td>
<td>2</td>
<td>D-11, D-12</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
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<tr>
<td>5 Often</td>
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<td>D-1, D-3, D-6, D-7, D-9,</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>D-19, D-20, D-24</td>
</tr>
</tbody>
</table>

GP comments

D-1 Often carers are not willing to disclose their needs and other individuals alert me to the fact there is a specific problem or need for the carer.

D-4 Domiciliary Care, and other agencies

D-5 When carer is reticent

D-8 Yes, discussing whole scenario/situation with

D-9 Good cross communication with others, ie. RDNS. Dom. Care is essential

Survey GPs

D-18 Other views always useful; carers often don't say

D-24 Carers may talk more openly with district nurses or social workers

D-25 I see most of my 'carers' fairly frequently and I do communicate with district nurses etc. but more often about 'practical issues'.
## SECTION II
### EFFECTS OF CARING ON CARER'S HEALTH & WELL BEING

13 Original GPs  
12 Survey GPs [Survey GPs presented in italics]  
Combined total (n) = 25

**Q. 2.1 How often have you observed that the health and well being of persons in a caring role can be affected negatively?**

**GP perceptions of the negative effects of caring on health and well being of carers**

<table>
<thead>
<tr>
<th>Effect on General health</th>
<th>Neve</th>
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<th>3</th>
<th>4</th>
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<th>Maximum possible n=25</th>
</tr>
</thead>
<tbody>
<tr>
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<td>0</td>
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</table>

<table>
<thead>
<tr>
<th>Existing health problems</th>
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<th>2</th>
<th>3</th>
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<table>
<thead>
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<table>
<thead>
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</table>

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Neve</th>
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<th>5</th>
<th>Maximum possible n=25</th>
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</thead>
<tbody>
<tr>
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<td>3</td>
<td>7</td>
<td>1</td>
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</table>

<table>
<thead>
<tr>
<th>Exhaustion</th>
<th>Neve</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>Maximum possible n=25</th>
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</thead>
<tbody>
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<td>10</td>
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<td>1</td>
<td>7</td>
<td>2</td>
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</table>

<table>
<thead>
<tr>
<th>Hypertension</th>
<th>Neve</th>
<th>2</th>
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<th>4</th>
<th>5</th>
<th>Maximum possible n=25</th>
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</thead>
<tbody>
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<td>2</td>
<td>9</td>
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<td>3</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical injuries (lifting disabled person etc)</th>
<th>Neve</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Maximum possible n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>4</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>5</td>
<td>5</td>
<td>3</td>
<td>9</td>
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</tr>
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</table>

<table>
<thead>
<tr>
<th>Sleep</th>
<th>Neve</th>
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<th>3</th>
<th>4</th>
<th>5</th>
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</thead>
<tbody>
<tr>
<td>0</td>
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<td>5</td>
<td>6</td>
<td>1</td>
<td>9</td>
<td></td>
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<td>0</td>
<td>5</td>
<td>6</td>
<td>0</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

**GP comments**

- Suppressed anger, guilt, sadness
- High degree of depression

**Q. 2.2 How often have you observed that persons in a caring role exhibit each of the following?**

13 Original GPs  
12 Survey GPs

<table>
<thead>
<tr>
<th>Poor compliance with drug regimes (for self)</th>
<th>Neve</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Maximum possible n=25</th>
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</thead>
<tbody>
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<td></td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Poor compliance with other treatments (for self)</th>
<th>Neve</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Maximum possible n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6</td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>9</td>
<td></td>
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<td>5</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reluctance to seek medical attention for self</th>
<th>Neve</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Maximum possible n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
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<td>5</td>
<td>6</td>
<td>0</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>
Q. 2.2
How often have you observed that persons in a caring role exhibit each of the following? [continued]

13 Original GPs
12 Survey GPs

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>S'times</th>
<th>Always</th>
<th>Maximum possible n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reluctance to have surgery (being away from dependent)</td>
<td>0</td>
<td>4</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Carer discharging self from hospital early</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>4</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Q. 2.3 Have you observed any other effects/impacts of caregiving on the health of carers, especially those who have pre-existing illnesses / conditions ?

D-1 Financial difficulties
D-2 Social isolation
D-3 Relationship conflicts or constraints in other relationships, eg conflict btw husband and wife where wife is caring for elderly parent
D-4 Reduced willingness to tackle their own health problems
D-5 Once they (carers) are in hospital, they are loath to leave
D-6 No answer
D-7 Often will ignore their own health i.e. put off seeking help
D-8 Reduced willingness to tackle their own health problems
D-9 Once they (carers) are in hospital, they are loath to leave
D-10 No answer
D-11 No
D-12 Guilt
D-13 No answer

Survey GPs

D-14 Do not cope well if their own illness/health starts to deteriorate
D-15 No answer
D-16 No answer
D-17 No answer
D-18 Unable to work/earn income
D-19 No answer
D-20 No answer
D-21 'No'
D-22 No answer
D-23 The strain of looking after someone may exacerbate their own health problems
D-24 No answer
D-25 They tend to get worn out and worry about their health in case they can’t care any more. Some ignore their own needs and some come in and get checked often to make sure they don’t get sick and unable to care anymore.
Q. 2.4 What have you observed to be the positive effects of caregiving on people who are carers?

- D-1 Sustaining an intimate relationship 'at home'
- D-2 Self esteem sometimes enhanced - eg. "a job well done"
- D-3 Relief of guilt
- D-4 Self satisfaction - complete their family role
- D-5 Satisfaction of giving and "loving"; Fulfilling their perceived life role
- D-6 It gives some people a meaning to their lives. On the other hand this can become a negative effect if the patient dies/leaves and the carer is left with a huge gap in their life.
- D-7 Life has a purpose, ie. meaning
- D-8 Sustaining an intimate relationship 'at home'
- D-9 Self esteem sometimes enhanced - eg. "a job well done"
- D-10 Relief of guilt
- D-11 Self satisfaction - complete their family role
- D-12 Satisfaction of giving and "loving"; Fulfilling their perceived life role
- D-13 It gives some people a meaning to their lives. On the other hand this can become a negative effect if the patient dies/leaves and the carer is left with a huge gap in their life.
- D-14 No answer
- D-15 Life has a purpose, ie. meaning
- D-16 Maintains integrity of family
- D-17 Sustaining an intimate relationship 'at home'
- D-18 No answer
- D-19 Life has a purpose, ie. meaning
- D-20 Sustaining an intimate relationship 'at home'
- D-21 No answer
- D-22 Life has a purpose, ie. meaning
- D-23 Sustaining an intimate relationship 'at home'
- D-24 No answer
- D-25 Life has a purpose, ie. meaning

Survey

Q. 2.5 Have you talked to family members / carers about how their caring role might impact on their own health and well being?

<table>
<thead>
<tr>
<th>GP's frequency of talking</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>to carer about their health</td>
<td>Respondents</td>
</tr>
<tr>
<td>1 Never</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>5 Always</td>
<td>2</td>
</tr>
</tbody>
</table>

n=25
### Q. 3.1
#### A. EMOTIONAL SUPPORT

13 Original GPs  
12 Survey GPs  

What general support do you already offer family caregivers and other carers?

<table>
<thead>
<tr>
<th>GP's frequency of providing</th>
<th>No. of GP responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes with emotional support</td>
<td></td>
</tr>
<tr>
<td>1 Never</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>3 S'times</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
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<td>5 Always</td>
<td>15</td>
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<td>D-15, D-22</td>
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<tr>
<td></td>
<td>D-1, D-4, D-7, D-8, D-9, D-10, D-11, D-12,</td>
</tr>
<tr>
<td></td>
<td>D-14, D-17, D-18, D-19, D-20, D-21, D-24</td>
</tr>
</tbody>
</table>

**GP Comments [about Emotional support]**  
I consider this to be extremely important  
Willing to home visit at any time

### Q. 3.1
#### B. INFORMATION

Have you provided family members and other informal carers with information about the following? ::

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>2</th>
<th>S'times</th>
<th>4</th>
<th>Always</th>
<th>Maximum possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>The dependent person's illness/disability</td>
<td>0</td>
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<td>4</td>
<td>8</td>
<td>n=25</td>
</tr>
<tr>
<td>What to do for After Hours medical care</td>
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<td>2</td>
<td>0</td>
<td>6</td>
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<tr>
<td>What to do in a medical Emergency</td>
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<td>2</td>
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<tr>
<td>Home services available</td>
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<td>0</td>
<td>4</td>
<td>7</td>
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<td></td>
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<tr>
<td>Home care appliances (- where to go for them)</td>
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<td>4</td>
<td>5</td>
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<td></td>
</tr>
<tr>
<td>Carer Support Groups</td>
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<td>0</td>
<td>4</td>
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<td>2</td>
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<tr>
<td>Carer Support Kit (Carers Assoc.)</td>
<td>10</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Govt benefits/allowance for carers</td>
<td>0</td>
<td>3</td>
<td>6</td>
<td>3</td>
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<td></td>
</tr>
</tbody>
</table>

-10-
Q. 3.1
C. REFERRALS:
13 Original GPs
12 Survey GPs

What information you have you provided to family members / other informal carers:

Have you directly referred family caregivers or other carers to the following agencies / health care professionals for assistance?

<table>
<thead>
<tr>
<th>Service</th>
<th>Never</th>
<th>S'times</th>
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<th>Maximum possible n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's Association</td>
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<td>0</td>
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<tr>
<td></td>
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<td>0</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Allied Health Services</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Community Health Centres</td>
<td>0</td>
<td>5</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>0</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Community Options Program</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Counselling Services</td>
<td>1</td>
<td>3</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Carer Support Group</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>0</td>
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<td>4</td>
</tr>
<tr>
<td>Day Care</td>
<td>0</td>
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<td>4</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>District Nursing Services</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Domiciliary Care Services</td>
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<td>1</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Financial / Legal Services</td>
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<td>4</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>0</td>
<td>9</td>
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<tr>
<td>Home Assist (HACC)</td>
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<td>1</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Inhome Emergency Respite Services (c/o Resthaven)</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>0</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Meals on Wheels Services</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>8</td>
</tr>
</tbody>
</table>
Q. 3.1 [continued]
C. REFERRALS:

Have you directly referred family caregivers or other carers to the following agencies / health care professionals for assistance?

13 Original GPs
12 Survey GPs

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>S'times</th>
<th>Always</th>
<th>Maximum possible n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological Resource Centre</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Respite Care (respite in general)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Social worker</td>
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<td>1</td>
</tr>
<tr>
<td>Stroke SA</td>
<td>4</td>
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<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Local Govt (Council)</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Community Services</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

Comments about other agencies or services?

D-1 Community and social services
D-3 Hospital care
D-9 Caring for Carers
D-8 Multiple Sclerosis Association - physio

Additional GP responses

D-2 The emotional and physical milieu
D-3 After hours contact
D-8 Access to respite and skills to convince patients to go
D-9 Usually give my own telephone number, or arrange appropriate partner to cover if away
D-11 Advice re hostel or nursing home placement
D-12 Early referral to Hospice Palliative Care team
D-24 Information re respite

Q. 3.2
Have you experienced problems with accessing any of these services in the past?

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td>No equiv. Q.</td>
<td>5</td>
</tr>
</tbody>
</table>
Q. 3.2 [continued]
Have you experienced problems with accessing any of these services in the past?

**GP comments**

D-2 I know the services, but with the exception of Brighton Council and Meals on Wheels they are unobtainable
D-6 Alzheimers’ Association - directing carer to speak to a specialist. GPs can diagnose + manage dementia
D-8 Often RDNS /Dom Care/ Meals on Wheels restricted
D-9 RDNS & Domiciliary Care occasionally get stretched
Community Options (specifically Hostel Options) full often
D-10 No answer
D-11 Dom Care provides an incomplete service
D-12 A run around! Usually (Services) closed/not available/ moved or long waiting list
D-13 No answer

**Survey GPs**

D-14 Difficulty accessing / getting through to correct service
D-15 Is a long wait for district nursing
D-16 No answer
D-17 No answer
D-18 Waiting lists
Restrictive target groups
D-19 Hard to access respite in emergency
In home respite rarely available
D-20 Not enough experience
D-21 Meals on wheels - often will not provide meals if a carer is available; no matter how exhausted they are
D-22 Either long wait for services - or limits to what they can do
Unaware of some of these services - how to access them - phone no. etc.
D-25 Only with timing

Q. 3.3
Would it have helped you assist family members and other carers, if you had had more information made available to you about local community and social services?

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>D-1, D-2, D-3, D-4, D-5, D-6, D-8, D-9, D-10, D-11, D-12, D-13, D-14, D-16, D-18, D-20, D-21, D-22, D-23, D-24</td>
</tr>
<tr>
<td>No</td>
<td>D-25</td>
</tr>
<tr>
<td>In part</td>
<td>D-7, D-15, D-17, D-19</td>
</tr>
</tbody>
</table>

If yes, in what form would you prefer that information?

Respondents gave multiple answers.

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directories</td>
<td>D-1, D-5, D-6, D-10, D-11, D-13, D-14, D-15, D-16, D-17, D-18, D-20 D-21, D-22, D-23, D-25</td>
</tr>
<tr>
<td>Phone hotline</td>
<td>D-3, D-5, D-6, D-7, D-11, D-12, D-13, D-14, D-15, D-17, D-18, D-19, D-20, D-21, D-25</td>
</tr>
<tr>
<td>Pamphlets</td>
<td>D-1, D-4, D-6, D-10, D-13, D-14, D-15, D-17, D-20, D-23, D-25</td>
</tr>
<tr>
<td>Data base</td>
<td>D-6, D-7, D-10, D-13, D-15, D-17, D-20, D-21, D-24, D-25</td>
</tr>
<tr>
<td>No answer</td>
<td>D-2, D-8, D-9</td>
</tr>
</tbody>
</table>

**GP Comments- and other ideas?**

D-1 Written material
D-4 One number to ring for all
D-5 In the short term, directories and telephone line most useful
In the medium long term - data base
D-7 No pamphlets - except as leaflet in waiting room
D-8  No answer  
D-9  A resource kit specific to the local area, updated p.r.n.  
D-10  No answer  
D-11  Access to social worker  
D-12  No answer  
D-13  No answer  

Survey  
D-14  No answer  
D-18  Would need regular updating ? yearly  
D-21  ONE Directory only  

Q. 3.4  
Are you familiar with a range of community services in your local area that would be of assistance to carers in your practice ?

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>D-1, D-2, D-3, D-5, D-6, D-7, D-10, D-12, D-15, D-17, D-18, D-19, D-21, D-25</td>
</tr>
<tr>
<td>In part</td>
<td>D-3, D-8, D-11, D-13, D-14, D-16, D-20, D-22, D-24</td>
</tr>
<tr>
<td>No answer</td>
<td>D-9, D-23</td>
</tr>
</tbody>
</table>

Community services GPs are familiar with -  
D-1  No answer  
D-7  Happy Valley Aged Services  
Aberfoyle Park Community Health Centre  
D-8  Mitcham Council had a project detailing services initiated, but still to see final draft  
D-9  Hills Community Health Centre  
Family House  
D-10  RDNS, Dom Care, Home Assist, Meals on Wheels, Library Visiting services  
D-11  Home Assistance  
D-12  No answer  
D-13  No answer  

Survey GPs  
D-14  RDNS / Dom care / SOS  
D-15  Meals on Wheels, Home Help, District Nursing  
D-16  No answer  
D-17  No answer  
D-18  No answer  
D-19  Social work, day care, respite, MOW, dementia support group, RDNS  
D-20  No answer  
D-21  Noarlunga Community Information Centre  
D-22  No answer  
D-23  District Nursing, Domiciliary care, Meals on Wheels, Palliative care  
D-24  Unley Council has support available, Dom. Care, Community Bus  
D-25  Council services, Day care - Bellevue / Resthaven, St John Ambulance, Meals on Wheels  

Q. 3.5  
Do you know how to contact the local Carer Support Groups in your area ?

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>D-6, D-8, D-9, D-12, D-15, D-17, D-18, D-19, D-21, D-23, D-25</td>
</tr>
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<td>No</td>
<td>D-10, D-11, D-13, D-14, D-16, D-20, D-22, D-24</td>
</tr>
<tr>
<td>No answer</td>
<td>D-1, D-2, D-3, D-4, D-5, D-7</td>
</tr>
</tbody>
</table>
Q. 3.6
Are other staff in your practice expected to be familiar with community or social services and Carer Support Groups in your local area? (eg receptionist, practice nurse)

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10 D-1, D-2, D-4, D-6, D-11, D-15, D-17, D-18, D-19, D-23</td>
</tr>
<tr>
<td>No</td>
<td>5 D-5, D-10, D-12, D-14, D-24</td>
</tr>
<tr>
<td>In-part</td>
<td>9 D-3, D-7, D-8, D-9, D-13, D-16, D-21, D-22, D-25</td>
</tr>
<tr>
<td>No answer</td>
<td>1 D-20</td>
</tr>
</tbody>
</table>

GP Comments:
Yes, some are quite knowledgeable of local support groups

Q. 3.7
Many family caregivers and other carers would welcome more help from their GP with accessing community and social support services. Is this a reasonable expectation?

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>18 D-6, D-7, D-9, D-11, D-12, D-13, D-14, D-15, D-16, D-17, D-18, D-19, D-20, D-21, D-22, D-23, D-24, D-25</td>
</tr>
<tr>
<td>No answer</td>
<td>7 D-1, D-2, D-3, D-4, D-5, D-8, D-10</td>
</tr>
</tbody>
</table>

GP Comments:
D-2 15 mins on the phone is worth quite a bit - can't afford to be mucked around.
D-8 I believe they are already getting enormous support from their GPs in this. Already we spend hours per week in unpaid for liaison and organisation.
D-10 Not asked, not adequately funded
Survey GP D-25 GP is a good source of information and can keep an eye on all aspects of health - patient and carer

Q. 3.8
Are there any particular frustrations or barriers that you as a GP experience when trying to help and support people who are carers?

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>20 D-1, D-2, D-3, D-4, D-5, D-6, D-7, D-8, D-9, D-10, D-11, D-13, D-14 D-15, D-17, D-18, D-19, D-21, D-22, D-24</td>
</tr>
<tr>
<td>No</td>
<td>2 D-16, D-23</td>
</tr>
<tr>
<td>No answer</td>
<td>2 D-12, D-20</td>
</tr>
</tbody>
</table>

GP Comments:
D-1 Time, constraints on the part of the GP - often takes a number of phone calls to co-ordinate.
D-2 Lack of resources in public sector, i.e. long waiting times in some areas that sometimes GPs give up.
D-3 Communication issues
D-4 Time
D-5 Lack of understanding
D-6 Obtaining respite care for public patients
D-7 Lack of knowledge of local community services
D-8 Seems to be a general trend for agencies to expect specialist diagnosis - why?
D-9 Time
D-10 Financial [no item no. for helping a carer
D-11 Information - never to hand when needed
D-8 Getting beyond the circle of carers into the next buffer (support) zone is sometimes difficult. Services are overloaded and often other community support groups have participants with their own needs, who may not understand the needs of carers.

[Refer diagram of circles with patient in the middle surrounded next by carer, then by next zone of community support (this is the zone to improve). Outer zone includes Meals on Wheels, Dom Care and RDNS.
P=patient  C=Carer  S= next zone of community support  O=organisations  [e.g. Meals on Wheels, Dom Care, RDNS]

D-9 I feel my knowledge of local support availability is not complete (hence resource kit suggestion above). Also Medicare Rebates are structured to discourage it. Financial recognition, help

D-10 Funding
Others low opinions of GPs
D-11 Agencies and support groups don't care as much as they should. Insufficient support is available.
D-12 Not paid
D-13 No answer

Survey GPs
D-14 Accessing information
D-15 Can be difficult finding a place to put dependant for respite at short notice
D-16 No answer
D-17 The tendency to put carers' health very much 2nd place to the dependent person's sometimes at great cost to themselves
D-18 My need for information - it keeps changing, new services arise, others fade, some change - very hard to keep up
D-19 Greater need for services than are available
D-20 Time - needs to be readily accessible
D-21 Limited hours of various agencies and needing to ring back
D-22 Unaware of other services, how to access them
D-23 No answer
D-24 Can be difficult to access appropriate information
D-25 Time consuming

Q. 3.9 What do YOU believe have been the causes of those frustrations / barriers ?

D-1 Lack of resources available to carers - especially respite care and accessing allied health care (podiatry, physio etc.)
Lack of good counselling service for carers e.g. psychologist or even support groups
D-2 The support organisations are less likely to offer access to GPs than patients and their families
D-3 Carers not wanting to separate, or unwilling to see need to separate.
D-4 Many GPs not familiar with what is available
Attitude of the family members/carers
D-5 Lack of current knowledge. You may have a pamphlet that's 2 years old about services, but then find that service has been axed due to funding cuts.
GP burnout.
Sometimes I just feel tired and that I'm unable to supply the level of support that I perceive some people want.
Lack of payment for doing this work, Lack of time
D-6 No answer
D-7 [1] Current structure of general practice and health funding
[2] Information overload + difficulty in gaining information
D-8 [1] Inadequate knowledge / education re carers + more respite facilities
[2] Lack of motivation
D-9 Government policy re rebate
Mistrust between community and private health sectors.
D-10 No answer
D-11 Each support agency runs its own show - a central coordinator is required ie a social worker under direction of the primary medical provider, ie GP
D-12 Funding for community services
D-13 No answer
Q. 3.9 What do YOU believe have been the causes of those frustrations / barriers?

Survey GPs
D-14 Lack of information on what services to approach
D-15 Lack of facilities
D-16 No answer
D-17 No answer
D-18 Where to start? multiple funding
D-19 Finance
D-20 No answer
D-21 Limited hours of various agencies and needing to ring back
D-22 Inadequate communication to GPs from these services about how to access them
D-23 No answer
D-24 Lack of consolidation of available facilities
D-25 I spend a lot of time outside consulting time attending at home visits etc, and usually don't get paid for the majority of it. The patients and carers are very appreciative though and this is worthwhile in itself.

13 Original GPs
12 Survey GPs

Q. 3.10 Have you helped carers by providing?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>After hours support</td>
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<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Emergency support</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Home visits to follow up or review the situation</td>
<td>0</td>
<td>4</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

Have you helped carers by arranging phone numbers for carer enquiries?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>n=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office Hours</td>
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<tr>
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<td>4</td>
<td>3</td>
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</tbody>
</table>

Q. 3.10 Have you helped carers by providing?

D-1 Trying to focus on carer as individual rather than as "Mrs E's daughter" + encouraging proactive role in own medical needs
D-2- D-6 No answer
D-7 Emergency accommodation, transport; Organisation of extra support
D-8 Arranging support -telephone etc.; Spending time listening to them
D-9 No answer
D-10 No answer
D-11 Deliver prescriptions/drugs; Home nursing support by my staff
Home visited when patient could have attended my surgery
D-12 No answer
D-13 No answer

Survey GPs: D-14 to 25 No answer
Q. 4.1
Do you see it as a role of the General Practitioner to provide support and other assistance to family caregivers and other carers?

<table>
<thead>
<tr>
<th>No. of GP Responders</th>
<th>n=12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
</tbody>
</table>

GP Comments
D-1 Vital part of holistic care for both recipient and carer
D-2 Dealing with carers is normal in general practice
D-3 It's our job
D-4
D-5 No answer
D-6
D-7 No answer
D-8 Our role in health, our situation in community and our education/skills should ideally place us as co-ordinators
D-9 GPs are in an expected and a central case manager role
D-10 No answer
D-11 Primary medical provider
Many services, e.g. social worker, not available so responsibility and work falls onto GPs' shoulders (NO PAYMENT)
D-12 No answer
D-13 No answer
Survey GPs
D-14
D-15 To
D-17
D-18 Either provide it or know where they can get it or who to lobby
D-19
D-20 To
D-24
D-25 We are well placed to be there to support and provide information and co-ordinate other services

Q. 4.2
If the carer became ill, how could the GP offer additional assistance? (e.g. with prescriptions, emergency respite while the carer is needing rest)

GP Comments
D-1 Regular home visits to recipient
D-2 [1] Identify other potential carers
[2] Reality check needs of patient (i.e. reduce demands etc.)
[3] Hospitalisation
D-3 Routine GP care
D-4 [1] Respite care
[2] Organising delivery of prescriptions and Meals on Wheels etc.
D-5 Respite is the main one
D-6 As above [prescriptions, emergency respite while the carer is needing rest]
D-7 Yes; Advising support services to help with dependent
D-8 By doing all of the things we do now
D-9 Mainly respite or additional home care + emotional support for the carer
D-10 Be funded (fee for service) for time spent with carer + on patient's behalf
D-11 GP do all he could e.g. deliver or arrange to have delivered prescriptions & food
D-12
D-13 No answer
Survey GPs
D-14 No answer
D-15 Treating carer & providing respite if possible
D-16 .... work referral
D-17 Try to provide other support
Emergency respite care
Frequent home visits
D-18 Emergency respite; day care
D-19 No answer
D-20 No answer
D-21 Emergency respite
Home sitter service - limited hours
D-22 Uncertain what to do - may contact S.A.R.T.
D-23 Respite
D-24 Emergency respite; Emergency admission
D-25 Home visits, coordinate other services,
Respite for the dependent patient,
Frequent review

Q. 4.3
Some family members and other carers have been unable to get adequate information about the condition of the person they are caring for. (i.e. so they can better understand the diagnosis, prognosis and treatments necessary to care for that person)

Please suggest how GPs (and others) could provide more helpful information in the future

D-1 to D-5 No answer
D-6 Pamphlets, written information
D-7 Needs database of information suitable for patient / carer education and ready access
D-8 This shouldn't be the case - this is a communication problem. Doctors should be available to be able (willing) to obtain any information they do not already have.
D-9 If GP were recompensed appropriately, they could supply this adequately.
Support groups could provide pamphlets too. Referral to specialists is possible but occasionally inadequate.
D-10 No answer
D-11 Carers should regularly meet with GP to discuss progress - preferably at Drs. surgery
D-12 Clarify the medico-legal aspect
D-13 No answer

Survey GPs
D-14 They just have to ask
D-15 Discussing it with the carer when appropriate
D-16 No answer
D-17 Listening and talking; - providing information to these people; working as a team
Acting as a liaison both with - family and hospital
D-18 Have carer there while they are providing a consultation with the dependant person and answer questions, give info. If GPs are not helpful I suggest patient changes doctor
D-19 Carer to attend consultation with person under care
D-20 No answer D-21 -carers to make appointments for that reason alone, to allow reasonable time -carers to have their questions written down
D-22 Better communication with specialist or hospital patient has been attending
D-23 Talk to them; Write it down if necessary
D-24 Arrange adequate time for history and exam'n and reading of relevant files etc of patient
D-25 Home visit to discuss issues or meeting at the clinic
Q. 4.4
Some family members and other carers have perceived a lack of recognition by health care professionals of the carer’s role and responsibilities.

GP Comments: what would help GPs to better recognise people who are carers in the future

D-1  GP unaware of the level of caring of the carer ie how much they are doing
D-2  They don’t ask. They can’t see
D-3  Time; lack of understanding; No Data on carers’ needs
D-4  GPs to see the real situation at home
D-5  No answer
D-6  Depends solely on the GPs and their interests
D-7  Take a good social history of new patients
D-8  Again this is a communication problem. GPs should be entitled to counsel carers and probably should be paid for it.
D-9  Spend more time inquiring exactly what a particular carer sees that their role entails.
D-10 No answer
D-11  Domiciliary visiting [ie. housecalls by GP quickly identifies carer]
D-12  GPs involvement is voluntary / unpaid
D-13 No answer

Survey GPs
D-14 to D-16 No answer
D-17  "as in answer to 4.3"
D-18  Training + information given at CME sessions, during medical school, during RACGP training program
       If carer and dependent person has same GP it is hard to GPs to ignore it
D-19  No answer
D-20  No answer
D-21  Awareness raising, which is occurring via frequent correspondence from carers support group
D-22  Full knowledge of help available to carer
D-23  Having a carer keeps patient out of hospital and nursing homes. This is going to be more and more important with limited gov’t. financial resources
D-24  Two way communication of problems
       Encourage carers to be more comfortable in questioning GPs.
D-25  Do home visits to see how they cope and what the true situation is. You can’t always tell in the Rooms what their difficulties really are.

Q. 4.5
Which other individuals / professionals do you think could assist GPs to identify and support carers?

<table>
<thead>
<tr>
<th>No. of GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Support Groups</td>
<td>15</td>
</tr>
<tr>
<td>Council Social Workers</td>
<td>15</td>
</tr>
<tr>
<td>District Nurse</td>
<td>16</td>
</tr>
<tr>
<td>Church based workers</td>
<td>4</td>
</tr>
<tr>
<td>No answer</td>
<td>5</td>
</tr>
</tbody>
</table>

GP Comments
D-1  All services mentioned in referrals
D-2  Local social workers know local networks
D-4  Agencies such as Day Care
D-18:  Why do GPs need help to identify carers ?? The carer’s presence at consultations should be all that is needed. If that doesn’t do it- change GP!!
Q. 4.6
If you are aware that the carer is the patient of another GP, what is your approach to offering the carer support or medical care?

D-1 | No answer
D-5 | No answer
D-6 | Suggestions to see own GP to discuss this
D-7 | Talk to other GP
D-8 | Ring the GP and discuss the matter. Inform the carer but offer access / back up.
D-9 | The usual ethics, but stating that you are able to support if the other (GP) is unavailable - also offering to share information re the caree with the other GP
D-10 | No answer
D-11 | None directly. Advise carer to discuss her situation with her own doctor.
D-12 | Discuss with carer and GP.
D-13 | No answer

Survey GPs
D-14 | Suggest to carer happy assist if needed
D-15 | Advice that they should consult their doctor
D-16 | Liaise with GP
D-17 | Suggest that they speak to the other GP but still provide support while underlining that they need to refer to their own Doctor
Offering to liaise
D-18 | I still do it if the carers requests it or I can see a need. If the carer is not my patient I don't know them so well, or they me, so communication is not as good. Same GP best.
D-19 | Liaise with other GP
Would offer support but not medical advice
D-20 | No answer
D-21 | Advise them to make an appointment with their GP to discuss this issue. If not helpful, could return to me, or I could refer them on
D-22 | Do not offer much medical support
D-23 | To suggest they should see their own doctor
D-24 | Open offer
D-25 | Offer to talk to person's own GP or offer advice- to be discussed with their own GP

Q. 4.7
If appropriate remuneration could be arranged, would you prefer to visit and talk to carers in the surgery or in their own homes?

<table>
<thead>
<tr>
<th>GP Responses</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the surgery</td>
<td>D-3, D-6, D-10, D-12, D-16, D-19, D-20</td>
</tr>
<tr>
<td>In their home</td>
<td>D-3, D-4, D-9, D-10, D-20, D-21, D-25</td>
</tr>
<tr>
<td>Both</td>
<td>D-1, D-2, D-3, D-5, D-7, D-8, D-10, D-14, D-15, D-17, D-18, D-20, D-22, D-23, D-24, D-25</td>
</tr>
</tbody>
</table>

What do YOU as a GP feel you need when trying to help caregivers

D-1
GP unaware of the level of caring of the carer - ie how much they are doing
Some constraints with confidentiality of the recipient

D-2
Carers are stuck in a rut. Can't recognise the problem and therefore the solution
D-4
Need for **An Emergency Kit** with the following information provided:

<table>
<thead>
<tr>
<th></th>
<th>Day time number of GP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Night time number of GP</td>
</tr>
<tr>
<td></td>
<td>Weekend number</td>
</tr>
</tbody>
</table>

What to do if acutely ill
i.e. ambulance first, doctor second

If Doctor away, who to ring
1)........................
2)........................
Ring your doctor between .......... hours for advice

<table>
<thead>
<tr>
<th>Phone Nos.</th>
<th>Clinic</th>
<th>Chemist who will deliver</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Specialist</td>
<td>Ambulance</td>
</tr>
</tbody>
</table>

D-5
This issue of spending more time and attention on the needs of carers is one example of a fundamental problem facing general practice today.

GPs are constantly being asked to do more, better and for longer periods of time i.e. care of chronically mentally ill, drug information etc. etc.

The proposed solution to many of today's health care problems seems to be "educate the GP to do it better".

What I would really like happen, is for someone to do a good study on exactly how much more time their proposal is going to take and then to work out some practical proposals as to how the GP can make this time.

Otherwise, at the end of the day, one simply feels pulled apart by the various different interest groups.

Of course, I think GPs paying more attention to carers is very important. However I wish someone would try and put this and all the other roles we play into an overall context.

D-8
Time!
In General Practice we already have to work long hours to make a reasonable income (granted we probably employ too many staff and spend too long with patients making this unprofitable).
Although we now provide considerable unpaid organisational hours - a lot is in trying to help caregivers. Some recognition of this by a system of payment for carer counselling would improve the quality of care I'm sure (by encouraging more GPs to do it).

D-11
GPs need a social worker whom is responsible to the GP

D-12
An item Number for "carers"

**MISC:** Be funded (fee for service), for time spent with carer + on patient's behalf.
What do YOU as a GP feel you need when trying to help caregivers

Survey GPs

D-18  Time
       Resources - payment for time
       Information [see Q 3.3 = Would need regular updating? yearly]
       Good local services

D-21  Time - they need to make appointments for themselves

D-22  Better knowledge of help available

D-23  More time

D-24  Good information of available resources so that information is appropriate, relevant and concise.
       Time for listening as often emotional support is important
       Time for home visits - extremely helpful in assessing any situation
SECTION III:
INFORMAL CAREGIVING AT THE POPULATION LEVEL

APPENDIX 12:

1994 Health Omnibus Results: First Original Report [1995]
Prepared by the Behavioural Epidemiology Department
South Australian Health Commission

Adults who are Carers: Comparison of SF-36 Profiles
Dear Anne

Please find enclosed a revised copy of your report concerning the SF-36 Health Status Questionnaire.

In preparing a more general report detailing the population norms for South Australia, we became aware that a minor omission had been made in the calculation of scores relating to the Vitality scale. As a result, the population mean score was recalculated from 67 to 64 for this scale. The report "South Australian population norms for the SF-36 health status questionnaire" has incorporated this correction.

However, the calculation of condition-specific profiles, such as the work we undertook for you, has also been affected. We have now rectified the scores in your report relating to the Vitality scale. Whilst all other scale scores remain the same, we have re-issued the whole report for your convenience so that you can simply replace the new report for the old one.

We hope that this has not caused any inconvenience on your part. Please do not hesitate to contact me on if you require further clarification.

Yours sincerely

Melanie Wakefield
Senior Behavioural Scientist
BEHAVIOURAL EPIDEMIOLOGY UNIT
SF-36 Mean Scale Scores for people who are Carers & people who are not Carers

- Non-Carers
- Carers

PF  RP  BP  GH  VT  SF  RE  MH
ADULTS WHO ARE CARERS: COMPARISON OF SF-36 PROFILES

Prepared for:

Anne Stacey
Department of General Practice
Flinders Medical Centre

By:

Behavioural Epidemiology Unit
South Australian Health Commission

June 1995
Revised September 1995
Introduction

The SF-36 (Short-Form 36) is a brief general health status measure developed by the Medical Outcomes Study (MOS) in the United States. In contrast to condition-specific scales, general measures of health status attempt to capture aspects of health that are important to all patients. They are useful for health status comparisons both among patients with the same condition and between patients with different conditions. Such measures can also be administered to general populations to see how a particular condition causes health to depart from a 'healthy standard'.

The SF-36 is a 36 item questionnaire, which measures eight parameters of health status, resulting in a profile of scores measuring physical functioning (10 items), social functioning (2 items), role limitations due to physical health problems (4 items) and emotional problems (3 items), mental health (5 items), vitality (4 items), pain (2 items), and general health perception (5 items). The responses to the questions on each scale are summed to provide eight scores between 0 and 100, with higher scores indicating better health.

The SF-36 measure evolved from the RAND Corporation's Health Insurance Experiment of the late 1970's, being continued by John Ware and Anita Stewart and MOS colleagues during the 1980's, in an effort to find the optimum trade-off between breadth and depth in a general health status measure (Stewart & Ware, 1992). The development of the SF-36 involved extracting items from other MOS instruments which had already been tested and validated (Ware & Sherbourne, 1992). The validity and reliability of the SF-36 in patient populations has been tested in studies in the United States (McHorney et al., 1993). The SF-36 discriminated between patients with major and minor physical and psychiatric conditions. Moreover, the scales measuring physical health best distinguished groups differing in presence and severity of physical health conditions, whilst the scales measuring mental health best distinguished between groups differing in the presence and severity of psychiatric disorders. Other studies have confirmed the ability of the SF-36 scales to distinguish between groups of patients with certain conditions (eg. McCallum, 1995; etc). These studies provide strong evidence of the clinical validity of the SF-36 as a measure of patients' perceived health.

Versions of the questionnaire have been adapted for use in specific countries and an authorised Australian version is available. The Australian version has made minor modifications to the wording of the questionnaire to bring it more in line with accepted Australian language. For example, the original question "do you feel full of pep?" was changed to "do you feel full of life?", walking a mile was changed to walking a kilometre, and so on.

Method

The SF-36 was included in the Spring 1994 Health Omnibus Survey. Each respondent to the survey was administered the Australian version of the questionnaire by a trained interviewer, along with a broad range of questions about other health-related issues, as required by subscribers to the survey. A copy of the
SF-36 as it appeared in the Health Omnibus Survey is contained in Appendix 1. All respondents were asked whether they were a carer of a dependent person, given the following which was read out "a dependent person is someone who has a chronic condition that is unlikely to improve. A carer is responsible for the permanent care of that person on a long term basis".

Mean scores for each of the eight scales of the questionnaire were derived for respondents with and without the specific condition or risk factor of interest and the differences were calculated. A negative score signifies poorer health in those with the condition compared to those without it. Since health status varies with age, sex and socio-economic status, comparisons between subgroups of the population need to adjust for these socio-demographic variables. For this reason, multiple linear regression was used to compare the mean score differences whilst adjusting for the effects of age, sex and occupational status.

Thus, for each scale, the scale score was included as the dependent variable, and age, sex, occupational status and carer status were included as independent variables. Age was included as a continuous variable, with sex, carer status, and occupational status as binary categorical variables. Occupational status was derived from ASCO codes, and a conventional method of aggregation applied to categorise respondents into higher (including high and very high) or lower (medium and low) status. In the multiple regression analysis, the partial regression coefficients, and their standard errors, of the carer status variable were used to calculate 95% confidence intervals for differences between those with and without the particular diseases.

**Results and interpretation**

The response rate for the survey was 72.4%. Overall, 3.4% of the 3010 respondents reported that they were carers, given the definition outlined above.

Table 1 shows the mean scores and differences in SF-36 scores for respondents who were or were not carers, after adjusting for age, sex and occupational status. At the conventional p < .05 level, it is apparent that scores for carers are lower across all scales of the SF-36, compared with their non-carer counterparts. However, scores are statistically significantly lower only for scales measuring social functioning, role limitations due to emotional problems and mental health. Figure 1 shows the profile of scores in a graphical display.

In terms of interpreting individual scale scores, comparison with the profile of differences for other conditions gives some indication of the clinical nature of differences observed. Table 2 shows scale scores for respondents with and without other conditions of characteristics of interest. In comparing across conditions, it is important to note that it is not the absolute or actual scores which are the subject of comparison, but the magnitude of the difference in scores between those with and without the condition of interest. This is because the reference groups (those without the condition of interest) are different for each condition examined. Thus, for example, for the physical functioning scale, those with asthma have an average
8.6 point reduction in functioning, compared with those who do not have asthma. In comparison, those with arthritis have a 13.6 point difference in function, compared with those who do not have arthritis. Whilst one might be tempted to conclude that the average person with arthritis would score 5 points lower than a person with asthma, this may not be the case. A more correct interpretation is that those with arthritis differ from people without arthritis to a greater extent than those with asthma differ from non-asthmatics.

Whilst carers do not evidence differences in functioning in the final three scales of the magnitude of differences apparent for people with/without high scores on the 12-item GHQ (indicating a strong likelihood of psychiatric impairment), they do show differences in functioning similar to those of people with/without asthma or other chronic limiting conditions such as arthritis or diabetes. Thus, for most people who are carers, there is evidence of impairment in aspects of living related to emotional, social and mental health, rather than in domains related to physical functioning.
APPENDIX 13:

1994 Health Omnibus Results:
Prepared by the Centre for Population Studies in Epidemiology
Department of Human Services, SA

Report Revised 1999

Adults who are Carers: Comparison of SF-36 Profiles
ADULTS WHO ARE CARERS: COMPARISON OF SF-36 PROFILES
(1994 Health Omnibus Survey)

Prepared for:

Anne Stacey

By:

Centre for Population Studies in Epidemiology
Department of Human Services

August 1999
Results

The response rate for the 1994 Health Omnibus Survey was 72.4%. Overall, 3.4% (n=104) of the 3010 respondents reported that they were carers of a dependent person. This was based on the definitions "a carer is responsible for the permanent care of that person on a long term basis" and "a dependent person is someone who has a chronic condition that is unlikely to improve".

Socio-demographic characteristics of carers

The proportion of respondents reporting they were carers according to demographic variables is shown in Table 1.
Table 1: Proportion of respondents reporting they were carers by demographic variables

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Carers</th>
<th></th>
<th>Non-carers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
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<td>65+</td>
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<td>32.1</td>
<td>474</td>
<td>16.3</td>
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<td><strong>Marital status</strong></td>
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<td></td>
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<tr>
<td>Married / de facto</td>
<td>79</td>
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<td>Separated / divorced</td>
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<td>10.6</td>
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<td>Still at school</td>
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<td>-</td>
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<td>Left before 15 years</td>
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<td>34.0</td>
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<td>27.4</td>
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<td>31.5</td>
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<tr>
<td>Bachelor Degree</td>
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<td><strong>Country of birth</strong></td>
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<td>Australia</td>
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<td><strong>Income</strong></td>
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<td>12,001-20,000</td>
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<td>60,001-80,000</td>
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<td>7.3</td>
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<td>More than 80,000</td>
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<td>17.1</td>
<td>445</td>
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<tr>
<td><strong>Total</strong></td>
<td>104</td>
<td>100.0</td>
<td>2906</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Effects of caring on the health and well being of carers

Respondents who identified themselves as being carers were asked if they felt that their caring role had affected their physical or emotional health or well being recently, or at any time in the past. These results are presented in Table 2.

Table 2: Effect of caring role on physical or emotional health of carer

<table>
<thead>
<tr>
<th>Health affected</th>
<th>Carers</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>48</td>
<td>46.4</td>
</tr>
<tr>
<td>Yes</td>
<td>56</td>
<td>53.6</td>
</tr>
<tr>
<td>Minor effect</td>
<td>19</td>
<td>18.8</td>
</tr>
<tr>
<td>Moderate effect</td>
<td>22</td>
<td>21.5</td>
</tr>
<tr>
<td>Major effect</td>
<td>14</td>
<td>13.3</td>
</tr>
<tr>
<td>Total</td>
<td>104</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Quality of life of carers

Table 3: Mean SF-36 scores and differences for carers and non-carers adjusted for age, gender and SES (occupation)

<table>
<thead>
<tr>
<th>SF-36 Scale</th>
<th>Carers (n=104)</th>
<th>Non-carers (n=2906)</th>
<th>Mean difference</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>82.8</td>
<td>85.0</td>
<td>-2.2</td>
<td>(-6.5,+2.1)</td>
</tr>
<tr>
<td>RP</td>
<td>76.0</td>
<td>79.9</td>
<td>-3.9</td>
<td>(-11.8,+4.0)</td>
</tr>
<tr>
<td>BP</td>
<td>72.6</td>
<td>77.0</td>
<td>-4.4</td>
<td>(-10.2,+1.4)</td>
</tr>
<tr>
<td>GH</td>
<td>69.6</td>
<td>73.1</td>
<td>-3.5</td>
<td>(-8.3,+1.4)</td>
</tr>
<tr>
<td>VT</td>
<td>60.8</td>
<td>63.8</td>
<td>-3.0</td>
<td>(-7.8,+1.8)</td>
</tr>
<tr>
<td>SF</td>
<td>81.7</td>
<td>88.4</td>
<td>-6.7</td>
<td>(-11.6,-1.8) *</td>
</tr>
<tr>
<td>RE</td>
<td>77.1</td>
<td>87.7</td>
<td>-10.6</td>
<td>(-17.2,-4.0) *</td>
</tr>
<tr>
<td>MH</td>
<td>73.5</td>
<td>78.8</td>
<td>-5.3</td>
<td>(-9.3,-1.3) *</td>
</tr>
</tbody>
</table>

* Significant difference at 0.05 level
Figure 1: Mean SF-36 scores for carers and non-carers, adjusted for age, gender and SES (occupation)
Table 4: Mean SF-36 scores and differences for carers and the general SA population

<table>
<thead>
<tr>
<th>SF-36 Scale</th>
<th>Total sample (n=3009)</th>
<th>Carers (n=104)</th>
<th>Mean difference</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>85.4</td>
<td>77.2</td>
<td>-8.2</td>
<td>(-13.6,-2.8) *</td>
</tr>
<tr>
<td>RP</td>
<td>80.2</td>
<td>72.1</td>
<td>-8.1</td>
<td>(-16.9,+0.7)</td>
</tr>
<tr>
<td>BP</td>
<td>77.2</td>
<td>70.2</td>
<td>-7.0</td>
<td>(-13.2,-0.8) *</td>
</tr>
<tr>
<td>GH</td>
<td>73.2</td>
<td>66.8</td>
<td>-6.4</td>
<td>(-11.6,-1.2) *</td>
</tr>
<tr>
<td>VT</td>
<td>64.0</td>
<td>59.1</td>
<td>-4.9</td>
<td>(-10.1,+0.3)</td>
</tr>
<tr>
<td>SF</td>
<td>88.2</td>
<td>81.0</td>
<td>-7.2</td>
<td>(-12.8,-1.6) *</td>
</tr>
<tr>
<td>RE</td>
<td>87.5</td>
<td>76.6</td>
<td>-10.9</td>
<td>(-19.2,-2.6) *</td>
</tr>
<tr>
<td>MH</td>
<td>78.7</td>
<td>73.7</td>
<td>-5.0</td>
<td>(-9.3,-0.7)</td>
</tr>
</tbody>
</table>

* Significant difference at 0.05 level
Figure 2: Mean SF-36 scores for carers and the total population
Table 5: Mean SF-36 scores for carers and the general SA population by gender

<table>
<thead>
<tr>
<th></th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total sample (n=1480)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Mean</td>
<td>88.6</td>
<td>82.6</td>
<td>79.9</td>
<td>74.3</td>
<td>68.0</td>
<td>90.6</td>
<td>90.3</td>
<td>81.3</td>
</tr>
<tr>
<td>SD</td>
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<td>32.5</td>
<td>24.4</td>
<td>21.0</td>
<td>20.1</td>
<td>19.1</td>
<td>25.5</td>
<td>16.5</td>
</tr>
<tr>
<td>Carers (n=43)</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
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<td>Mean</td>
<td>82.3</td>
<td>69.0</td>
<td>74.8</td>
<td>68.7</td>
<td>66.0</td>
<td>86.6</td>
<td>81.7</td>
<td>77.0</td>
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<td>40.7</td>
<td>27.7</td>
<td>22.2</td>
<td>20.7</td>
<td>18.8</td>
<td>36.8</td>
<td>16.8</td>
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<tr>
<td>Females</td>
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<tr>
<td>Mean</td>
<td>82.4</td>
<td>77.9</td>
<td>74.6</td>
<td>72.2</td>
<td>60.1</td>
<td>86.0</td>
<td>84.7</td>
<td>76.2</td>
</tr>
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<td>23.2</td>
<td>36.9</td>
<td>26.3</td>
<td>22.2</td>
<td>22.0</td>
<td>23.0</td>
<td>31.6</td>
<td>18.4</td>
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<td>Carers (n=61)</td>
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<td>74.2</td>
<td>67.1</td>
<td>65.4</td>
<td>54.4</td>
<td>77.2</td>
<td>73.1</td>
<td>71.3</td>
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<tr>
<td>SD</td>
<td>25.6</td>
<td>38.0</td>
<td>26.9</td>
<td>23.4</td>
<td>23.3</td>
<td>27.9</td>
<td>38.5</td>
<td>20.7</td>
</tr>
</tbody>
</table>
Table 6: Mean SF-36 scores for carers and the general SA population by age

<table>
<thead>
<tr>
<th></th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-34 years</td>
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<td></td>
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<td>88.4</td>
<td>87.3</td>
<td>77.8</td>
</tr>
<tr>
<td>SD</td>
<td>11.4</td>
<td>30.0</td>
<td>22.7</td>
<td>18.4</td>
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<td>20.0</td>
<td>28.8</td>
<td>17.6</td>
</tr>
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<td></td>
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<td>74.9</td>
<td>55.7</td>
<td>65.9</td>
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<td>36.9</td>
<td>27.8</td>
<td>21.8</td>
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<td>27.1</td>
<td>47.0</td>
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<td>35-54 years</td>
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<td>76.0</td>
<td>64.4</td>
<td>89.3</td>
<td>88.0</td>
<td>78.8</td>
</tr>
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<td>SD</td>
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<td>25.3</td>
<td>21.0</td>
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<td>20.6</td>
<td>28.3</td>
<td>17.6</td>
</tr>
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<tr>
<td>Mean</td>
<td>85.2</td>
<td>84.7</td>
<td>73.8</td>
<td>76.1</td>
<td>63.6</td>
<td>83.6</td>
<td>87.6</td>
<td>75.4</td>
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<td>SD</td>
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<td>33.5</td>
<td>28.0</td>
<td>19.2</td>
<td>19.4</td>
<td>23.7</td>
<td>30.8</td>
<td>19.0</td>
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<tr>
<td>55-74 years</td>
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</tr>
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<tr>
<td>Mean</td>
<td>74.8</td>
<td>72.9</td>
<td>71.7</td>
<td>65.6</td>
<td>62.8</td>
<td>87.8</td>
<td>87.9</td>
<td>79.7</td>
</tr>
<tr>
<td>SD</td>
<td>24.3</td>
<td>38.4</td>
<td>27.4</td>
<td>23.2</td>
<td>22.4</td>
<td>22.5</td>
<td>28.7</td>
<td>18.1</td>
</tr>
<tr>
<td>Carers (n=43)</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Mean</td>
<td>71.2</td>
<td>68.5</td>
<td>67.8</td>
<td>59.5</td>
<td>57.7</td>
<td>80.2</td>
<td>75.8</td>
<td>76.2</td>
</tr>
<tr>
<td>SD</td>
<td>23.8</td>
<td>41.6</td>
<td>26.8</td>
<td>24.1</td>
<td>23.0</td>
<td>26.2</td>
<td>36.7</td>
<td>18.4</td>
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<tr>
<td>75+ years</td>
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<td></td>
</tr>
<tr>
<td>Total sample (n=203)</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Mean</td>
<td>52.8</td>
<td>57.4</td>
<td>67.1</td>
<td>58.6</td>
<td>54.2</td>
<td>83.4</td>
<td>84.3</td>
<td>80.4</td>
</tr>
<tr>
<td>SD</td>
<td>30.4</td>
<td>42.9</td>
<td>29.5</td>
<td>24.5</td>
<td>25.1</td>
<td>26.7</td>
<td>32.9</td>
<td>17.7</td>
</tr>
<tr>
<td>Carers (n=8)</td>
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<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Mean</td>
<td>58.9</td>
<td>58.0</td>
<td>74.6</td>
<td>61.3</td>
<td>58.9</td>
<td>90.8</td>
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</tr>
<tr>
<td>SD</td>
<td>34.8</td>
<td>45.0</td>
<td>29.7</td>
<td>20.9</td>
<td>27.4</td>
<td>14.1</td>
<td>25.7</td>
<td>15.9</td>
</tr>
</tbody>
</table>
Figure 3: Mean SF-36 scores for carers and the total population aged 15-34 years
Figure 4: Mean SF-36 scores for carers and the total population aged 35-54 years
Figure 5: Mean SF-36 scores for carers and the total population aged 55-74 years
Figure 6: Mean SF-36 scores for carers and the total population aged 75+ years
Figure 7: Mean SF-36 scores for carers according to age (years)
Table 7: Mean difference in SF-36 scores (95% CI) for self reported disease conditions adjusted for age, sex and SES (occupation)

<table>
<thead>
<tr>
<th></th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>-8.7</td>
<td>-10.1</td>
<td>-6.4</td>
<td>-13.7</td>
<td>-6.9</td>
<td>-8.0</td>
<td>-9.0</td>
<td>-4.9</td>
</tr>
<tr>
<td>(n=287)</td>
<td>(-11.6, -5.8)</td>
<td>(-15.5, -4.7)</td>
<td>(-10.4, -2.4)</td>
<td>(-17.0, -10.4)</td>
<td>(-10.2, -3.6)</td>
<td>(-11.3, -4.7)</td>
<td>(-13.6, -4.4)</td>
<td>(-7.7, -2.2)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>-10.8</td>
<td>-11.0</td>
<td>-9.4</td>
<td>-11.1</td>
<td>-9.1</td>
<td>-2.5</td>
<td>-7.2</td>
<td>-2.6</td>
</tr>
<tr>
<td>(n=117)</td>
<td>(-14.9, -6.7)</td>
<td>(-18.6, -3.4)</td>
<td>(-14.9, -3.9)</td>
<td>(-15.7, -6.5)</td>
<td>(-13.7, -4.5)</td>
<td>(-7.2, +2.2)</td>
<td>(-13.6, -0.8)</td>
<td>(-6.5, +1.3)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>-13.6</td>
<td>-16.6</td>
<td>-18.5</td>
<td>-12.9</td>
<td>-10.4</td>
<td>-7.9</td>
<td>-4.8</td>
<td>-4.4</td>
</tr>
<tr>
<td>(n=666)</td>
<td>(-15.8, -11.3)</td>
<td>(-21.0, -12.2)</td>
<td>(-21.7, -15.3)</td>
<td>(-15.5, -10.3)</td>
<td>(-12.9, -7.9)</td>
<td>(-10.6, -5.2)</td>
<td>(-8.3, -1.3)</td>
<td>(-6.4, -2.4)</td>
</tr>
</tbody>
</table>
Figure 8: Mean difference in SF-36 scores for self-reported disease conditions and carers, adjusted for age, sex and SES (occupation)
APPENDIX 14:

1998 Health Omnibus Results:
Prepared by the Centre for Population Studies in Epidemiology
Department of Human Services, SA

Report Revised 1999

Adults who are Carers: Comparison of SF-36 Profiles
ADULTS WHO ARE CARERS: COMPARISON OF SF-36 PROFILES
(1998 Health Omnibus Survey)

Prepared for:
Anne Stacey

By:
Centre for Population Studies in Epidemiology
Department of Human Services

August 1999
Results

The response rate for the 1998 Health Omnibus Survey was 70.2%. Overall, 4.2% (n=127) of the 3010 respondents reported that they were carers of a dependent person. This was based on the definitions "a carer is responsible for the permanent care of that person on a long term basis" and "a dependent person is someone who has a chronic condition that is unlikely to improve".

Socio-demographic characteristics of carers

The proportion of respondents reporting they were carers according to demographic variables is shown in Table 1.
Table 1: Proportion of respondents reporting they were carers by demographic variables

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Carers</th>
<th></th>
<th>Non-carers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>57</td>
<td>45.0</td>
<td>1407</td>
<td>48.8</td>
</tr>
<tr>
<td>Female</td>
<td>70</td>
<td>55.0</td>
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<td>51.2</td>
</tr>
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<td>Age</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-44</td>
<td>42</td>
<td>33.0</td>
<td>1628</td>
<td>56.5</td>
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<tr>
<td>44-64</td>
<td>46</td>
<td>35.9</td>
<td>767</td>
<td>26.6</td>
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<tr>
<td>65+</td>
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<td>16.9</td>
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<tr>
<td>Marital status</td>
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<td></td>
</tr>
<tr>
<td>Married / de facto</td>
<td>109</td>
<td>85.5</td>
<td>1741</td>
<td>60.5</td>
</tr>
<tr>
<td>Separated / divorced</td>
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<td>210</td>
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<td>Still at school</td>
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</tr>
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<td>Left before 15 years</td>
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</tr>
<tr>
<td>Left after 15 years</td>
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<td>Up to 12,000</td>
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<td>30,001-40,000</td>
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<td>60,001-80,000</td>
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<td>267</td>
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<td>More than 80,000</td>
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<td>246</td>
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<tr>
<td>Not stated</td>
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<td>427</td>
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<td>2882</td>
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</table>
Effects of caring on the health and well being of carers

Respondents who identified themselves as being carers were asked if they felt that their caring role had affected their physical or emotional health or well being recently, or at any time in the past. These results are presented in Table 2.

Table 2: Effect of caring role on physical or emotional health of carer

<table>
<thead>
<tr>
<th>Health affected</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>69</td>
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<tr>
<td>Yes</td>
<td>58</td>
<td>45.5</td>
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<tr>
<td>Minor effect</td>
<td>32</td>
<td>24.8</td>
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<tr>
<td>Moderate effect</td>
<td>17</td>
<td>13.7</td>
</tr>
<tr>
<td>Major effect</td>
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<td>7.0</td>
</tr>
<tr>
<td>Total</td>
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</tr>
</tbody>
</table>

Quality of life of carers

Table 3: Mean SF-36 scores and differences for carers and non-carers adjusted for age, gender and SES (occupation)

<table>
<thead>
<tr>
<th>SF-36 Scale</th>
<th>Carers (n=127)</th>
<th>Non-carers (n=2879)</th>
<th>Mean difference</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>80.9</td>
<td>83.1</td>
<td>-2.2</td>
<td>(-6.2, +1.8)</td>
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<tr>
<td>RP</td>
<td>75.4</td>
<td>80.0</td>
<td>-4.6</td>
<td>(-11.9, +2.7)</td>
</tr>
<tr>
<td>BP</td>
<td>73.8</td>
<td>76.6</td>
<td>-3.4</td>
<td>(-7.6, +0.9)</td>
</tr>
<tr>
<td>GH</td>
<td>72.9</td>
<td>73.9</td>
<td>-1.0</td>
<td>(-5.4, +3.4)</td>
</tr>
<tr>
<td>VT</td>
<td>61.1</td>
<td>64.5</td>
<td>-3.4</td>
<td>(-7.6, +0.9)</td>
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<tr>
<td>SF</td>
<td>83.8</td>
<td>88.1</td>
<td>-4.3</td>
<td>(-8.8, +0.2)</td>
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<tr>
<td>RE</td>
<td>81.9</td>
<td>88.1</td>
<td>-6.2</td>
<td>(-12.4, -0.03) *</td>
</tr>
<tr>
<td>MH</td>
<td>76.2</td>
<td>80.2</td>
<td>-4.0</td>
<td>(-7.6, -0.4) *</td>
</tr>
</tbody>
</table>

* Significant difference at 0.05 level
Figure 1: Mean SF-36 scores for carers and non-carers, adjusted for age, gender and SES (occupation)
Table 4: Mean SF-36 scores and differences for carers and the general SA population

<table>
<thead>
<tr>
<th>SF-36 Scale</th>
<th>Total sample (n=3007)</th>
<th>Carers (n=127)</th>
<th>Mean difference</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>83.0</td>
<td>75.5</td>
<td>-7.5</td>
<td>(-12.4, -2.6) *</td>
</tr>
<tr>
<td>RP</td>
<td>79.8</td>
<td>71.2</td>
<td>-8.6</td>
<td>(-16.8, -0.4) *</td>
</tr>
<tr>
<td>BP</td>
<td>76.5</td>
<td>71.8</td>
<td>-4.7</td>
<td>(-10.3, +0.9)</td>
</tr>
<tr>
<td>GH</td>
<td>73.9</td>
<td>70.8</td>
<td>-3.1</td>
<td>(-7.8, +1.6)</td>
</tr>
<tr>
<td>VT</td>
<td>64.3</td>
<td>59.8</td>
<td>-4.5</td>
<td>(-8.7, -0.3) *</td>
</tr>
<tr>
<td>SF</td>
<td>87.9</td>
<td>83.2</td>
<td>-4.7</td>
<td>(-9.7, +0.3)</td>
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<tr>
<td>RE</td>
<td>87.8</td>
<td>81.8</td>
<td>-6.0</td>
<td>(-12.8, +0.8)</td>
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<tr>
<td>MH</td>
<td>80.0</td>
<td>76.4</td>
<td>-3.6</td>
<td>(-7.3, +0.1)</td>
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</tbody>
</table>

* Significant difference at 0.05 level
Figure 2: Mean SF-36 scores for carers and the total population
Table 5: Mean SF-36 scores for carers and the general SA population by gender

<table>
<thead>
<tr>
<th></th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
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<tbody>
<tr>
<td><strong>Males</strong></td>
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<td></td>
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<tr>
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<tr>
<td>Mean</td>
<td>85.4</td>
<td>82.3</td>
<td>77.7</td>
<td>73.5</td>
<td>66.9</td>
<td>88.9</td>
<td>90.4</td>
<td>81.7</td>
</tr>
<tr>
<td>SD</td>
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<td>24.6</td>
<td>20.9</td>
<td>19.8</td>
<td>20.8</td>
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<td>16.1</td>
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<td>73.5</td>
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<td>60.9</td>
<td>83.3</td>
<td>87.1</td>
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<td>27.3</td>
<td>23.4</td>
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<td>75.3</td>
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<td>87.0</td>
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<td>70.4</td>
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<td>83.2</td>
<td>77.5</td>
<td>76.2</td>
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<td>17.6</td>
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Table 6: Mean SF-36 scores for carers and the general SA population by age

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<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
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<tbody>
<tr>
<td>15-34 years</td>
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<td></td>
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<tr>
<td>Total sample</td>
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<td>85.3</td>
<td>79.7</td>
<td>76.6</td>
<td>65.9</td>
<td>88.1</td>
<td>87.4</td>
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<td>19.5</td>
<td>20.1</td>
<td>30.1</td>
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<td>90.1</td>
<td>88.8</td>
<td>79.6</td>
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<td>16.9</td>
<td>21.8</td>
<td>13.3</td>
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<td>77.5</td>
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<td>88.0</td>
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<td>82.0</td>
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<td>83.6</td>
<td>77.9</td>
<td>75.8</td>
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<td>63.4</td>
<td>87.2</td>
<td>88.6</td>
<td>81.3</td>
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<td>72.6</td>
<td>68.0</td>
<td>62.5</td>
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<td>90.3</td>
<td>79.1</td>
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<td>16.2</td>
<td>20.1</td>
<td>25.9</td>
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<td>70.0</td>
<td>62.3</td>
<td>56.5</td>
<td>83.2</td>
<td>86.6</td>
<td>81.7</td>
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<td>41.5</td>
<td>26.8</td>
<td>21.9</td>
<td>23.9</td>
<td>27.3</td>
<td>31.8</td>
<td>17.9</td>
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<td>Carers</td>
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<td>44.8</td>
<td>68.9</td>
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<td>56.0</td>
<td>73.6</td>
<td>73.3</td>
<td>71.7</td>
</tr>
<tr>
<td>(n=22)</td>
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<td>42.3</td>
<td>28.7</td>
<td>20.7</td>
<td>24.7</td>
<td>31.8</td>
<td>41.7</td>
<td>23.8</td>
</tr>
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</table>
Figure 3: Mean SF-36 scores for carers and the total population aged 15-34 years
Figure 4: Mean SF-36 scores for carers and the total population aged 35-54 years

![Graph showing mean SF-36 scores for carers and the total population. The graph includes scales for Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role Emotional (RE), and Mental Health (MH).]
Figure 5: Mean SF-36 scores for carers and the total population aged 55-74 years
Figure 6: Mean SF-36 scores for carers and the total population aged 75+ years
Figure 7: Mean SF-36 scores for carers according to age (years)
Table 7: Mean difference in SF-36 scores (95% CI) for self reported disease conditions adjusted for age, sex and SES (occupation)

<table>
<thead>
<tr>
<th>Condition</th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>-9.7</td>
<td>-15.0</td>
<td>-9.5</td>
<td>-11.3</td>
<td>-6.7</td>
<td>-6.1</td>
<td>-4.1</td>
<td>-2.8</td>
</tr>
<tr>
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<td>(-13.2,-5.7)</td>
<td>(-14.4,-8.2)</td>
<td>(-9.8,-3.7)</td>
<td>(-9.3,-2.8)</td>
<td>(-8.5,4.0)</td>
<td>(-5.4,-0.3)</td>
</tr>
<tr>
<td>Diabetes</td>
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<td>-18.2</td>
<td>-8.6</td>
<td>-17.0</td>
<td>-6.3</td>
<td>-9.3</td>
<td>-7.2</td>
<td>-2.9</td>
</tr>
<tr>
<td>(n=127)</td>
<td>(-14.2,-6.2)</td>
<td>(-25.5,-10.8)</td>
<td>(-13.9,-3.3)</td>
<td>(-21.4,-12.6)</td>
<td>(-10.6,-2.0)</td>
<td>(-13.9,-4.7)</td>
<td>(-13.4,1.0)</td>
<td>(-6.4,4.0)</td>
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<tr>
<td>Arthritis</td>
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<td>-20.0</td>
<td>-18.4</td>
<td>-13.2</td>
<td>-10.0</td>
<td>-8.4</td>
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<td>(-11.1,-5.7)</td>
<td>(-11.4,-4.1)</td>
<td>(-7.6,-3.4)</td>
</tr>
</tbody>
</table>
Figure 8: Mean difference in SF-36 scores for self-reported disease conditions and carers, adjusted for age, sex and SES (occupation)
Table 8: Mean AQoL scores and differences (95% CI) adjusted for age, gender and SES (occupation)

<table>
<thead>
<tr>
<th>AQoL variable</th>
<th>Carers</th>
<th>Non carers</th>
<th>Mean difference</th>
<th>(95% CI)</th>
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Figure 9: Mean AQoL scores for carers and non-carers, adjusted for age, gender and SES (occupation)
Figure 10: Mean SF-36 scores for carers and non-carers in 1994 and 1998, adjusted for age, gender and SES (occupation)
SECTION III: INFORMAL CAREGIVING AND POLICY

APPENDIX: 15

Carers Recognition and Services Act, 1995, [UK]

[Exerpts only]

The Carers (Recognition and Services) Act states in the accompanying Policy Guide to the Carers Act that:

- "The focus of the carer's assessment for the purposes of the Act should be on the carer's ability to care and to continue caring. The assessment should take account of the carer's circumstances, their age, view and preferences, the support available to them.

- Carers may have community care needs in their own right by reason of their old age, physical or mental ill health or disability......

- Primary care staff, including GPs and community nurses through their contact with users and carers, are in a good position to notice signs of stress, difficulty or rapidly deteriorating health particular in carers. The provision of the Act will help primary care staff to meet the medical and nursing needs of their patients who are carers."
Article: Perring, R:

Commonwealth Government Support for Carers with Particular Reference to Information Services and Respite Provision.
"COMMONWEALTH GOVERNMENT SUPPORT FOR CARERS WITH PARTICULAR REFERENCE TO INFORMATION SERVICES AND RESPITE PROVISION"

THE AUSTRALIAN PERSPECTIVE

'Share the knowledge'
2nd International Conference on Caring

Raino Perring
Director Carer Support
Community Care Branch
Aged & Community Care Division
Commonwealth Department of Health & Aged Care

March 2000

Setting the Scene

For those who are not familiar with Australia, I will begin with a brief description of the Australian scene - the Australian system of government, distribution of funds and an outline of the current social welfare system. This will assist in understanding where Australian welfare policies are placed in the international context. I will then describe in some detail current Commonwealth Government support for carers with particular reference to information services and respite provision.

Australia has federal system of government comprising three tiers of administration – Commonwealth, State and Territory, and Local Government. The constitution defines the key areas of responsibility between the Commonwealth and the States and Territories. The States in turn determine the responsibilities of local government.

Each sphere of Australian government has its own responsibilities and all three are involved in the delivery of community services.

The Commonwealth Government has the major taxation powers and, in broad terms, distributes funding on a modified per capita basis to the States and Territories. Much of this funding is non-specific financial assistance but funding, for example, for health, education, housing and community services, is tied to a specific purpose.

The policy basis underpinning the Government’s approach to community services is one of the establishment of a ‘social coalition’, or a partnership of individuals, families, business, government, welfare and charitable organisations, each contributing their unique resources and expertise to tackle disadvantage at its source. This recognises that each sector of society has a role to play in addressing social disadvantage. Government accepts its role but balances this against the contribution to be made by, as well as the needs of, people.

In this way, a safety net is provided to assist those in greatest need. Government funding is directed at support programs that assist people to help themselves.

Broad Outline of support services for older people and people with a disability.

Australia has a compulsory universal hospital and medical insurance scheme, Medicare. This funds free public hospital treatment through agreements with States and Territories and subsidises general medical treatment costs to individuals. In addition, the Pharmaceutical Benefits Scheme subsidises the cost of approved prescription drugs and medications for people in receipt of Government pensions and older people within set income limits and has safety net provisions for people whose annual pharmaceutical costs exceed a prescribed limit.

Australia also has a universal pension scheme – pensions are income and assets tested and are available to people who qualify such as those who are aged, disabled, a carer, war widow/er, blind, a sole parent or unemployed. Australian pension rates are broadly comparable to the international average of OECD countries. They are supported by Government assisted superannuation. People who receive pensions may also qualify for
other family payments, further subsidised medical and pharmaceutical costs, rent assistance and a range of allowances such as the Carer Allowance, telephone rental and assistance to meet transport costs.

At the Commonwealth level community services for people who are frail, chronically ill or have a disability are delivered through different agencies and under different funding arrangements. Some services are delivered direct, such as residential aged care, others through joint funding arrangements with the States and Territories, such as hospital services, disability services, mental health services and community support services.

At the same time Australia has a strong community care sector and has had for some years. Independent charitable and religious bodies were main providers of special services in the early half of the last century. Their role in combination with Government has grown considerably since the 1950’s. It was from this time that the Commonwealth entered into direct service provision as an adjunct to the attainment of national policies in support of health care and fiscal constraint. This partnership with community organisations and volunteers is the basis of many service programs. This facilitates the development of relevant services appropriate to the needs of a community and those in the community needing support.

The provision of residential care services for older people and community care services is funded outside health funding and under separate legislation. Service provision is based on eligibility not entitlement. Services specifically for people with disabilities are provided principally under shared costing arrangements between Commonwealth and State/Territory Governments. For older people the Commonwealth Government directly provides the bulk of funding for the provision of two levels of residential care – high and low levels of care need and dependency.

Community care programs delivered through the Department of Health and Aged Care include a mix of direct programs and programs funding jointly with the State and Territory Governments. Of these the Home and Community Care (HACC) program is the most significant.

Carers programs fall within the broader community care policies of the Government, which in turn support the aged care, disability care and health care policies.

The Client Base

In 1998 there were 3.6 million Australians with a disability, some 19 percent of the population. Of these, the majority (87%) experienced specific restrictions in activities such as self-care, mobility or communication, or their ability to participate in schooling or employment.

The Australian Bureau of Statistics has identified a steady increase in the number of people with a disability since the first survey in 1981. This is partly attributed to the ageing of the population but also to other factors such as improved health technology.

Informal assistance was provided by 2.3 million Australians to those who needed help because they had a disability or needed assistance because they were ageing. Of those providing informal assistance, 19 per cent (just over 450,000) were identified as primary carers who provided most help with personal care activities to a person with a disability. (See Attachment 1).

Service Development

The Commonwealth Government has a long tradition of supporting the delivery of community care services. In 1969 cost shared funding was made available to State and Territory Governments for the delivery of home nursing, paramedical and home care services, and a subsidy was provided directly to local government and community organisations for the provision of home delivered meals. These schemes introduced the principles of government support to people so they could remain living independently.

The next significant step in support for carers was the introduction of HACC in 1985. HACC subsumed the grants to State and Territory Governments for home nursing, paramedical and home care services and the Delivered Meals Subsidy and brought them together as a single program with additional funding and a wider range of services. The total expenditure in HACC has grown from $152 million in 1984/85 to an estimated $864 million this year.

HACC provides specifically for carers as part of its service focus. In this respect, carers where identified as eligible clients receive services under the program. In practice, carers received little specific attention; the assumption being made that their needs are addressed when the needs of the person they care for are
addressed. Some service types, such as community and centre based respite care, are particularly useful for carers, as are some of the research and information/advocacy programs. However, their design and delivery is not necessarily carer focussed.

Respite care as an element of aged residential care was also given some attention over this period with Nursing Homes and Hostels, providing high care and low care respectively being funded to provide facility base respite services.

In 1992 the Commonwealth introduced Community Care Packages as an in-home community based alternative to people with complex care needs who would otherwise require low level residential care. From its original pilot phase, when the concept was tested with 527 packages at a cost of $3.3 million, the program has grown to just under 16,000 packages at a cost of $165 million. All prospective recipients must be assessed as eligible for services by an Aged Care Assessment Team that assesses all prospective recipients of residential care. Service providers use a case management approach to develop and monitor care delivery to the older person.

In 1992 the first initiatives by the Commonwealth with a specific focus on carers were introduced. This included their information and respite needs.

The Carer Support Kit, a practical and comprehensive information kit to help carers with the issues and concerns they face in caring, was developed and distributed through the State and Territory Carer Associations. The English language kit was followed three years later by other language versions in ten major community languages. A specific remote area Aboriginal and Torres Strait Islander kit was also produced. Over 200,000 kits have been distributed.

An evaluation of the kit in 1998 found that its most valuable outcomes were to improve carers self esteem by acknowledging their needs, to raise community awareness of the issues and concerns faced by carers, and to promote awareness of the contribution of carers to the community.

The attention to carers needs also saw the introduction of the Commonwealth Respite for Carers Program in 1992. This did offer a specific carer focus to provide for carers' need for flexible and responsive respite services. The program was to provide service models to meet the needs and preferences of carers. Through this initiative respite services were expanded and extended and, together with the standard models of day care and in home respite provided under HACC, provided carers with options for the services they require.

Similar developments have occurred in support of younger people with a disability. In 1985/86 the residential care program was split between that for the aged and that for younger people with a disability. In subsequent years these residential services were, in accordance with the Commonwealth State Disability Agreement, converted into more suitable programs including community based housing and support programs. Education and employment programs for the younger disabled are the responsibility of the Commonwealth while community base accommodation and support services are the responsibility of State and Territory Governments.

Carer support

Responsibility for carer policy is with the Minister for Aged Care, within the Health and Aged Care portfolio. Portfolio responsibility for people with disabilities is with the Minister for Family and Community Services, as is income support arrangements such as the Carer Payment and Carer Allowance.

For the purposes of this rest of this paper, the focus is the Health and Aged Care component of Commonwealth responsibility in community care.

The history of service development shows an ongoing recognition by Government of the need to assist people who are ageing and younger people with a chronic illness or a disability and their carers through supportive community services.

This recognises that the motivation for caring is clearly stated in a majority of cases as a perceived family responsibility (1998 ABS Survey of Disability, Ageing and Carers). Further to this, just over half of all carers believe they can provide better care.

Some three-quarters of all assistance to people who are ageing or disabled is provided by informal carers. The value of this level of support has been estimated to be worth just over $23 billion in 1997-98 (Australian Institute of Health and Welfare, Australia's Welfare, 1999).
It was apparent to government that the needs, circumstances and preferences of carers were given inadequate recognition in assessment processes and service responses. The policies of the Government under the National Carer Action Plan announced in 1996, emphasise the importance of focusing on carers needs and on providing increased opportunities for carers to exercise choice and control over respite care arrangements and other support and assistance they require.

This policy has been the basis of specific carer support since 1996.

**Major Commonwealth (Health and Aged Care) funded community care programs - estimated expenditure 1999/2000**

- Home and Community Care Program $525 million (Commonwealth contribution)
- Community Aged Care Packages $165 million
- Day Therapy Centres $27.7 million
- National Respite for Carers Program $58.9 million
- Carer Information and Support $1.9 million
- Aged Care residential respite $75 million

(Attachment B to this paper provides further detail on all Commonwealth funding in support of carers)

HACC is a central element of the Commonwealth Government's community care policy, providing community care services to frail aged and younger people with disabilities and their carers. It is a jointly funded program between the Commonwealth and the States with the Commonwealth providing about 66 percent of the funds on average.

HACC funds service providers for the delivery of services such as community nursing, home help, personal care, meals, transport assistance, respite care and home maintenance.

Community care packages are another major initiative that has seen the establishment of home based packages of support for individuals who would otherwise have entered a residential care facility. The level of care is at least low care (equivalent to hostel based personal care support) though pilot projects are exploring packages in support of high care needs (equivalent to nursing home care). Up to the 1999/2000 financial year, some 18,000 care packages had been approved at an annual cost of $165 million.

The Commonwealth Government funds a range of other community sector programs. All of these focus on the needs of frail aged people, people with disabilities and their carers.

Carer programs are concerned with income support, respite service support and information support.

**Recent Developments in Carer Services**

The expansion and consolidation of support for carers was a major policy initiative of the then Coalition prior to its election to government in 1996.

The National Carer Action Plan identified three key elements of a national carer policy to bring carer support into a more coherent, coordinated and responsive framework. The three elements responded to the priority areas of need as identified by carers. The three elements to which the Government committed its support were:

- carer needs assessment, information and support;
- a new carer respite centre program (including existing services); and
- other assistance including financial support for carers.

Financial support for carers is the responsibility of the Department of Family and Community Services. It will be the subject of other papers to the conference.

**Implementation of the Government’s objectives since 1996**
The National Respite for Carers Program was established as a 1996-97 Budget initiative at a cost of $36.7 over four years following a national review of respite services for carers which identified the need for further information and support for carers and better coordination of respite services.

The 1998-99 Budget announced the 'Staying at Home – care and support for older Australians' package which included $30.9 million over four years to expand and enhance the operations of Carer Respite Centres and $10.3 million over four years to provide additional respite for people with dementia.

The 1999-2000 Budget again acknowledged the vital role of carers and announced an additional $82.2 million over four years to further boost respite services for carers of people with dementia and other cognitive and behavioural disorders. The initiative includes a specific focus on carers in rural areas and will explore service delivery options that meet their needs.

That Budget also included $20 million over four years to extend respite support for carers of young people with disabilities to be funded through the Department of Family and Community Services.

The National Respite for Carers Program

The National Respite for Carers program has three components:

- Carer Respite Centres;
- Carer Resource Centres; and
- respite service provision (incorporating the Commonwealth Respite for Carers Program)

The aim of the NRCP is to contribute to the support and maintenance of caring relationships between carers and their dependent family members and friends. It does this by facilitating access to information, respite care and other support or assistance appropriate to their individual needs and circumstances, and those of the persons for whom they care.

Government support for carers recognises that, wherever possible, all members of the community, including those with significant levels of handicap, prefer to remain living at home. The availability of family members and friends willing to provide care is often a key factor in the ability of some people to remain at home.

Government recognition, assistance and support for carers serves the purpose of reinforcing these private and individual caring relationships.

All services provided to carers under the NRCP:

- have a clear carer focus;
- recognise the importance of readily accessible and comprehensive information to a carer's ability to make informed choices about their caring role; and
- help carers gain access to support and assistance, particularly respite care, that are appropriate to their needs and the needs of the people for whom they care.

Carer Respite Centres

A national network of Carer Respite Centres has been established in 58 regions across Australia to improve the coordination of respite service provision and help meet emergency and unplanned respite needs that can not be met by other services.

In addition to Carer Respite Centres having the capacity to arrange respite for carers from existing services, they also have a pool of funds to be used to purchase short-term respite care in the absence of other services or if a more flexible approach is needed, particularly in an emergency.

Carers can seek assistance from their nearest Carer Respite Centre through a single national toll free 1800 number – 1800 059 059.

In 1997-98 (their first full year of operation) Carer Respite Centres provided assistance to access respite to an estimated 15,000 carers. This more than doubled in 1998-99 to over 40,000 as program expansion enabled them to take on a broader role.

Funding for the Carer Respite Centre Network has grown from $9.3m in 1997-98 to $14m in
1998-99. This is expected to increase by a further $8 million this financial year (1999-2000) under the dementia respite and younger disability respite initiatives announced in the budget.

What do Carer Respite Centres do?

The objectives of the National Respite for Carers Program Carer Respite Centres are to contribute to the support and maintenance of caring relationships by:

- providing carers with a clearly identifiable and accessible single point of contact within a region or area for information and advice on the full range of respite care services and other assistance available in their area;
- reducing fragmentation in respite care program management and service delivery by establishing single focal points for respite care in regions or areas;
- stimulating appropriate service responses in order to:
  - achieve better matching of services to the individual needs and circumstances of carers and care recipients;
  - ensure equitable access for carers across and within regions or areas to a range of services offering respite care in different settings, including in-home settings and out-of-home settings; and
  - improve carers' access to respite care on a planned basis or in emergency or unplanned situations;
- improving the appropriateness of the use of respite care resources;
- contributing to a better understanding of carer stress and the effectiveness and appropriateness of services or supports; and
- encouraging the development of informal or volunteer networks to provide support to carers.

To achieve these objectives, Carer Respite Centres are required to:

- provide a clearly identifiable and readily accessible regional focal point for carers needing information and advice about the full range of respite care services and other resources available in the region or area to support them in their caring role. In doing this they must develop carer respite service directories for their regions to identify appropriate respite options suitable to the carer;
- with the carer, plan the most appropriate ways for meeting their respite care needs and, where appropriate, organise, facilitate or manage the delivery of packages of respite care assistance (including formal and informal services) that are tailored to the individual needs of carers and those for whom they care;
- coordinate access to respite care services in aged care facilities (nursing homes and hostels) including
  - assistance with the booking of residential respite; and
  - counselling and/or practical and emotional support to carers and care recipients considering or using residential respite care;
- provide assistance to clients on low incomes to access respite, including on occasion the payment of service fees (including for residential respite),
- coordinate or facilitate carers' 24 hour access to respite care services in emergency situations;
- coordinate appropriate volunteer support programs for carers, in conjunction with the Carer Resource Centre in the particular State or Territory;
- work cooperatively with Carer Resource Centre in each State or Territory to optimise benefits to carers and reduce unnecessary duplication.

Carer Resource Centres

Over the same period, a Carer Resource Centre in each State and Territory has been established to act as a single point of contact for carers seeking information and advice about the full range of services and other support and assistance available to them.

A national toll free 1800 number for Carer Resource Centres assists carers access information support – 1800 242 636. Carer Resource Centres respond to over 3,000 calls on the 1800 number each month.

The Resource centres distribute carer specific information, assist carers to find and access services, assist carers to access support groups and obtain counselling. They work closely with the Carer Respite Centre Network, service providers and with other networks such as Centrelink.
The Carer Resource Centres are supported in their work by the Carer Information and Support Program which funds the information resources required to assist carers in undertaking their role.

The 1997/98 Budget announced funding of $1 million in 1997/98 and $2 million per year in 1998/99 to provide for continued funding for the carer information and support program.

This program enables the development of carer resource materials, including education programs for carers and information about government programs in support of carers for distribution through the Carer Resource Centres.

The major product for information to carers has been the Carer Support Kit, which gives carers information and practical advice on their caring role and the condition of the person they care for. The Kit was evaluated in 1998 and the evaluation report is now being acted on to provide Carers with information resources which are up to date, appropriate to their caring circumstances, well-designed, easily understood and relevant.

A Kit developed specifically to meet the needs of Aboriginal and Torres Strait Islander carers who live in remote communities was produced in 1998 and is distributed through Carer Resource Centres.

A Carer Contacts brochure has been produced to provide carers, service providers and health professionals with an easily accessed guide to Government and other services to assist carers. This has proved a particularly useful and popular resource. By December 1999 over 350,000 brochures had been printed and distributed.

The Carer Information Support Program is undertaking a major overhaul of all information products in line with the findings of the evaluation of the Carers Information Kit. New content material, production and distribution processes will be introduced to improve access to up to date and appropriate information for carers.

Under the dementia respite initiative some $1.5 million will be available each year for carer education and respite service provider training to improve the quality and use of respite services.

What do Carer Resource Centres do?

The objectives of the Carer Resource Centres are to contribute to the support and maintenance of caring relationships by:

- improving the accessibility, scope, reliability and relevance of information for carers,
- improving the accessibility and appropriateness of the range of services and assistance available for carers, particularly respite care services;
- improving the capacity of carers to undertake their role;
- increasing the appropriate use of volunteers for carer support; and
- enhancing the recognition and awareness of the role and needs of carers among service providers and other key agencies, groups, health professionals and organisations.

To achieve these objectives, Carer Resource Centres are required to:

- provide carers with a clearly identifiable and accessible single point of contact in each State and Territory for information and advice on the full range of services, particularly respite care services and other support and assistance available to carers;
- assist carers to make contact with the network of services available in their area, according to their needs and preferences, particularly through referral to Carer Respite Centres;
- develop and/or facilitate access to other sources of information relevant to carers, including training programs to assist carers with the practical tasks of caring;
- provide management support and training resources to Carer Respite Centres in their development and coordination of the use of volunteers to support carers; and
- promote recognition and awareness of the role and needs of carers among service providers and other key agencies, groups, health professionals and organisations.
To facilitate the development and management of carer information materials the Commonwealth has funded a National Carer Resource Centre. This facility is currently managing new product development under the Carer Information Initiative that has been established to meet the current and future information needs of carers across the range of their needs and circumstances. The initiative, which commenced in 1998, acknowledges resources that are already in use and valued by carers and outlines activities to address areas where there is an information gap.

The main objectives of the Carer Information Initiative are to develop core information products and identify strategies for distribution which:

- increase carers' knowledge of the services, support groups and financial assistance available to assist them and the people they care for;
- focus on practical caring issues which support the carers in their role and improve their wellbeing and quality of life;
- develop resources which meet identified needs;
- improve access;
- encourage carers to make contact with the wider network of support agencies and services;
- respond appropriately to other information issues which may be identified as the initiative progresses;
- educate and resource other community agencies to provide information and support to carers; and
- consider the development of information on specific/medical conditions which provides a brief description of the condition and information on the expert organisation/s, which can assist carers with more detailed information and support.

Respite service provision

Directly funded respite services under the National Respite for Carers Program were funded at about $16 million in 1998/1999.

The old Commonwealth Respite for Carers program, which forms the base of the new program, contains over 300 projects and is funded at about $14 million per annum. The range of respite services includes in-home, family based, centre based, and peer support services.

Increased funding in 1998 provided for twenty-six, four-year dementia respite pilot projects to be established at an estimated cost of $2.3m for 1998-99.

Extra funding of $14 million will be available this year to expand the service base under the dementia, cognitive and behavioural respite initiative.

What do respite services do?

The objectives of the Commonwealth in developing these direct respite services are to:

- increase the availability of respite care as a direct support to carers taking their needs into account, thereby providing an appropriate and valuable service to the carer and the person they care for;
- increase and extend the range of respite services to provide choice to the carer and care recipient;
- enhance the capacity of carers to continue to provide care, thereby reducing the risk of premature or inappropriate admission to institutional care services.

To achieve these objectives the respite services are required to:

- fill unmet needs or gaps in respite care services;
- increase or expand existing services;
- target highly dependent carers, eg carers of people with dementia, or carers who are unable to maintain their caring role due to an emergency or other unplanned situation;
- offer flexible services to meet carers needs;
- develop new approaches to offering a carer a break from caring; and
- to address carers needs in difficult to reach localities through new service models such as mobile respite services.

Residential Respite

In addition to community based respite provided through the National Respite for Carers Program, the Commonwealth provides residential respite through over 2,000 aged care facilities.
Residential respite care in aged care facilities provides short term residential care for frail aged people to assist them remain in the community as well as to assist their carers to continue to provide care for them.

Residential respite care has been made more flexible, more focused and more attractive. As a result, use of residential respite is growing. Around 35,000 people receive Commonwealth subsidised residential respite care annually at a cost of approximately $75m.

The new aged care system introduced on 1 October 1997 allows nursing home (high level) respite care to be provided in all aged care facilities including hostels. Similarly, hostel (low level) respite care can now be provided in all types of aged care facilities including nursing homes.

Residential respite care has also been more tightly targeted towards those people who need it since October 1997 by requiring people using residential respite care to have a specific approval from an Aged Care Assessment Team. Previously, anyone approved to receive longer-term residential care could occupy a respite place whether or not that was the most appropriate form of care for him or her.

As well, residential respite care is financially and administratively more attractive to both user and provider. A person using residential respite care doesn't have to undergo an income and assets test and the nursing home or hostel does not have to assess the person against the Resident Classification Scale (RCS) to obtain the Commonwealth subsidy. Unlike longer-term residents, users of residential respite do not have to pay an accommodation charge or bond.

To ensure service providers do not lose income by providing respite care, the Commonwealth pays a respite supplement (as well as the standard daily subsidy) for respite residents and it pays the pensioner supplement for all respite residents whether or not they are pensioners.

Around one and a half million days of residential respite care annually are allocated to over 2,000 aged care facilities. Allocated days may be used in any of the facility's approved care places. Use of the available allocated respite days grew from 51 per cent of the total in 1997/98 to 61 per cent in 1998-99.

In the 1997-98, 800,000 days of residential respite were used. In 1998-99, the figure was 990,000 days – an increase of over 23 per cent.

The challenges

There are a series of challenges facing the Commonwealth in consolidating the achievements of the last decade. They all fall broadly under the one principal aim -- to provide carers with a consistent, coherent, easily accessible range of services which meet their caring needs and support them so they are able to maintain their role.

This NRCP is intended to complement the services and support already provided to the community under the Home & Community Care (HACC), other programs and informal networks. It is not intended that it reproduces or unnecessarily duplicates the existing respite care system.

With the significant growth in funding for carer support including respite service coordination and provision under the National Respite for Carers Program the challenges are to:

- ensure that the objectives of Carer Respite Centres and Carer Resource Centres are fully realised, ie that a carer contacting either Centre can be confident of receiving useful advice of a practical nature with direct assistance where this is relevant;
- ensure the complementary role of the mix of services under the NRCP is clearly understood and the functionality of each service is optimised by cross referencing to each other;
- broaden the targeting of respite provision so that service gaps are identified and the needs of carers are met, eg carers who care for people with dementia or other disturbed behaviours;
- expand the network of existing respite services and ensure flexible service design to meet the needs of carers;
- improve the flexibility and responsiveness of respite provision to the needs of the carer whether that be at home, in the community or in residential care;
- explore new models of service delivery;
- broaden the coverage of respite provision with particular focus on the gaps in service provision in rural and remote communities and isolated carers, and
- ensure a practical relevance to information products to meet the needs of carers;
- provide a distributed support network for carers using information technology and other means to provide information, counselling and advice;
• build relationships with other service providers to ensure support rather than confusion for carers in finding out about the services that are available to support them.

The Commonwealth role

Within the overall focus on carers, the Commonwealth has a critical role in ensuring that:

• carers are the focus of the program;
• carer needs are met;
• service provision is nationally available;
• the levels of service provision comply with national standards;
• access to services is nationally equitable; and
• service provision is culturally and linguistically sensitive.

In implementing this role the Commonwealth has built a comprehensive strategy for the development and delivery of information resources and respite services which recognises and acknowledges the responsibilities of the contributing agencies and programs.

Australian care provision is characterised, through history and culture, by a wide range of service provision, undertaken by thousands of agencies – from direct support by Commonwealth and State/Territory Governments, through large charitable, religious or other non-profit and private agencies, to small organisations working in their local area. The Commonwealth role therefore is in integrating service provision by facilitating the networking and information sharing among and between the plethora of service providers, identifying service provision gaps and establishing services which fill them.
Client Group Statistics

The Australian Bureau of Statistics in the 1998 Disability, Ageing and Carers Survey, A summary of Findings estimated the number of people caring in Australia at 2.3 million of which 450,900 were primary carers.

A primary carer is someone of any age who provides the most informal assistance to a person with one or more disabilities. The assistance is ongoing and is provided for one or more of the core activities of communication, mobility and self-care.

Core activity restrictions may be profound (person unable to do a core activity task), severe (sometimes needs help with a core task), moderate (has difficulty with a core task but does not need help), or mild (has a level of disability that requires no help but has some difficulty in a range of every day activities).

Of all primary carers aged 15 and over, 220,500 (49%) are already receiving assistance while 51% (227,400) are not. A proportion of both groups say they need (further) assistance:

<table>
<thead>
<tr>
<th>PRIMARY CARERS</th>
<th>WHO NEED ASSISTANCE OR NEED MORE ASSISTANCE</th>
<th>WHO SAY THEY DO NOT NEED (FURTHER) ASSISTANCE</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALREADY RECEIVING</td>
<td>70,300 (32%)</td>
<td>150,200 (68%)</td>
<td>220,500 (100%)</td>
</tr>
<tr>
<td>ASSISTANCE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NOT RECEIVING</td>
<td>41,300 (18%)</td>
<td>186,100 (82%)</td>
<td>227,400 (100%)</td>
</tr>
<tr>
<td>ASSISTANCE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ALL PRIMARY CARERS</td>
<td>111,600 (25%)</td>
<td>338,300 (75%)</td>
<td>447,900 (100%)</td>
</tr>
</tbody>
</table>

11
### Funds in Support of Carers – direct and indirect.

<table>
<thead>
<tr>
<th>Fund Type</th>
<th>1998/99</th>
<th>1999/2000 (estimate)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Direct Commonwealth Respite</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Respite Centres</td>
<td>$13m</td>
<td>$20m</td>
</tr>
<tr>
<td>Commonwealth Respite for Carers Program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- base projects</td>
<td>$16m</td>
<td>$18m</td>
</tr>
<tr>
<td>- dementia respite</td>
<td>$2.3m</td>
<td>$2.4m</td>
</tr>
<tr>
<td>- dementia/behavioural</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential respite</td>
<td>$70m</td>
<td>$75m</td>
</tr>
<tr>
<td>Total DH&amp;AC direct</td>
<td>$101.3m</td>
<td>$129.4m</td>
</tr>
<tr>
<td>Disability respite (DFCS)</td>
<td>-</td>
<td>$4.0m</td>
</tr>
<tr>
<td>- additional CSDA contribution</td>
<td>-</td>
<td>$50m</td>
</tr>
<tr>
<td>Indirect respite (through States)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HACC (C’wealth and States)</td>
<td>$115m est</td>
<td>$120m</td>
</tr>
<tr>
<td><strong>TOTAL RESpite</strong></td>
<td>$216.3m</td>
<td>$303.4m</td>
</tr>
<tr>
<td><strong>General Service Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HACC (not inc respite)</td>
<td>$708m est</td>
<td>$745m</td>
</tr>
<tr>
<td>CSDA employment/education</td>
<td>$258m</td>
<td>$271m</td>
</tr>
<tr>
<td>CSDA accommodation and related services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Commonwealth</td>
<td>$338m</td>
<td>$355m</td>
</tr>
<tr>
<td>- States</td>
<td>$1399m</td>
<td>$ not known</td>
</tr>
<tr>
<td><strong>Carer Information and Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Resource Centres</td>
<td>$0.9m</td>
<td>$0.9m</td>
</tr>
<tr>
<td>Carer information materials</td>
<td>$1.8m</td>
<td>$1.9m</td>
</tr>
<tr>
<td>Carer training</td>
<td>$1.5m</td>
<td>$3.0m</td>
</tr>
<tr>
<td>Carer Associations (HACC)</td>
<td>$2.9m</td>
<td>$3.0m</td>
</tr>
<tr>
<td><strong>Income Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Direct</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Payment</td>
<td>$308m</td>
<td>$371m</td>
</tr>
<tr>
<td>Carer Allowance</td>
<td>$97m</td>
<td>$400m</td>
</tr>
<tr>
<td><strong>Indirect</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability Support Pensions</td>
<td>greater than $6 billion</td>
<td></td>
</tr>
<tr>
<td>Aged pension proportion unknown</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health benefit card</td>
<td>proportion not known</td>
<td></td>
</tr>
<tr>
<td>Pharmaceuticals</td>
<td>proportion not known</td>
<td></td>
</tr>
<tr>
<td><strong>DH&amp;AC</strong></td>
<td>Department of Health and Aged Care</td>
<td></td>
</tr>
<tr>
<td><strong>DFCS</strong></td>
<td>Department of Family and Community Services</td>
<td></td>
</tr>
<tr>
<td><strong>CSDA</strong></td>
<td>Commonwealth State Disability Agreement</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX: 17

Home And Community Care Act, 1985
[Australia]
Home and Community Care Act 1985

No. 184 of 1985

An Act relating to financial assistance to the States and to the Northern Territory in connection with the provision of home and community care services

[Assented to 16 December 1985]

BE IT ENACTED by the Queen, and the Senate and the House of Representatives of the Commonwealth of Australia, as follows:

Short title
1. This Act may be cited as the Home and Community Care Act 1985.

Commencement
2. This Act shall come into operation, or shall be deemed to have come into operation, on the day on which the Home and Community Care (Miscellaneous Amendments) Act 1985 receives or received the Royal Assent.

Grants for home and community care services
3. (1) Where an agreement has, whether before or after the commencement of this Act, been entered into between the Commonwealth and a State, being an agreement that is substantially in accordance with the
form set out in the Schedule, the Minister may, by writing, authorise payments (including advances) to be made to that State, by way of financial assistance to that State, in accordance with that agreement.

(2) A reference in sub-section (1) to an agreement that has been entered into between the Commonwealth and a State includes a reference to that agreement as varied, in accordance with the provisions of that agreement, by a further agreement a copy of which has been laid before each House of the Parliament as required by the first-mentioned agreement.

(3) An amount repayable by a State to the Commonwealth in accordance with a provision of an agreement referred to in sub-section (1) is a debt due by the State to the Commonwealth.

(4) In this section, "State" includes the Northern Territory.

Appropriation

4. Payments (including advances) under this Act shall be made out of money appropriated from time to time by the Parliament for the purpose.

Delegation

5. (1) The Minister may, by writing, either generally or as otherwise provided by the instrument of delegation, delegate to any officer of the Department all or any of the Minister's powers under this Act, other than this power of delegation.

(2) A power so delegated, when exercised by the delegate, shall, for the purposes of this Act, be deemed to have been exercised by the Minister.

(3) A delegation of a power under this section does not prevent the exercise of the power by the Minister.
Subsection 3(1)

AN AGREEMENT made the day of One thousand nine hundred and eighty-five between--
the COMMONWEALTH OF AUSTRALIA (in this Agreement called "the Commonwealth")
of the one part, and
the STATE OF (in this Agreement called "the State")
of the other part.

WHEREAS--

(A) for many years, the States, local governments and community organisations have been providing and funding a range of home and community care services;

(B) the Commonwealth has been providing financial assistance and subsidies in respect of the provision of certain home and community care services pursuant to--

the Home Nursing Subsidy Act 1956,

the States Grants (Paramedical Services) Act 1969,

the States Grants (Home Care) Act 1969, and

the Delivered Meals Subsidy Act 1970

of the Commonwealth Parliament;

(C) the Commonwealth and the State wish--

(i) to develop a comprehensive range of integrated home and community care services for frail or at risk aged persons and younger disabled persons in order to facilitate the maintenance of those persons in their own homes; and

(ii) to provide moneys, on a co-ordinated basis, to assist in the provision of those services,

NOW IT IS HEREBY AGREED as follows:

PART I--OPERATION OF AGREEMENT

1. This agreement shall be deemed to have come into force on 1 July 1985 and shall continue in force until terminated in accordance with clause 31.

2. Acts or things consistent with the provisions of this agreement which have been done by or on behalf of a party in anticipation of its coming into force shall be regarded as having been done under this agreement and in accordance with its provisions.

PART II--INTERPRETATION

3. (1) In this agreement--
"Commonwealth Minister" means the Minister of State of the Commonwealth for the time being responsible for the administration of this agreement for the Commonwealth; and

"State Minister" means the Minister of State of the State for the time being responsible for the administration of this agreement for the State, or when there is more than one such Minister, means the Minister having for the time being responsibility for the matter or class of matters in respect of which the relevant provision or provisions of this agreement is or are being applied.

(2) A reference in this agreement to a Minister includes a Commonwealth Minister or other member of the Federal Executive Council or Minister of the State, as the case may require, for the time being acting for or on behalf of the Minister referred to.

4. (1) In this agreement, unless the contrary intention appears--

"approved project" means a project that is eligible for funding in accordance with clause 8;

"base year" means the financial year that began on 1 July 1984;

"Commonwealth base" means the unadjusted amount referred to in paragraph 13 (1) (a);

"community organisation" means--

(a) an organisation (other than an organisation conducted or controlled by, or by persons appointed by, the Government of the Commonwealth or of the State) that is carried on otherwise than for the purpose of profit or gain to its individual members and is--

(i) a religious organisation;

(ii) an organisation the principal objects or purposes of which are charitable or benevolent; or

(iii) any other organisation agreed upon by the Commonwealth Minister and the State Minister for the purpose of this sub-paragraph;

(b) the trustee or trustees for the time being under a trust established by an organisation referred to in paragraph (a) or by a local government;

(c) a corporation established by an organisation referred to in paragraph (a) or by a local government;

(d) the trustee or trustees for the time being under a trust established for charitable or benevolent purposes agreed upon by the Commonwealth Minister and the State Minister for the purpose of this paragraph; or

(e) such other organisation as is agreed upon by the Commonwealth Minister and the State Minister;

"financial assistance" means financial assistance provided pursuant to this agreement;

"financial year" means a period of 12 calendar months beginning on 1 July;
"first grant year" means the financial year commencing on 1 July 1985;

"former Commonwealth-funded project" means a project that, immediately prior to this agreement being signed, was approved for funding under an Act referred to in recital (B);

"grant year" means--

(a) the first grant year;

(b) the second grant year;

(c) the third grant year; or

(d) the financial year commencing on 1 July 1988 or any subsequent financial year while this agreement remains in force;

"guidelines" means (other than in clause 10 and sub-clauses 11 (2) and (3)) guidelines referred to in clauses 10 and 11;

"joint body" means any two or more of the following acting jointly--

(a) the State;

(b) a local government; and

(c) a community organisation;

"local government" means a local governing body established by or under a law of the State;

"long term residential care" includes long term care provided in a hospital or other institution, or through a residential care service within the meaning of the Aged Care Act 1997;

"program" means the Home and Community Care Program established pursuant to clause 5;

"second grant year" means the financial year commencing on 1 July 1986;

"State base" means the unadjusted amount referred to in paragraph 14 (a);

"target population" means the persons referred to in paragraph 6 (a); and

"third grant year" means the financial year commencing on 1 July 1987.

(2) In this agreement, unless a contrary intention appears--

(a) a reference (other than in this paragraph) to this agreement or to a part or provision of this agreement includes, where the agreement is varied, a reference to this agreement or that part or provision as varied;

(b) a reference to a clause is to the relevant clause of this agreement;
(c) a reference to a sub-clause is to the relevant sub-clause of the clause in which the reference appears;

(d) a reference to a paragraph, if no clause is specified, is to the relevant paragraph of the clause in which the reference appears, and a reference to a sub-paragraph, if no paragraph is specified, is to the relevant sub-paragraph of the paragraph in which the reference appears;

(e) words in the singular include the plural and words in the plural include the singular; and

(f) words importing a gender include every other gender.

PART III--THE PROGRAM AND THE OBJECTIVE

5. (1) The Commonwealth and the State shall jointly establish a Home and Community Care Program which shall be administered in accordance with the provisions of this agreement and within available resources and which shall have the following principles and goals--

(a) to promote the provision of a comprehensive and integrated range of home and community care designed to provide basic maintenance and support services, both directly and through their carers, to persons within the target population and thereby to assist them to enhance their independence in the community and avoid their premature or inappropriate admission to long term residential care;

(b) to expand and develop home and community care services through the joint cooperation of the Commonwealth, the State, local governments and community organisations representing both service providers and users under a single cost-shared arrangement;

(c) to ensure access to home and community care among all groups within the target population, including migrants, aboriginals, persons suffering from brain failure and financially disadvantaged persons;

(d) to ensure that, within available resources, priority is directed to persons within the target population most in need of home and community care;

(e) to provide for persons within the target population an effective and integrated means of assessment of the need for and referral to home and community care services;

(f) to ensure that, within available resources, home and community care services are provided equitably between regions and are responsive to regional differences;

(g) to ensure that home and community care services are delivered in a manner that is cost-effective, achieves integration, promotes independence and avoids duplication;

(h) to enable the testing and evaluation of new and differing approaches to planning, co-ordination and service delivery;

(i) to enable regular and systematic client focussed monitoring of the effectiveness and efficiency of the program and the assessment of priorities;
(j) to promote an integrated and co-ordinated approach between the delivery of home and community care and related health and welfare programs, including programs providing residential or institutional care;

(k) to facilitate the involvement of community organisations representing both service providers and users in the provision of advice to the Commonwealth Minister and the State Minister on needs and priorities under the program;

(l) to develop a home and community care information system suitable for agency use that will facilitate planning and evaluation of the program at national, State and regional levels; and

(m) to ensure that effective planning and co-ordination arrangements are established that enable the above principles and goals to be achieved in a co-operative manner.

2. The objective of this agreement is the provision of moneys by the Commonwealth and the State--

(a) to assist the State, local governments and community organisations to develop, through the rationalisation and expansion of existing services and the development of new services, a comprehensive range of integrated home and community care for persons within the target population where possible and appropriate; and

(b) to facilitate the maintenance of those persons in their own homes, and avoid their premature or inappropriate admission to long term residential care and thereby improve their quality of life.

6. The program shall be directed towards assisting--

(a) persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the program, are at risk of premature or inappropriate long term residential care, including--

(i) frail or at-risk aged persons, being elderly persons with moderate or severe disabilities;

(ii) younger disabled persons, being persons with moderate or severe disabilities; and

(iii) such other classes of persons as are agreed upon by the Commonwealth Minister and the State Minister; and

(b) the carers of those persons.

7. (1) Subject to sub-clauses (3) and (4), a service is within the scope of the program if it provides or will provide basic maintenance and support to persons within the target population, being a service that provides or will provide one or more of the following--

(a) home help or personal care (or both);

(b) home maintenance or modification (or both);
(c) food;

(d) community respite care;

(e) transport;

(f) a community paramedical service;

(g) community nursing;

(h) assessment or referral (or both);

(i) education or training for service providers and users (or both);

(j) information;

(k) co-ordination; or

(l) such other service as is agreed upon by the Commonwealth Minister and the State Minister.

(2) A capital facility is within the scope of the program if it is used or to be used for or in connection with the provision of any service within the scope of the program pursuant to sub-clause (1).

(3) A service of the following kind shall be outside the scope of the program--

(a) the provision of accommodation (including rehousing and supported accommodation) or a related support service; or

(b) the provision of an aid or appliance.

(4) A service of the following kind shall be within the scope of the program but only to the extent and for the period that it is eligible for funding by virtue of sub-clause 8 (2)--

(a) a rehabilitative service directed primarily towards increasing a person's level of functioning;

(b) a service providing direct treatment for acute illness (including a convalescent or post-acute care service);

(c) a service designed specifically for persons with the same disability other than a service provided to persons within the target population suffering from brain failure;

(d) a service primarily for families in crisis; or

(e) a palliative care service.

PART IV--PROJECTS
8. (1) Subject to sub-clause (2), a project shall be eligible for funding pursuant to this agreement if it is--

(a) a service or capital facility that is--

(i) within the scope of the program;

(ii) provided or to be provided by or on behalf of the State, a local government, a community organisation or a joint body;

(iii) provided or to be provided to persons within the target population; and

(iv) approved for funding pursuant to clause 9; or

(b) a former Commonwealth-funded project.

(2) A project referred to in sub-clause 7 (4), being a former Commonwealth-funded project, shall be eligible for funding pursuant to this agreement but only--

(a) to the extent that is necessary in order to maintain the project at the activity level at which it was provided prior to this agreement coming into force; and

(b) while no alternative arrangements for the funding of the project have been made pursuant to sub-clause (3).

(3) By the end of the third grant year, the Commonwealth Minister and the State Minister shall jointly review the continued funding under this agreement of all projects to which sub-clause (2) applies and, if they think fit, make alternative arrangements for funding. If no such alternative arrangements are made for their funding, those projects shall continue to be eligible for funding to the extent referred to in sub-clause (2).

9. (1) The Commonwealth Minister and the State Minister shall jointly from time to time, but at least annually, consider which projects (if any), that are not already approved projects should be approved for funding in accordance with this agreement and, subject to the availability of funds for the purpose, they may jointly approve such projects for the purposes of sub-paragraph 8 (1) (a) (iv) and for such period as is specified in the approval.

(2) The State Minister shall, in consultation with the Commonwealth Minister, review the operation and level of funding of--

(a) approved projects eligible for funding pursuant to paragraph 8 (1) (a) during the period for which approval under sub-clause (1) has been given; and

(b) approved projects eligible for funding pursuant to paragraph 8 (1) (b) annually.

(3) The Commonwealth Minister and the State Minister may at any time jointly revoke or vary an approval given under sub-clause (1), and may at any time jointly agree that an approved project eligible for funding pursuant to paragraph 8 (1) (b) is no longer eligible for funding or that the approved project as varied is eligible for funding for the purpose of this agreement.

(4) In taking action under sub-clause (1), (2) or (3), the Commonwealth Minister and the State Minister respectively shall have regard to--
(a) the objective and the principles and goals set out in clause 5 and any guidelines; and

(b) the views of local governments, community organisations and service users on needs and priorities under the program.

(5) The Commonwealth Minister and the State Minister shall, unless they otherwise agree, jointly announce action taken pursuant to sub-clause (1) and may jointly announce action taken by them pursuant to sub-clauses (2) or (3).

10. The Commonwealth Minister from time to time may, after consultation with the State Minister and, where appropriate, local governments and community organisations and service users, give national program guidelines by notice published in the Commonwealth Gazette including guidelines relating to the scope and setting standards and the level of provision of services within the scope of the program. The Commonwealth Minister and the State Minister will agree on the application of the guidelines in the State.

11. (1) Subject to this agreement, the State will be responsible for the management of the program, in accordance with the guidelines and any administrative arrangements approved pursuant to sub-clause (2).

(2) The Commonwealth Minister and the State Minister shall jointly approve and may from time to time vary--

(a) arrangements for the planning and administrative machinery necessary for the effective management of the program, such machinery to allow for participation of representatives of both the Commonwealth and the State;

(b) arrangements for consultative processes whereby local governments, community organisations and service users are consulted on needs and priorities under the program; and

(c) priorities and sub-program guidelines.

(3) Until such time as the Commonwealth Minister and the State Minister jointly approve sub-program guidelines pursuant to sub-clause (2), the provisions of an Act referred to in recital (B) shall, in relation to a service or facility provided for under this agreement similar in kind to a service or facility to which that Act applied, be sub-program guidelines.

(4) As soon as practicable after this agreement is signed the Commonwealth Minister and the State Minister shall make arrangements for the transfer to the State during the first 3 grant years of the Commonwealth's responsibilities in relation to former Commonwealth-funded projects and such arrangements may include the provision of assistance to the State as a means of facilitating the transfer of responsibility.

PART V--FUNDING--COMMONWEALTH FINANCIAL ASSISTANCE AND STATE EXPENDITURE

12. In order to assist the State in the achievement of the objective of this agreement, the Commonwealth will, upon and subject to the provisions of this agreement and to the appropriation by the Commonwealth Parliament of funds for the purpose, provide to the State in respect of each grant year financial assistance to meet or reimburse expenditure incurred for any purpose related to the provision of approved projects, by way of interest free non-repayable grant.
13. (1) Subject to clauses 15 and 19, the Commonwealth will provide base financial assistance to the State in respect of the first and second grant years of an amount equal to the sum of--

(a) the amount expended by the Commonwealth in the State in respect of the base year, by way of financial assistance or subsidy, in relation to the provision of--

(i) former Commonwealth-funded projects; and

(ii) other projects that, by the commencement of the grant year, become approved projects,

adjusted in accordance with clause 17; and

(b) such other amounts expended by the Commonwealth in the State in respect of that first or second grant year (as the case may be) as the Commonwealth Minister and the State Minister agree should be taken into account for the purpose of this paragraph.
HACC Carers Policy  Home And Community Care 1996
[Australia]
HACC CARERS POLICY
This statement acknowledges the fundamental role of carers in the provision of care in the community and outlines the Home and Community Care (HACC) Program's commitment to provide the highest quality of support and assistance for carers.

Carers are recognised in the Program as those people who provide care and support for a parent, partner, child or friend who has a disability, is frail, suffers from dementia or a chronic illness. Carers come from all social, cultural and economic backgrounds and often provide care at great personal cost. Every caring situation is special and requires an individual and personal approach to determine the appropriate service or services which will be of most benefit to both the carer and the person for whom they care.

This Statement outlines the specific objectives for carers under HACC and will underpin the Program's overall philosophy to enhance the quality of life of frail and elderly people, people with disabilities and the carers of these people in the community through the provision of high quality services and assistance.

The HACC Program funds a range of services which provide help and support to enable frail aged and people with disabilities to live independently in their own homes and to participate in their communities. Carers are a special group within the Program and benefit both directly and indirectly from the provision of services to those for whom they care, and directly from services specifically targeted to their needs.

Those receiving care have the benefit of being able to remain in their own homes - with assistance from HACC where necessary - for as long as possible. In this way carers contribute enormously to the quality of life of the person receiving care. The HACC Program recognises that this contribution benefits the whole community.

After extensive consultation with carers and consumers, a number of key objectives in relation to carers have been identified for the Program. These include:

- greater recognition of the work of carers, including carers who are in part or full time paid employment;
- expansion in the range, quality and flexibility of services available to assist carers in the community;
- increased provision of support and assistance to carers and to carer organisations; and
- targeted assistance to carers in special needs groups such as Aboriginal and Torres Strait Islander people or those from an non-English speaking background.
In order to meet these objectives the HACC Program will:

- continue to provide support to carers by funding community care services designed specifically to assist carers. These include services such as respite care, heavy linen services, carer support groups, training and information;

- promote further recognition of the valuable role fulfilled by carers, including carers in paid employment in the community and seek to encourage an understanding in the broader community, including health and welfare professionals, of the vital role and needs of carers;

- accept carers as partners in the provision of care in the community and involving carers in the development of appropriate care plans;

- seek the views of carers about care needs and consult with carers and carer organisations about the development of appropriate strategies to improve the range and quality of services in the community.

Carers deserve and must have respect, recognition and support through appropriate services provided in a flexible manner. This policy statement provides a formal recognition by the HACC Program of the importance of carers in the community. Their contributions enrich the lives of many thousands of Australians by providing them with choices and enabling them to remain at home among family and friends.
19a: Proposed A.I.M. Model
-Carer Health / Caring Role Assessment in General Practice

19b: Stages of Caregiving
Proposed AIM model for Carer (Health / Social) Assessment in General Practice

The AIM Model for Carer Assessment aims to provide both a carer role / social focus and a clinical health focus for carer health maintenance and carer health enhancement.

The first part of the process [AIM-I] is designed as an introductory phase and involves an informal verbal assessment (in contrast to the clinical health assessment of AIM-II).

AIM-I establishes the level of carer experience and coping and the stage the carer is at in their caring pathway (Early, established or end stage - for either the carer's ability to continue to the deterioration of the cared for person.) See The 6 stages of caring.

**AIM-I: INFORMAL ASSESSMENT OF CARER**

A: **ASK**  How is the carer feeling / coping?
I: **INFORM**  Contacts for Carer/Community Support, Carer Benefits/ Resources/Respite
M: **MONITOR**  Monitor carer health / coping with role. Arrange follow up

The GP ASKS how the carer is feeling, how he or she is coping. The GP then INFORMS the carer of useful contacts or support services, referring-on where necessary. From that point the GP MONITORS the carer's general health.

Depending on carer responses to the AIM-I, the GP may be satisfied that no further action is required at that point and the GP follows up with the carer at a later stage. However in the event that the GP perceives there are potential / acute problems with the carer's health or the caring role requires formal support, the GP would proceed with AIM-II.

**AIM-II: FORMAL ASSESSMENT OF CARER**

A: **ASSESS**  Clinical Health Assessment and assess carer role / respite needs
I: **INTERVENTION**  For health &/or social needs
M: **MANAGEMENT**  Work through with carer & other health care professionals if needed
   **PLAN**  Follow up and monitor carer's progress

AIM-II involves a formal ASSESSMENT of the carer's health and social support needs, and based on those assessments, appropriate INTERVENTIONS are instituted using various respite options, other services and EPC protocols (May involve supporting / changing patient care. A formal MANAGEMENT PLAN is drawn up for the carer so the carer's progress can be followed and monitored. As the carer improves the cycle will return to AIM-I. Ideally this ongoing support mechanism could be repeated at each of the six stages of caregiving thus providing both the GP and the carer a way of achieving health maintenance as well as health enhancement.
THE SIX STAGES OF CARING

Experiences reported by carers as the caring role changes over time

6 major time bound phases to caring were identified from qualitative data (Stacey research)

Stage 1
At the time of diagnosis
Confusion
A time of confusion and uncertainty for the family member or significant other in the patient's early acute phase;
Involves transition from family member/close friend to "carer";
It may not have been that person's choice to become the carer;
Becoming a carer may occur suddenly - or come on slowly.

Stage 2
The new carer
Unsure / Overwhelmed by new responsibilities
Starting out as carer - alone and uniformed, untrained;
Initial adjustment and transition stage;
Understanding the new role / learning to cope;
Searching for information, support, resources;
Many 'new' carers have a short term view.

Stage 3
Intermediate
Awareness and acceptance of role
Developing new patterns of coping as carer;
Developing new social / carer/community support networks;
Coping with destabilising changes to dependent's condition;
Progression of person's illness - changes in patient's functioning;
Looking at the longer term.

Stage 4
The experienced carer
Carer managing responsibilities and fine tuning role
Carer has learned from experience / Consolidating knowledge;
Has established routines and may try teamwork approach;
Increased tolerance to person's behaviour (or illness) but may be becoming tired - constant cycle of care;
Some carers ageing themselves or have existing illnesses made more difficult by ongoing caring role.

Stage 5
The secondary carer
Handing over
Anguish when dependent leaves home care and goes into formal care, involves anxiety, guilt, fear for person's well being;
Loss of control for quality of care of the dependent person.

Stage 6
The retired carer
After the caring is over - Grief, loss and emptiness
Time to live for one person - for self;
Self renewal may require rehabilitation, reflection;
Time for carer to recover their strength, their life, their health;
Much knowledge and experience to share with others who are informal or family caregivers.

"Enhancing the Health Of Informal Caregivers. Implications for General Practice and Public Health".
Department of Public Health, Faculty of Medicine, University of Adelaide.
SECTION IV: DISCUSSION AND IMPLICATIONS

APPENDIX: 20

20a: A.I.M. MODEL: Carer Health / Caring Role Assessment in General Practice

20b: AIM-1 and AIM-2
THE A.I.M. MODEL
CARER HEALTH / CARING ROLE ASSESSMENT IN GENERAL PRACTICE

AIM-I
Informal [verbal assessment]

1. A: ASK How they feel / are coping
2. I: INFORM Support services, Contacts
3. M: MONITOR Carer general health

AIM-II
Formal [written assessment]

4. A: ASSESSMENT Clinical health
   Caring Role / coping
5. I: INTERVENTION Social &/or health
6. M: MANAGEMENT PLAN
   MONITOR
A.I.M. MODEL
CARER HEALTH / CARING ROLE ASSESSMENT
IN GENERAL PRACTICE

Acknowledge:
- Stage of Caring Pathway
  [Early - Mid-End stage]
- Level of Carer Experience

1. ASK
   How is carer feeling/coping

2. INFORM
   Carer Support Services
   Contact Persons

3. MONITOR
   PROGRESS
   Follow up

4. ASSESSMENT
   Caring role needs
   Clinical health

5. INTERVENTION
   Health Social

6. MANAGEMENT
   PLAN & MONITOR

II. Formal
   [Written]

I. Informal
   [Verbal]