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NATURAL CAUSES?
PALLIATIVE CARE AND DEATH CAUSATION IN PUBLIC POLICY AND THE LAW

THESIS

DOCTOR OF MEDICINE

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SUMMARY

Two opposing views of death causation, as it applies to care at the end of life, appear to be operating in western societies. On the one hand, modern medical practice, based on the Judaeo-Christian tradition of law and ethics, takes a *forensic* view of 'natural' death and does not permit human agency to be implicated. Consistent with this, palliative care practitioners hold a position of causal 'neutrality', whereby the process of dying is stated to be neither hastened nor prolonged. On the other hand, there is widespread support for euthanasia, which explicitly allows death to be caused in certain circumstances, at the patient's request.

This thesis examines medical, legislative, legal and parliamentary scrutiny of end of life issues in Australia 1983-1998, and in four comparable OECD countries: the United Kingdom, Canada, USA and New Zealand. It collates and analyses the arguments about death causation in palliative medicine. All the reports, judgments and parliamentary committee proceedings studied assume that palliative care interventions and treatment abatement decisions may constitute a cause of death. However, this is allowed in law due to the public policy imperative to relieve pain and suffering and avoid prolongation of the dying process.

The incorporation of this causal assumption into law and public policy can be traced back to a famous passage of Justice Devlin's instructions to the jury in the case of *R v Adams* in 1957. Devlin J used double effect reasoning to render lawful the use of escalating morphine and heroin doses which contemporary medical evidence had informed the court might have the incidental effect of shortening the life of a dying person. The experience of the hospice and palliative care movement over the past three decades has shown that the safe and effective use of morphine, other opioids, and sedatives in pain and symptom control need not bring cause of death into question. Similarly, treatment abatement is undertaken when futility can clearly be demonstrated for dying persons. It is clear that there is no basis for fear of legal sanction by health professionals if the prevailing standards of palliative care are adhered to. The law takes a

common sense and multifactorial view of causation, and will often not even apply a causal analysis, focusing more on legality of actions and presence or absence of duties instead.

Causation can be an important analytical and reflective component of the process of determining whether palliative care is ethical and legal. However, neither the natural death concept, in the strictly forensic sense, nor the palliative care position of causal neutrality can be empirically defended in all cases, and it is not usually helpful or appropriate to do so. Natural death can be more fruitfully understood in a broader *existential* sense of inevitability, as a composite of causality, autonomy and dignity, and not solely in terms of the presence or absence of human agency. The goals and intentions of drug prescribing and principles of pharmacology in palliative care can and should be made clear. The doctrine of double effect is seen to be unhelpful and unnecessary in the determination of what is permissible in palliative care.

DECLARATIONS

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

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

Signed

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The Parliament of South Australia (through the Select Committee of the House of Assembly on the law and practice relating to death and dying, 1991) funded the research conducted for three papers on attitudes towards death and dying (appendices 2, 3 and 4).

ABBREVIATIONS

ACT	Australian Capital Territory
AAHPC	Australian Association for Hospital and Palliative Care
AHA	Artificial hydration and alimentation
BC	British Columbia
CMTPC	Consent to Medical Treatment and Palliative Care Act (SA) 1995
e.g.	for example
EPA	Enduring Power of Attorney (Medical Treatment) Act 1990
MN & H	Medically administered nutrition and hydration
MTAA	Medical Treatment (Agents) Act 1992
MP	Member of Parliament
MTA	Medical Treatment Act 1988 (Victoria)
NDA	Natural Death Act 1983
NHS	National Health Service
NT	Northern Territory
OECD	Organisation for Economic Co-operation and Development
RTI	Rights of the Terminally Ill Act
SA	South Australia
UK	United Kingdom
USA	United States of America
VAE	Voluntary Active Euthanasia

INTRODUCTION

Death and the manner of dying are issues of fundamental concern to everyone. Inevitably, in complex societies there are diverse avenues of approach, points of view, and ways of looking at death and dying. In particular, medicine, ethics and the law each has its own professional perspective, academic tradition, and concerns, which generate subtle but important differences in the assumptions made and language used when viewing the same issues. The thinking in each of these areas may be misunderstood beyond these professional boundaries, with the capacity to profoundly influence the other domains.

Much of the thinking about death in society centres on the idea of natural death – a major source of confusion in itself. Though widely used in common parlance, natural death is a difficult and ambiguous concept. Two overlapping but distinct meanings will be explored in this work. At one level – in its forensic sense – it implies a consideration of the cause of death and in particular, the presence or absence of any human contribution to that cause – again, a problematic notion. At a deeper level, natural death is also broader than this, with existential or spiritual connotations. This conception encompasses the importance of conscious preparation for death, as a key component in the quest for meaning and dignity in human life.

Cause of death is, nevertheless, a matter of central importance for both medicine and the law. Medicine, and in particular, palliative care – that branch of medicine that cares for people who are dying – adopt the position that medical intervention should neither hasten death nor prolong the process of dying when cure or remission of disease are no longer realistic goals. This position of what might be called causal 'neutrality' has grown from, and is consistent with, the Judeo-Christian ethic – the dominant ethic in Australian society, and of the other countries to be considered in this work. Each of the three major monotheistic

religions holds that humans have a natural life span determined by God; that the mode and timing of death does not lie with man, and human agency cannot be involved. Law tends to be shaped over centuries by the dominant religious tradition of the country or jurisdiction concerned, and all have historically forbidden causing the death of a person, unless sanctioned by the state. This position of causal neutrality has been challenged over recent decades on two fronts.

Firstly, euthanasia has become a topic of wide public debate. Overwhelmingly the public has indicated that, in certain circumstances at the end of life, most notably where suffering is unrelieved or where quality of life is impaired to such a degree that the person feels their life is no longer worth living, it is permissible to have someone else help that person to die. This runs directly counter to the values laid down by religion and reflected in the law. With a few notable exceptions, most jurisdictions explicitly forbid third party assistance in dying.

Secondly, in public policy and the law there has long been the assumption that some palliative interventions, or deliberate lack of intervention, do indeed contribute to the cause of death – interventions such as the giving of escalating doses of opioids and/or sedatives at the end of life, or the withdrawal or failure to initiate various medical treatments. This, however, is allowed because of the ethical and public policy imperative to relieve suffering and avoid a purposeless prolongation of dying and its attendant suffering and loss of function.

The assumption concerning cause of death and the use of opioid and sedative drugs in palliative care is wrong. The knowledge and skills built up over some thirty years of palliative care practice have shown that opioids and other similar drugs can quite safely be used for symptom control without bringing causation into question if the parameters of accepted practice are followed. Any drug can endanger life if used inappropriately. It is also clear that the use of escalating opioid and

sedative drugs close to the point of death might have some influence on precise timing of death, although it is not possible, and nor does it seem appropriate or important to, validate such an observation one way or the other. Such understanding did not, however, exist in 1957, when (the then) Justice Devlin gave advice to an English jury in the famous case of *R v Adams*.[1] Devlin, concerned specifically with the use of morphine and heroin in terminal care, was reliant on medical opinion of the day, which held that opioid drugs were dangerous and their use at the end of life inevitably entailed causing or contributing to the cause of death through respiratory depression. To accommodate this within the law, Devlin introduced, for the first and only time into such legal deliberations, the doctrine of double effect. This has its origin in the Roman Catholic moral theological tradition, in which an outcome forbidden by religion, in this case causing or contributing to the premature death of a dying patient, is permissible, provided that certain conditions are met, notably that this outcome must not be intended.

Despite the general falsity of the medical assumption underpinning it, and the fact that the intentions and motives of the doctor on trial were also open to question, Devlin's advice is still frequently quoted when end-of-life issues are considered in the English common law tradition. The law continues to assume that palliative care interventions may indeed contribute to cause of death, but, taking a commonsense and humane approach, it has developed a range of legal reasonings to accommodate this. Devlin's invocation of the principle of double effect is still the predominant one.

Due in no small part to its incorporation into the legal reasoning in this frequently cited case, this false causal assumption, combined with the legacy of the Judeo-Christian imperative, continues to generate anxiety amongst doctors, nurses and the general public. Health workers, imbued with the scientific tradition, tend to believe that the law just looks at bare

[1] *R v Adams*, Central Criminal Court, London, 1957. Unreported but discussed in Palmer, Dr Adams' trial for murder, [1957] Crim LR 365.

causality, and, it seems, palliative care may contribute to cause of death in the eyes of the law. However, while the law looks at the facts of a case, it is also concerned with the legal process of determination of legal liability, and in legal parlance the term 'causation' encompasses both these aspects.

Every clinical decision regarding end-of-life management involves some degree of causal analysis – viz, does the decision or intervention have the potential to contribute to cause of death? This is a concern not only to medical and nursing practitioners, but also and often more importantly, of patients themselves, and their relatives, when patients are too ill or cognitively impaired to express a view.

At the same time, medical practice is to a large degree based on, and informed by, an imperative to keep patients alive at all costs, and to do everything possible to achieve this. The massive technical advances within medicine throughout the twentieth century have promoted the illusion, both within medicine and in the public mind, that death can be indefinitely postponed. To admit death is to admit defeat. This, combined with the widespread assumption that palliative interventions may incidentally contribute towards a patient's death, has generated a resistance within mainstream medicine to the delivery of appropriate care of people who are dying.

In this context, palliative care practitioners often find themselves, in their everyday clinical work, to be the proponents of natural death, not so much in the forensic sense, but in the existential sense. Here death is understood, recognised and accepted as an inevitable consequence of having life. This goes far beyond causal analysis, to encompass human dignity and a recognition of mortality in a setting that often appears to deny it. This is not to dismiss the importance of understanding cause of death altogether, but it does acknowledge that whilst the empirical medical facts continue to be important, they cannot alone guide how people who are dying should cared for.

For the past half century at least, the interchange between the three major disciplines of medicine, ethics and the law has been unsatisfactory, limited, and underpinned by some fundamental misunderstandings. This thesis attempts to synthesise the various elements of that interchange, to translate and interpret across and between the domains in which that conversation occurs – public opinion, public policy, professional discourse, and the justice system. This is of importance for medicine in particular, as false or inappropriate perceptions by medical practitioners of what the law and ethics have to say regarding the end of life can lead to clinical decisions that are not in the patient's best interests. The thesis attempts to provide the language and the common ground for genuine dialogue to occur, to enable health care workers to discuss death and dying in a wider context.

Chapter 1 will consider how palliative care defines the ethics of its practice, with brief considerations of its history, sociological framing as a social movement, and Christian origins. The two principal meanings of the term 'natural death' outlined above are explored: the concept of death without intervening human causal agency, and the reality of death as an inevitable consequence of living. It will be argued that the recognition of a natural dying process is fundamental to palliative care practice. An approach to medical decision making is described, which acknowledges the transitions from curative to palliative and terminal phases of an illness, based on setting goals of care.

Chapters 2 and 3 will review medical, legislative, legal and parliamentary scrutiny of palliative medicine and related end of life issues in Australia and four other comparable western countries: Canada, the United Kingdom, New Zealand, and the United States, over the last two decades.

Chapter 4 will examine concerns about causation in relation to the use of opioids for pain management, and sedative drugs in terminal care. The pharmacological component of palliative medicine is narrowly defined as symptom relief, based on a clear notion of intention and causality, summarised in what is termed the 'Ontario coroner's principles'.

However, it will be argued that empirical causal analysis alone has a limited capacity to determine what constitutes ethical palliative and terminal care practice.

Chapter 5 will address causal aspects of treatment abatement, concentrating on the key issue of artificial hydration and alimentation. It will be proposed that there is a clinical distinction between such abatement for dying and non-dying persons. Treatment abatement in palliative care takes place because the treatment(s) in question are no longer working and the person is dying, and causal analysis is not usually directly relevant. Abatement of life support and artificial hydration and alimentation for non-dying persons, such as those who have severe and irreversible brain damage (e.g. persistent vegetative state), raise more contentious causal issues.

Chapter 6 will analyse the various legal arguments about death causation and palliative medicine which have been advanced to defend its legality. The doctrine or principle of double effect is also considered, as most of the legal reasoning applied to palliative care has invoked it. The doctrine is differentiated from the clear formulation and communication of what are intended, desired and foreseen outcomes of proposed medical treatment. Such discussions are a mandatory component of obtaining consent to medical treatment, and although the formulation and language may resemble double effect–based analyses, they can be conducted independently of it.

The referencing software system used throughout this work is Endnote version 3.1, with citations inserted as full references in the footnotes, using a generic author-date citation style based on the Harvard system. Copies of the author's publications of relevance to the thesis are appended (appendices 1 to 13, 21-25), preceded by a bibliography. The appendices also include copies of submissions and transcripts of oral evidence given by the author to three parliamentary select committees (appendices 14, 17, 18); extracts of the reports of these committees which either cite the author's contribution or illustrate key points or arguments (appendices 15,

16, 19, 20); copies of three key pieces of legislation considered at length in the thesis (appendices 26-28), and a series of articles about artificial hydration and alimentation to show fully a running debate on this issue in which the author was involved (appendices 9, 29-32).

CHAPTER 1

PALLIATIVE CARE ETHICS AND NATURAL DEATH[2]

Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying with "dignity" – shows how important it is that life ends appropriately, that death keeps faith with the way we want to have lived.[3]

'Cause nature has a funny habit of breaking what does not bend. (From 'Innocence Maintained' a song by Jewel from the CD 'Spirit').

During the course of the twentieth century, the developed world has seen unparalleled progress in medical science. But death and the process of dying were neither specifically recognised nor addressed in what seems to have been a golden age of technological optimism, until the advent of the hospice and palliative care movement in the late 1960s. This movement has developed over the past three decades as a practical response to the care needs of dying people. It has brought about significant and continuing improvement in the way health care systems deal with the process of dying, and Australia has been at the forefront of these developments. However, to many who chose to specialise in palliative medicine as services started to expand in Australia during the 1980s, the pace of change has often seemed slow.[4] If it were merely a matter of the

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[2] This chapter is based on a much longer collaborative piece of work which considers the philosophical and medical perspectives of the 'natural' death concept. In this thesis, the emphasis is on legal causation, because of its relevance to clinical practice and behaviour, rather than a philosophical analysis of the terrain. The chapter concerned is appended in full (Appendix 22), Stoffell, B. and M. A. Ashby (1997). On natural death and palliative care. Health care law and ethics. L. Shotton. Katoomba, Social Science Press: 163-178.

[3] Dworkin, R. (1993). Life's Dominion. An argument about abortion and euthanasia. London, Harper Collins. p199

[4] The author has held the positions of first Medical Director of Palliative Care at the Royal Adelaide Hospital and Mary Potter Hospice, Calvary Hospital, Adelaide in 1989, until 1995, and subsequently the chair of Palliative Care at Monash University in Melbourne since then. The thesis is based on over ten year's experience of articles, speeches, contributions to reports and evidence to parliamentary committees on the ethics and practice of palliative medicine (see appendices). These have resulted in a process of exploration, reading and research, and participation in public debates and private conversations with colleagues from many disciplines. Most of all the central themes of the thesis have arisen on countless occasions, and the approach set out here has been used to assist the author to work through with colleagues, patients and families, concerns about causation as death approaches. As a result, insights have been gained, positions changed and ideas modified, in a controversial area, where strong arguments and beliefs abound, interpretation of similar experiences differ, and empirical data are often so hard to gather.

acquisition of appropriate knowledge and skills, by doctors and other health care professionals, to bring about these improvements, it would surely not be taking this long. Clearly, profound attitudinal issues are operating. In this passage from his 1993 book The Troubled Dream of Life, Daniel Callahan identifies these influences as follows:

> Doctors still do not, as a rule, talk comfortably and directly with patients about death ... A worry about malpractice, a zest for technology, a deep-seated moral belief in the need to prolong life, and the pressure of families and others still often lead to over-treatment and an excessive reliance on technology. [5]

In a nutshell, curative intent dominates all medical decision-making. If the pursuit of cure is compromised at any point up until perhaps the last hours of life, the health care professionals involved, and possibly also family members could be seen as being responsible for causing the death, in which case the death then could not be said to be 'natural'. A key question to be examined then becomes: what does the phrase 'natural death' mean, and if this is taken to mean death without intervening human agency, and therefore, from natural causes, are most deaths in modern health care systems really natural at all, and if they are not, does it matter? At a practical level, in clinical decision-making, how can treatment be abated (i.e. stopped or not initiated) and symptoms be treated appropriately without notions of causality being invoked. Or, put another way, how can death be due to natural causes unless all treatments which have any potential to lengthen life have been deployed, and/or if opioid and sedative drugs are used, in escalating doses, to treat symptoms for dying persons?

Palliative care teams, especially those working in acute hospitals, often find themselves working through (overtly and covertly) these causal issues in end of life care with the treating team, patients and families. They become advocates for the recognition of natural death in the sense of acknowledgement of its imminence and inevitability, often in situations

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[5] Callahan, D. (1993). The troubled dream of life: living with mortality. New York, Simon Shuster.

where heroic but futile and disproportionate treatment options are being offered to dying persons. The challenge is to bring about a transition in the goals of care to comfort and dignity rather than cure or length of survival. This tends to be resisted by a willing co-conspiracy between desperate patients and families, and their doctors, in a system which all too readily constructs death as an enemy to be fought at almost any cost until the last possible moment. Death is often described in terms of personal defeat, either by the patient or members of the health care team.

Over the same time period euthanasia has become the major aspect of death and dying which generates media interest and debate in most developed societies. The central question at stake is whether it is permissible for a terminally ill person to have third party assistance to die. Euthanasia is an old issue and campaigning groups have existed for over a century, but the debate has been developing considerable momentum in the nineties and public opinion in favour of euthanasia has risen steadily in most developed countries. There have been a number of unsuccessful legislative initiatives around the world, several of which have been in Australia. Three jurisdictions have legalised euthanasia: the Netherlands, the state of Oregon, USA (physician-assisted suicide) and (transiently) the Northern Territory of Australia. There have also been a number of court cases either seeking court approval for treatment abatement decisions, or to try acts of so-called mercy killing. As a result, end of life issues have received unprecedented attention from courts, parliaments, professions and the media. Distinguishing between palliative care, which is legal, and euthanasia, which is not, has been a recurring central theme in these deliberations, and, specifically, the contribution of human agency to death causation. For palliative care workers, the standard ethical position is that the process of dying is neither hastened nor prolonged by accepted interventions. Advocates of euthanasia reject this causal defence, and it is often argued that since accepted palliative care practices can be shown to contribute to death causation, they cannot be morally differentiated from the rendering of assistance, at the request of a person, to explicitly bring about their death.

Analysis of causation is, therefore, central to any deliberative process which has as its object the determination of the moral character and legality of medical decisions or palliative interventions at the end of life. But there are semantic, evidential and argumentation difficulties which require elucidation.[6] This quotation from a 1996 judgment in the Ninth Circuit Court of Appeal of the United States, articulates a prevalent international medico-legal view of palliative care interventions and death causation: 'as part of the tradition of administering comfort care, doctors have been supplying the causal agent of patients' deaths for decades'.[7]

This chapter therefore examines the ethics of palliative medicine and the concept of natural death, as preparation for the subsequent consideration of arguments about death causation in palliative medicine in law and public policy. It will focus on the putative contribution of views about death causation to both public and professional unease about treatment and decision-making at the end of life on the one hand, and the claim that palliative care and euthanasia cannot be morally distinguished on the other.

1.1 The hospice and palliative care movement

Modern hospice and palliative care is usually regarded as starting with the opening of St Christopher's Hospice in Sydenham, south east London by Dame Cicely Saunders and colleagues in 1967. During the ensuing two decades there was rapid growth of services for dying people in the United Kingdom, particularly free-standing hospices and specialist home care programs.[8] Similar developments then spread preferentially to present

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[6] See the author's three main publications on this issue (appendices 11, 12 and 25):
Ashby, M. (1997). "The fallacies of death causation in palliative care." Medical Journal of Australia 166: 176-177.
Ashby, M. (1997). "Of Life and Death: the Canadian and Australian Senates on palliative care and euthanasia." Journal of Law and Medicine 5: 40-51.
Ashby, M. (1998). "Palliative care, death causation, public policy and the law." Progress in Palliative Care 6(3): 69-77.

[7] Annas, G. J. (1996). "The promised end-constitutional aspects of physician-assisted suicide." New England Journal of Medicine 335: 683-687.

[8] Higginson`, I. (1993). "Palliative care: a review of past changes and future trends." Journal of Public Health Medicine 15: 3-8.

and past Commonwealth countries: Canada, Australia, New Zealand, South Africa, Eire. Balfour Mount, a surgeon from the Royal Victoria Hospital in Montreal visited Dame Cicely Saunders and subsequently set up the first unit in North America in 1975.[9] Despite some early activity in the USA,[10] progress has been variable and predominantly community-based, coming into major teaching institutions relatively recently. Spread to the rest of Europe and some Asian countries has largely occurred from the early 1990s onwards.[11]

However, as Clark has shown, drawing heavily from Dame Cicely Saunders' own writings, the origins are apparent earlier in the development of the National Health Service in postwar Britain,[12] and in charitable religious foundations which have offered care to the terminally ill in far older institutions sporadically around the world since the end of the nineteenth century.

James and Field have made a sociological description of the modern history of hospice and palliative care as a Weberian social 'movement', with St Christopher's and Dame Cicely as the epicentre of what has become an international wave of change in the care of dying people.[13] Consistent with this model, there have been concerns about deviation

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[9] The opening of St Boniface Hospital's unit in Winnipeg also occurred at this time.

[10] Notably Dr Sylvia Lack and the Connecticut Hospice Ford, G. (1998). "Evolution and development of hospice and specialist palliative care services." Clinical Oncology 10: 50-55.
See also correspondence of Dame Cicely Saunders. Clark, D. (1998). "An annotated bibliography of the publications of Cicely Saunders - 1: 1958-67." Palliative Medicine 12: 181-193.
Clark, D. (1999). "An annotated bibliography of the publications of Cicely Saunders - 2: 1968-77." Palliative Medicine 13: 485-501.

[11] For reflections on the history of the hospice/palliative care movement see Doyle, D., G. Hanks, et al., Eds. (1993). Oxford Textbook of Palliative Medicine. Oxford, Oxford University Press. p vi, and Saunders, C. (1993). "Some challenges that face us." Palliative Medicine 7(suppl 1): 77-83.

[12] Clark, D. (1998). "Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957-1967." Mortality 3: 43-63.
Clark, D. (1999). "Cradled to grave? Terminal care in the United Kingdom, 1948-67." Mortality 4(3): 225-247.

[13] James, N. and D. Field (1992). "The routinization of hospice: charisma and bureaucracy." Social Science and Medicine 34(12): 1363-1375.

from founding ideals as the movement ventures back into the 'mainstream' of health care, a trend which has been well underway in Australia for the last decade,[14] and also about excessive 'medicalisation' of death.[15]

This movement has promoted the treatment of pain and other symptoms located in a holistic framework with multi-disciplinary professional and volunteer input which addresses medical, psychological, spiritual and social dimensions of the person's illness and death, with bereavement support for surviving family and friends.[16] It has strong roots in the Christian tradition, and has, with a few notable exceptions[17] consistently opposed the legalisation of euthanasia. Death causation itself is rarely addressed in the founding ideals, although Saunders twice recognises the

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[14] For a discussion of medical aspects of the generalist v specialist debate in palliative care, see Ashby, M. A. (1997). "Palliative care as a medical specialty." Palliative care: challenges and explorations. J. Parker and S. K. Aranda. Sydney, Maclennan and Petty: pp 46-55 (appendix 21). Other chapters offer a useful snap shot of the main controversies in palliative care, both in Australia and elsewhere.

[15] Field, D. (1994). "Palliative medicine and the medicalization of death." European Journal of Cancer Care 3: 58-62.

[16] Palliative Care Australia defines Hospice and Palliative Care as:

> "a concept of care which provides co-ordinated medical, nursing and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional and spiritual support for patients, and support for patients' families and friends. The provision of Hospice and Palliative Care services includes grief and bereavement support for the family and other carers during the life of the patient and continuing after death."

The World Health Organisation definition (WHO 1990) is:

> "the active total care of patients at a time when their disease is no longer responsive to curative measures and when control of pain and other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is the highest possible quality of life for the patient and family."

[17] See Hunt, R. (1994). Palliative care: the rhetoric-reality gap. Willing to listen, wanting to die. H. Kuhse. Melbourne, Penguin: 115-137.
Hunt, R., I. Maddocks, et al. (1995). "The incidence of requests for a quicker terminal course." Palliative Medicine 9: 167.
Hunt, R. and K. McCaul (1996). "A population-based study of the coverage of cancer patients by hospice services." Palliative Medicine 10: 5-12.
Hunt, R. (1998). "A critique of the principle of double effect in palliative care." Progress in Palliative Care 6(6): 213-215.
Hunt, R. (1999). "Taking responsibility for affecting the time of death." Palliative Medicine 13: 439-441.
See also Marcel Boisvert mentioned in: Mullens, A. (1996). Timely death. Considering our last rights. Toronto, Alfred A Knopf.

difficulties of maintaining the position of neither hastening nor prolonging death.[18]

1.2 Policy Statements by palliative care peak bodies

Fundamental to palliative care work is an acknowledgment of death as natural, in the sense of being an inevitable intrinsic part of human existence, rather than an enemy to be defeated, or a sign of medical or personal failure. It is stated that the process of dying is neither hastened nor prolonged by accepted palliative care practice. Both the Australian and Canadian national palliative care peak bodies have reasserted this position in recent years.[19]

The Australian Association for Hospice and Palliative Care Inc (AAHPC) issued the following position statement on voluntary active euthanasia on 27th October 1995:[20]

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[18] See Clark, D. (1998). "Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957-1967." Mortality 3: 43-63. Clark shows that early conceptions of St Christopher's by Saunders included a religious community model, routed firmly in the Anglican tradition. Also in a study of the correspondence of Dame Cicely Saunders, Clark, D. (1998). "An annotated bibliography of the publications of Cicely Saunders - 1: 1958-67." Palliative Medicine 12: 181-193. In commenting on Saunders C, "The management of patients in the terminal stage." In Raven R ed Cancer, vol 6. London: Butterworth, 1960b: 403-17, Clark writes: 'Euthanasia is again opposed', but the important point is made that 'with the means we have at present, although the motive is different, it is not always easy in practice to distinguish between proper relief and the hastening of death'. And with regard to another paper, Saunders C, The management of terminal illness. British Journal of Hospital Medicine, 1966d; December: 225-28, Clark comments: 'The difficulties of distinguishing between the prolongation of living and the prolongation of dying are acknowledged and it is asserted that requests for euthanasia in this context can be avoided by the provision of appropriate care.'

[19] Comparing the Canadian Palliative Care Association Board Position on Euthanasia (September 19th, 1993) with the Australian Association for Hospice and Palliative Care Position Statement on Voluntary Active Euthanasia (October 27th, 1995) both are very similar, and explicitly oppose the legalisation of euthanasia. They also adopt similar definitions of euthanasia, and seek to differentiate proper standards of palliative care practice (particularly pain and symptom relief and treatment abatement) from any kind of euthanasia. See also two editorials from Palliative Medicine which show the firm view against euthanasia taken by palliative care practitioners: Dame Cicely Saunders Saunders, C. (1992). "Voluntary euthanasia." Palliative Medicine 6: 1-5. And Finlay, I. (1994). "Palliative care overtakes euthanasia." Palliative Medicine 8(4): 271-272. The word 'euthanasia' will be used in its 'narrow' sense throughout this paper, as defined by the Australian Association for Hospice and Palliative Care in its position statement of October 1995: 'the deliberate action to terminate life by someone other than, and at the request of, the patient concerned.'

[20] The author was involved in drafting this policy statement.

The Australian Association for Hospice and Palliative Care:

1. defines Hospice and Palliative Care as a concept of care which provides coordinated medical, nursing and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional and spiritual support for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient, continuing after death;
2. defines Voluntary Active Euthanasia (VAE) as the deliberate action to terminate life by someone other than, and at the request of, the patient concerned;
3. believes that dying is a natural process and that the refusal or withdrawal of futile treatment is not voluntary active euthanasia;
4. believes that legalisation of voluntary euthanasia is not a substitute for the proper provision of palliative care services to all Australians;
5. believes that public interest in voluntary active euthanasia reflects a concern about lack of adequate support for people who are dying, and will continue to campaign for improved services, education and research in all aspects of palliative care;
6. states that currently accepted palliative care practice does not include deliberate ending of life, even if this is requested by the patient;
7. asserts that palliative care experience shows that appropriate and effective use of morphine and other drugs for pain relief does not cause death;
8. recognises that there is a wide divergence of views about voluntary active euthanasia in Australian society, and also within the caring professions, including the palliative care community;
9. recognises and respects the fact that some people rationally and consistently request voluntary active euthanasia;
10. acknowledges that, while pain and symptoms can be addressed, complete relief is not always possible in all cases, even with optimal palliative care;
11. welcomes open and frank discussion within the community, and particularly with the health professions, about all aspects of death and dying, including voluntary active euthanasia;
12. nevertheless, due to the inherent risk to individuals and society, opposes all legalisation of euthanasia.

The claim here then is one of what might be termed causal 'neutrality', a position of neither *intending* (the key ethical precept) to hasten nor prolong

dying. This position is utterly consistent with the earliest founding ideals of the movement. Advocates of euthanasia argue that this position is empirically unsustainable as drug treatment and treatment abatement decisions which are part of accepted palliative care practice, and deemed to be legal, do indeed make a causal contribution to death. Therefore, they see no moral distinction between these accepted interventions and the rendering of explicit active assistance to die at a competent patient's request. The key issue is therefore identified as being the nature of natural death,[21] the presence or absence of human agency in the causing of death.

1.3 What is natural death?

If death is said to be natural, it is important to be able to examine what is meant by the term. The noun 'nature' and its adjective 'natural' may appear at first glance to be reliable words with clear meanings, but analysis of their use in medical matters, inter alia, soon reveals complexity. The social and cultural historian Raymond Williams states that ' "nature" is perhaps the most complex word in the language'.[22]

It is derived from the past participle (*natura*) of the Latin verb *nasci*, to be born. Williams shows that, historically, the word commences (like 'culture') as a quality or process, defined by a specific reference, which later became a noun. Williams identifies three areas of meaning:

> (i) The essential quality and character of something, (ii) the inherent force which directs either the world or human beings or both; (iii) the material world itself, taken as including or not including human beings.[23]

However following the approach of Ludwig Wittgenstein it is fruitful to ask: how is the term used in modern medical practice, rather than: what

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[21] See also a paper entitled "On the nature of nature" Jacob Klein (given at St John's College, Annapolis, Maryland, USA on 28/2/64) whose title parodies the problem of meaning for the word 'nature'. (unpublished).

[22] See Williams, R. (1985). Keywords: a vocabulary of culture and society. New York, Oxford University Press. pp 219-224 for a discussion of the complexity of meaning of the word 'nature'.

[23] Idem.

does the word natural mean?[24] There are four main terms in current usage in the medical context: natural history, natural therapy, natural causes, and natural death.

It is clear that for many there is a notion of nature as a moral construct, where nature is governed by forces or laws which should also be recognised and obeyed by human beings[25] (see natural law[26]), or that in natural therapy, substances which are extracted from nature, rather than being man-made, are inherently safer or healthier. For instance, one of the fastest growing so-called alternative or complementary therapies is naturopathy.

If the term natural is understood in an extreme way, as for example in the Hobbesian sense of 'man's natural condition',[27] then a completely barren scenario is conjured up, of unprotected life at the mercy of the rigors of the natural world. Death would occur with unrelieved pain and suffering, which was presumably the reality for many of our ancestors. There can be no serious modern proposal of natural death, in these terms, as an absolute goal in its own right, and it seems without question that a large range of therapeutic (and hence 'unnatural') interventions will be required to ensure comfort, dignity and some degree of autonomy and

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[24] One of the major tenets of the philosopher Ludwig Wittgenstein is the notion of language games, and the need to seek meaning in usage. Wittgenstein, L. (1953). Philosophical investigations. New York, Macmillan.

[25] See a series of papers addressing the question posed in series of articles entitled "Can nature serve as a moral guide?" Hastings Center Report, 26(6) 1996, pp 21-7. The introduction (assumedly written by Daniel Callahan but not directly attributed to him) states the following: 'a greater attention to nature will help inoculate us against that silliest of all modern views: that our deepest values and institutions are nothing more than social constructs, dissoluble at will.' Leon Kass believes that this role that Callahan proposes for nature is better invested in religious traditions also stating that ' "natural" knowledge may be very useful in selecting our means, but not in discerning our ends; and it is utterly useless in deciding how to balance one good against another'. Kass, L. (1996). "The troubled dream of nature and as a moral guide." Hastings Center Journal 26(6): 22-24.

[26] See Stephen Buckle. Buckle, S. (1991). Natural law. A companion to ethics. P. Singer. Oxford, Blackwell: 161-174.

[27] See Thomas Hobbes, Leviathan, Hobbes, T. (1929). Leviathan. Oxford, Oxford University Press., Chapter 13. It should be noted that Hobbes also recognises man's social context, so that we are subject to the rigors of the natural world and each other (Stoffell personal communication).

independence during a person's dying. It is, however, desirable to work in harmony with the reality and meaning of death, and to that end, the recognition of natural limits to curative medical interventions is decisive. The course of a disease process, from preclinical or undetectable stages right through until remission, recovery or death is referred to as the natural history of that disease. It is usually understood that the natural history describes the course of biological events without modification by treatment, but also may encompass the course which proceeds relentlessly when treatment is ineffective.

'Natural causes', in the forensic context of death causation, means death without intervening human agency.[28] The term 'natural death', with regard to end of life decision-making and 'natural death' legislation, has also been taken to mean death without obstruction by medical intervention, which, in the setting of a terminal illness, would only have the effect of prolongation of the dying process. This is a causal construct, in that death is then seen to be caused by the underlying disease or injury, not the abatement of life sustaining treatment. So treatment abatement decisions may be seen as having two contradictory causal positions: either removing an obstacle to natural death, or causing death, which is then not due to natural causes, but attributable to the treatment abatement itself. As has been seen, this causal tension has occupied a great deal of ethical and legal reasoning on end of life issues, usually framed in the killing versus letting die, acts versus omissions debate.

Natural Death Acts (see next chapter) reinforced in statute the pre-existing common law right to refuse medical treatment in the setting of impending death. There is an underlying theme of the need to bolster patients' rights to refuse treatment, redressing a power imbalance between doctors and

[28] See for instance the quote from the British Columbia Crown Counsel Policy Guidelines: "withholding or withdrawing treatment means .... discontinuing or not intervening with medical procedures to prolong life beyond its *natural length.*" (italics added). Parliament of Canada (1995). Of Life and Death: Report of Special Senate Committee on euthanasia and assisted suicide. Ottawa, Minister of Supply and Services Canada. At p40. For a discussion of natural causes of death in a respirator withdrawal case see Schneiderman, B. (1996). "A Winnipeg Inquest: a case of natural death or physician assisted suicide?" Manitoba Law Journal 24: 365-380. The term 'natural causes' is used ubiquitously in coronial enquiries.

their patients. It has often been argued (wrongly in this writer's view) that these legislative instruments allowed for so-called 'passive euthanasia'.[29] They acknowledge incurability, terminality, and consequently by implication, they recognise a natural dying process and death. By the phrase 'natural death' the legislators appear to have meant a death that is, from the patient's personal point of view, unencumbered by treatments that could only postpone the moment of an imminent death.

Justice Thomas, a New Zealand judge, made the following statement in his judgment in the case of *Auckland Area Health Board v Attorney-General,* where the court was being asked to consider the removal of ventilatory support from a patient with very severe Guillain-Barré syndrome:

> Medical science and technology has advanced for a fundamental purpose: the purpose of benefiting the life and health of those who turn to medicine to be healed. It surely was never intended that it be used to prolong biological life in patients bereft of the prospect of returning to an even limited exercise of human life. Nothing in the inherent purpose of these scientific advances can require doctors to treat the dying as if they were curable. Natural death has not lost its meaning or significance. It may be deferred, but it need not be postponed indefinitely.[30]

Thomas' view of natural death here appears to be that death is an inevitable consequence of being, and he is making it clear that the law does not require medical practitioners to treat the dying with curative intent. Death is the inevitable outcome of an inexorable underlying process.

However, within medicine itself there is no clear agreement on forensic aspects of the natural death concept. The majority of palliative care

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[29] See Cica, N, Williams G. A Clumsy Attack on Territories. The Australian, 22 October 1996. They write 'Legislation has operated for some time in the Northern Territory and the ACT - as well as in Victoria and South Australia - explicitly allowing this kind of "euthanasia". One effect of the passage of the Andrews Bill could be that the territories lose the power to amend or replace their existing "passive voluntary euthanasia" legislation.'

[30] The court allowed the cessation of ventilatory support. *Auckland Area Health Board v Attorney-General* [1993] 1 New Zealand LR at 253.

practitioners, and all of their peak bodies, maintain the position that in clinical practice, provided that the prevailing standards of the field are adhered to, the process of dying is neither hastened nor prolonged. Death is therefore natural in a *forensic* sense, that is it results from natural causes. However, there is a growing view, particularly in the health professions, that there are now very few natural deaths because they are mostly orchestrated[31] by medical decisions. At the very least timing and mode of death, if not the main cause (disease or injury) are now determined, wholly or in part by human intervention. For example, in 1997, Kuhse et al conducted a survey of a cross sectional sample of the Australian medical work force to study attitudes to end of life care and decision-making.[32] Their work was based on the approach taken by van der Maas and co-workers, which generated the first data about the incidence of euthanasia in the Netherlands, where a legal channel for such practices exists.[33] In these studies euthanasia is categorised as a type of *medical decision at the end of life* (MDEL), this term encompasses:

> all decisions by physicians concerning courses of action aimed at hastening the end of life of the patient or courses of action for which the physician takes into account the probability that the end of life of the patient is hastened.[34]

Two of the other categories (in addition to euthanasia) are: firstly, administration of 'high' doses of opioids that: 'almost certainly would

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[31] See Brian Stoffell, "Orchestrating Death" in preparation.

[32] Kuhse, H., P. Singer, et al. (1997). "End of life decisions in Australian medical practice." Medical Journal of Australia 166: 191-196.

[33] Van der Maas, P. J., J. J. M. Van Delden, et al. (1991). "Euthanasia and other medical decisions concerning the end of life." Lancet 338: 669-674.
Pijneneborg, L., J. M. v. Delden, et al. (1994). "Nationwide study of decisions concerning the end of life in general practice in the Netherlands." British Medical Journal 309: 1209-1212.
Van der Maas, P. J., G. Van der Wal, et al. (1996). "Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995." New England Journal of Medicine 335(22): 1699-1705.

[34] Van der Maas, P. J., J. J. M. Van Delden, et al. (1992). Euthanasia and other medical decisions concerning the end of life. Amsterdam, Elsevier.

shorten the life of the patient' and secondly, decisions in which: ' "life-prolonging" treatment was withheld or withdrawn'.[35]

The Australian authors reported that some kind of end of life decision was made in 64.8% of cases. The largest sub-group was 'alleviation of pain and suffering through the administration of opioids in sufficient doses to hasten death'- 30.9% (with a stated intention to hasten death in 6.5%), followed by 'decision not to treat' - 28.6% (with an explicit intention to hasten death stated in 24.7%).[36] This study was based on doctors' perceptions and interpretations of their management and decision-making for the most recent patient who died under their care in the year prior to the completion of the study questionnaire. There was no attempt to validate these impressions, and the results should be viewed with caution. However, at the very least, they show that these general practitioners and non-palliative care specialists considered themselves to be making significant contributions to the cause of death of their dying patients, far in excess of what most palliative care specialists would expect.[37] In a recent survey of Australian surgeons, 36% reported having administered drugs in higher doses than those required to control symptoms, with the intention of hastening death.[38]

It therefore seems clear that there is a widespread belief that not only do most deaths occur in a medical settings, but that they commonly involve some kind of decision which causes or partly causes the death. Indeed, even the diagnosis of death (which might seem to be a fairly firm

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[35] Idem.

[36] By the demonstration of such a high incidence of so-called 'medical decisions at the end of life' (65% of the deaths studied by Kuhse et al), that all have the same outcome of causing death, it is presumably hoped that the case for the legalisation of voluntary active euthanasia is advanced by undermining existing medical practice, which is thereby shown to be inconsistent in both its principles and processes. Euthanasia accounted for 1.8% of cases, and in 3.5% life was ended without the patient's request.

[37] Ashby, M. (1997). "The fallacies of death causation in palliative care." Medical Journal of Australia 166: 176-177.

[38] See The Age, 13th May 2000 reporting on a national survey of 992 surgeons undertaken by Dr Charles Douglas of Newcastle at the Annual Scientific meeting of Royal Australasian College of Surgeons in Melbourne.

endpoint) can be shown to have changed its criteria in history, influenced by a wide range of societal factors apart from the obvious one, of medical technology.[39] Scrutiny of the medical certification of death can also show, that even today, with a significant fall-off in routine autopsy rates, cause of death is often somewhat arbitrarily entered on death certificates, and the multifactorial nature of death causation may be important here.[40]

Palliative care literature and practice is infused with a notion of the 'naturalness' of death in an *existential* sense,[41] that is death is an inevitable consequence of living and dying is a normal part of the life cycle. Palliative care practice is therefore based on the recognition of a natural dying process and death. The wilful obstruction of this process may well

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[39] Powner, D. J., B. M. Ackerman, et al. (1996). "Medical diagnosis of death in adults: historical contributions to current controversies." Lancet 348: 1219-1223.

[40] Brumley, personal communication.

[41] It seems to the author that the adjective 'existential' is employed in palliative care discourse to describe death as natural in a broader sense than mere empirical causality, based largely on forensic data. 'Existential' means 'of or pertaining to human existence' (Shorter Oxford English Dictionary, Oxford, Clarendon Press, 1987). The historical uses of the word are outlined by Williams, op cit, pp123-125.
Death is natural because it is an inevitable consequence of being. Acknowledgement of this seemingly obvious fact is an important component of the 'good' or 'good-enough' death (see page 129, footnote 265). It underpins palliative care practice when helping patients and families to make important choices concerning, for example, medical treatment and location of care.
The acknowledgement of death as natural and inevitable also allows important spiritual, emotional and practical issues to be addressed. There is the opportunity to say important farewells, clarify relationships, arrange personal affairs, decrease family burden, to be understood in context of one's life, values and preferences, also to make contributions to others: of gifts, time and knowledge (see Annals of Internal medicine 2000;132:825-32).
This use of the word 'existential' in the palliative care context needs to be distinguished from 'existentialist philosophy' (see Kierkegaard, Husserl, Sartre). This 'tendency' in philosophy consists of what has been termed 'semi-rigorous' enquiry of the human 'predicament'. Everything exists but human beings are aware of their existence. The problem of being takes precedence over those of knowledge or language, and is specifically pitted against idealism and any type of determinism. Man is faced with choices in an 'absurd' world (one where there are no predeterminants of human character or goals) and in which no meaning can be discovered over and above one's own existence, and non-existence. Any existentialist worldview therefore confronts the reality of death without consolation. Man's foreknowledge of certain death and extinction generates anxiety and is not amenable to reason or faith.
This line of enquiry does not appear to inform modern palliative care practice, even though death, or non-existence, is a common point to both. In palliative care this 'existential' perspective appears to encompass spirituality, searches for meaning, and the possibility of transcendence (depending on the patient's beliefs, social context and psychological state). Such consolation does not appear to arise from writers such as Jean Paul Sartre and Albert Camus. It may be the case that the distinction between *forensic* and *existential* is best understood as death viewed externally and objectively, as opposed to a subjective shared human experience.

involve a futile denial of one of life's fundamental realities, and it can be argued that the consequences for the individual and for society are both unkind and wasteful. Relief of symptoms and suffering is the guiding imperative in the palliative and terminal modes. It can then be proposed that any medical intervention which is not for a comfort endpoint represents obstruction of this process, and may be seen as unduly burdensome or futile. The term absolute futility[42] is used when a proposed procedure has little or no chance of achieving its immediate technical objective. If however there is a chance of temporary success in achieving the technical objective, but the procedure is considered to be disproportionate to the underlying clinical situation, futility is described as relative or situational. Medical decision making is based on proportionality; by a careful assessment of the therapeutic ratio, of desirable beneficial effects weighed against unwanted side effects. The therapeutic ratio may be unfavourable per se, or unfavourable in the circumstances, due either to prevailing factors which result from the disease, or other aspects of the patient's situation. The probability of a favourable outcome from a given treatment may be low, but is rarely non-existent.

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[42] This is the author's categorisation of futility with regard to medical treatment. Futile treatment is judged solely in medical terms, by asking what we know of the outcome of a proposed medical treatment, from such data as can be found in the medical literature, and local experience. Once this is established, a discussion can take place with the patient or agent about whether to proceed in the particular case. There may be situations in which futile treatment may be declined, contrary to the wishes of the patient or agent.

This is, of course, a highly contentious topic with a large literature. This mainly revolves around who determines futility (patient or medical team) and what criteria apply to make this decision. Futility is often mobilised in discussions about cardio-pulmonary resuscitation. See:
Tomlinson, T. and D. Czlonka (1995). "Futility and hospital policy." Hastings Center Report 25(3): 28-35.
Capron, A. (1994). "Medical futility: strike two." Hastings Center Report 24(5): 42-3.
Sugarman, J. (1996). "Talking about futility." Hastings Center Report 26(3): 41. A review of Schneiderman, L. and N. Jecker (1995). Wrong Medicine. Baltimore, Md, Johns Hopkins University Press.
Also Collins, D. (1999). Medical futility and rationing health resources. Festchrift fur Erwin Deutsch, Carl Heymans Verlag.

1.4 Goals of care and transitions from curative to palliative and terminal care

If modern palliative care medicine is based on the recognition of a natural dying process and death, there needs to be a way of incorporating this recognition into decision-making and clinical practice. This can be done by adopting a framework of three phases (or modes), based on goals of care, which have been described in the management of life-threatening illness: curative, palliative and terminal.[43] (see table 1, and appendix 1). In the curative phase all efforts are directed towards cure or sustainable remission. A high level of adverse effects and even a significant chance of treatment-related mortality may be accepted for curative treatment. In the palliative phase the disease is deemed to be incurable and progressive, and the goals of care are modified in favour of comfort, quality and dignity. Active treatment of the underlying disease in order to improve quality of life may still occur, and any putative prolongation of life which may occur as a result is regarded as a welcome spin-off, but not the prime object of the therapy in question. In terminal phase, death is believed to be hours or days away, and no treatment-related toxicity is acceptable. Whereas artificial hydration and alimentation may well be a part of care in the palliative phase, it is not usually part of terminal care.

Decreasing levels of treatment-related toxicity are then considered acceptable as the goals of treatment change with the transition from curative mode to palliative and terminal modes of care in a life-threatening illness (see Table 1). In all three phases, therapeutic interventions must be proportionate to the circumstances, and, specifically, treatment-related toxicity should be reduced to virtually nil in terminal care.

The key issue becomes the cut off between reasonable and realistic medical treatment, and its corollary of futile, intrusive or burdensome treatment which obstructs a natural dying process. In practice the

[43] Ashby, M. and B. Stoffell (1991). "Therapeutic ratio and defined phases: proposal of an ethical framework for palliative care." British Medical Journal 302: 1322-1324.

question becomes: at what level of the therapeutic ratio do we stop treatment, and what degree of influence does the setting have on decisions based on the same therapeutic ratio? When it is recognised that no further curative treatment is possible, acknowledgement of a natural dying process allows the slate to be wiped clean, and only those measures which are required for comfort and dignity are left in place or introduced as indicated. This can be done in positive rather than negative language, instead of removing each therapeutic intervention as part of an anguished opting out process.

It is both philosophically and medically contentious to suggest that it is possible to predict accurately when a person will die. In fact medical prognostication has recently been the subject of work by Christakis et al, which shows wide discrepancies between what doctors predict and actual survival of patients.[44] Although hard and fast objective clinical criteria for the onset of the terminal phase or mode are not available, the recognition of a natural dying process is central to the ethics and practice of palliative care. Impending death, when a person is said to be 'dying' or 'actively dying', is recognised by a combination of clinical and behavioural features, although they may all go unnoticed or be denied. The objective clinical evidence consists of declining appetite, weight loss, recumbency, lassitude, physiological systems failure, disease progression, vital organ failure. There is an associated decrease in oral intake which usually ceases altogether as the patient's conscious state lapses. Although very variable and personal, the overt or covert psychological evidence may consist of anticipatory grief, emotional withdrawal, and future planning which acknowledges the impending death – e.g. funeral planning, by either the person who is dying and/or family members.

In the recognition of a person's dying process, no suggestion is made that the dying days are of lesser worth than non-dying ones, or that the dying have different rights to those which they previously enjoyed before they

[44] Christakis, N. B. and E. B. Lamont (2000). "Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study." British Medical Journal 320: 469-73.

were dying. Caution should be exercised in appearing to label people as 'dying', with attendant dangers of depersonalisation. Rather their dying process is acknowledged by all, and their vulnerability increases our care and respect, but does not lead us to give treatment that confers no benefit upon them. Even those who support a fairly strong sanctity of life position with regard, for example, to treatment and nutritional abatement recognise the process of dying, as Ramsey, Dyck, Grisez and Boyle have argued, a distinction is possible, and necessary, between those persons who are dying and those who are not.[45]

All of the above senses may be explicit or implicit when the term 'natural death' is used. The place of man and human intervention in conceptions of nature and the natural world is pivotal. If human agency is dismissed, then the possibility remains of either nature itself or divine providence being the agent.[46] In the practice and philosophy of palliative care, a natural death is understood in a way much closer to the legislative intent evident in the Natural Death Acts; namely a death that fits a person's perceptions of their end, free from medical treatments that can do nothing but prolong an unwanted process. But there is also a strong sense of death

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[45] Ramsey, P. (1976). "Prolonged dying: not medically indicated." Hastings Center Report 6: 14-17.
Dyck, A. (1984). "Ethical aspects of care for the dying incompetent." Journal of the American Geriatric Society 32: 661-664.
Grisez, G. and J. Boyle (1979). Life and death with liberty and justice. Notre Dame, Indiana, University of Notre Dame Press.
Boyle, J. (1991). Journal of Medicine and Philosophy 16: 475-494.

[46] The Christian position lines up with the natural death construct, in the sense that death absent human agency is important if the belief is that the timing and manner of one's death has to be entirely a matter of God's will.

being an important part of living, that preparation for death (where this is possible) should occur in a holistic way, and that the embracing of life's end, and final things is an important expression of human dignity.[47]

[47] See Richard Reoch's beautiful book (published in Australia by Hodder and Stoughton): Reoch, R. (1997). Dying well: a holistic guide for the dying and their carers. London, Gaia Books. And his reference to the Natural Death Movement Albery, N. (1993). The Natural Death Handbook. London, Virgin Books.

1.5 Table 1

Priorities In Three Modes Of Treatment Of Incurable Disease

Mode	Supremacy	Survival	Toxicity	Measures to support physiological systems	Artificial hydration and alimentation
Curative	Survival	Prolong	May be high	Yes	Yes
Palliative	Quality and value of life	No	Low	Maybe (for quality only)	Maybe (for quality only)
Terminal	Quality and value of life	No	None (or minimal)	No	No

CHAPTER 2
PALLIATIVE MEDICINE IN PUBLIC POLICY AND THE LAW:
PART 1: AUSTRALIA

2.1 Introduction

Over the past two decades Australia has been active in the field of end of life policy and law-making. Socially and clinically, there has been an early and effective involvement in the hospice and palliative care movement. As might be expected from history and tradition, state and territory parliaments have dealt with the issues by incorporating many British and American ideas, with cross-fertilisation from other Commonwealth countries. Whilst there is evidence in parliamentary debates that a British pragmatic influence has led to a general wariness of over-reliance on law and ethics, there has been a clear willingness in certain jurisdictions to seek effective legislative responses to complex moral and ethical issues.[48] Although federal (Commonwealth) governments have had a significant policy and funding role in palliative care service provision initiatives, typically each state and territory has adopted its own approach, with federal institutions only making a relatively recent entrance into this area with the overriding of the Northern Territory's euthanasia legislation.[49] In what follows, the legal and policy initiatives in the various jurisdictions will be reviewed, with the object of analysing what they have had to say about palliative care, death causation and agency.

Modern legislative activity in Australia concerning end of life issues commenced in 1983, with the passage of the *Natural Death Act* in South Australia. In the sixteen years to 1999, seventeen pieces of legislation or state government guidelines have been initiated, resulting in nine acts of

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[48] Lanham, D. (1993). Taming death by law. Melbourne, Longman.

[49] Australian states and territories are separate criminal jurisdictions. Western Australia, Tasmania and Queensland have criminal codes. States also have responsibility for many aspects of health provision, notably hospitals, and health legislation. Hence, most legislative initiatives have been from the states and territories.

parliament, with one (in the Northern Territory) being overridden (see Table in section 2.8). Most of them have not been primarily concerned with palliative care, but rather with patients' rights to refuse treatment, appointment of a medical agent(s), and advance directives. However, palliative care has always emerged in the deliberative process, especially in the relevant parliamentary inquiries, as the single most important solution to most of the issues raised in favour of the legalisation of euthanasia. Certain aspects of palliative care have also been specifically addressed in legislation, notably in the definition sections of the Acts, and in terms of the scope of what an agent or substitute may refuse on a patient's behalf. Specific aspects of palliative care has been directly concerned in two statutes: one (SA) Act explicitly deals with palliative care and causation[50], and another (NT) legislated for medical assistance to die, and required palliative care to have been offered as part of the process of rendering such assistance.[51]

2.2 South Australia 1983 and 1991-1995

The passage of the *Natural Death Act* 1983 (SA) (NDA)[52] marks the entry of Australia into a legal and public policy trend which originated in the United States in the mid 1970s, in which the prime objective was to facilitate the abatement of life-saving or prolonging treatment in certain defined circumstances for incompetent persons. The South Australian Act was based on the landmark *Natural Death Act* 1976 (California).[53] NDA

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[50] *Consent to Medical Treatment and Palliative Care Act* 1995 (SA). See chapter 6.3. For full text of the Act, see appendix 28.

[51] *Rights of the Terminally Ill Act* 1995 (NT). See Northern Territory section of this chapter.

[52] For full text of Act, see appendix 28.

[53] 'Natural death' was taken, in broad terms, to mean death unencumbered by so-called *extraordinary measures* (see below), which only have the effect of prolonging the dying process, in the setting of a terminal illness.

There appears to have been remarkably little discussion of the complexities of meaning of the word 'natural' in this context in the political deliberations which preceded the eventual passage of the Act in South Australia. For an invaluable summarising account of the passage of NDA (SA), see Tideman, S. (1985). A bioethical study: foregoing life-sustaining treatment. Ethical issues in medical approach and practice, South Australia (1960-1985). Thesis for Degree of BM, BS, Department of Medicine, The Flinders University of South Australia. Similarly, in the USA, where the ethical and legal concept

(SA) enabled a terminally ill person, over the age of 18 years, to make a declaration stating that he/she did not wish to have extraordinary measures[54] in the event of a future terminal illness.[55] There was widespread anxiety expressed at the time that it would lead to litigation and euthanasia,[56] neither of which proved to be the case. In fact there was evidence that NDA (SA) was neither widely known amongst public or health professions, nor often used.[57]

In 1991, further public interest in end of life issues led to another state parliamentary select committee, moved by Jennifer Cashmore, former Liberal MP and Health Minister. She was responding to growing public concern, but was clear about also having some personal reasons for wishing to explore this area, resulting in part from the experiences of those

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originated, there appears also to have been remarkably little analysis of the term at the time of the passage of the Californian Act. See Weir, R. F. (1989). Abating treatment with critically ill patients. Ethical and legal limits to the prolongation of life. New York, Oxford University Press. Chapter 5: Planning for the possibility of treatment abatement, pp 170-213. See also short articles in the Hastings Center Report at the time (1976-7): Garland, M. (1976). "The right to die in California: politics, legislation, and natural death." Hastings Center Report 6: 5-6. and Lebacqz, K. (1977). "Commentary on "Natural Death'." Hastings Center Report 7: 14.

[54] In NDA (SA), extraordinary measures are defined as: 'medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation.' This characterisation of treatments into ordinary and extraordinary has been challenged in ethics and law, and largely abandoned. (See Margaret Somerville of McGill University, Montreal, advice to the Minister for Health, South Australia, December 1992, concerning the Consent to Medical Treatment and Palliative Care Bill, personal communication). The main thrust of Somerville's argument is that the use of such a distinction in the characterisation of medical treatments allows 'the introduction of subjective judgements under the façade of their being objective assessments.' From a medical point of view the distinction derives from moral theology, is unsustainable on any clinical or scientific basis, constitutes no distinction at all, and is of no practical use. The underlying points of proportionality and patient choice which are articulated in the extraordinary/ordinary discussions would be widely accepted as reasonable, but do not require the characterisation of treatments to be viable and important.

[55] In NDA (SA), terminal illness was defined as: 'any illness, injury or degeneration of mental or physical faculties-
(a) such that death would, if extraordinary measures were not undertaken, be imminent;
(b) from which there is no reasonable prospect of a temporary or permanent recovery, even if extraordinary measures were undertaken.'

[56] Tideman, op cit.

[57] Ashby, M. and M. Wakefield (1993). "Attitudes to some aspects of death and dying, living wills and substituted health care decision-making in South Australia: a public opinion survey for a parliamentary select committee." Palliative Medicine 7: 273-282. Ashby, M., M. Wakefield, et al. (1995). "General practitioners and living wills." British Medical Journal 310: 230.

close to her.[58] The terms of reference of the select committee show that the emphasis in public policy and debate had shifted from treatment abatement to considering end of life issues more broadly, and in particular to focus on palliative care. The Committee was to examine:

> (a) the extent to which both the health services and the present law provide adequate options for dying with dignity,
> (b) whether there is sufficient public and professional awareness of pain relief and palliative care available to patients facing severe prolonged pain in a terminal illness; whether there is adequate provision of such services; whether there is sufficient public awareness of the Natural Death Act and, if not, what measures should be taken to overcome any deficiency; and
> (c) to what extent, if any, community attitudes towards death and dying may be changing and to what extent, if any, the law relating to dying needs to be clarified or amended.

In the media, and in public debate, this select committee was seen as being largely about euthanasia, which is not an unreasonable inference given the above terms of reference. However, the committee did indeed receive substantial evidence in support of the legalisation of euthanasia, but chose to focus most of its attention on the health system, and its capacity for

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[58]Jennifer Cashmore's account of this is given in an unpublished paper entitled: "Parliaments and public opinion: a case study from the South Australian Parliament. 'The Law and Practice Relating to Death and Dying' House of Assembly Select Committee 1990-1992 and the *Consent to Medical Treatment and Palliative Care Act* 1995." Presented by Jennifer Cashmore (Member for Coles 1977-93) to the Australasian Study of Parliament Group 17th Annual Conference 1995 'The Public Face of Parliament', Parliament House, Adelaide, September 16th 1995.

See also Cashmore's political autobiography for an account of her commitment to end of life issues. Cashmore, J. (1991). A chance in life. Adelaide, Ferguson Publications. This stems largely from conversations with her husband (the writer Stewart Cockburn) about the deaths of his wife and another family member. Cockburn is also the biographer of Sir Mark Oliphant, distinguished physicist and former governor of South Australia whose wife had a protracted dying process with dementia. Both men favoured euthanasia (Oliphant was a patron of the South Australian Voluntary Euthanasia Society). These private experiences and debates (Cashmore is not in favour of legalising euthanasia) informed the public contribution, an important example of how, particularly in the area of end of life issues, the personal can inform and motivate the public and the political. Although this might not always have good consequences (eg, when someone imports prejudice or anger from a personal experience into his or her public life), in this instance it informed an attitude of open engagement and genuine interest in the issues, compassion for the patients and families, and great integrity, which appeared to be shared by the whole Select Committee.

appropriate care and decision-making at the end of life.[59] Its legal recommendations resulted in the *Consent to Medical Treatment and Palliative Care Act* (SA) 1995 (CMTPC).[60] This Act replaced both the *Natural Death Act* 1983 (SA) and the *Consent to Medical and Dental Treatment Act* 1985 (SA). It lays down in statute the broad principles of consent to medical treatment (including emergencies) of adults and children, and allows for both the appointment of agents (enduring medical power of attorney) and advance directives.[61] Most of these steps were innovative in the Australian context, but had already been extensively enacted in various forms in the state jurisdictions of the United States. However, the Act contains the first statutory articulation of the principle of double effect in palliative care in the world, and is also the only statute to include palliative care in the title.[62] It incorporated statutory support for good palliative care in legislation governing the whole practice of medicine.

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[59] See the paper by SAVES (South Australian Voluntary Euthanasia Society) entitled 'None so blind: a rejoinder to the Second Interim Report (SIR) of the Select Committee on the Law and Practice Relating to Death and Dying', 21 August 1992, to see the views of advocates of euthanasia, who felt that the select committee avoided the issue. The select committee members were mostly opposed to euthanasia, but wished to achieve improvements to care and decision-making at the end of life for all South Australians, and their recommendations had to have a reasonable chance of getting through parliament, which they eventually did.

[60] Parliament of South Australia (1991). First Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliamentary Paper No 164, Adelaide.
Parliament of South Australia (1991). Second Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliamentary Paper No 185, Adelaide.

[61] The author also worked with a small group to study advance directives as a consequence of the passage of the legislation providing for these. The Advance Directive Study Group consisted of Michael Ashby, Margaret Brown, Eric Gargett, John Fleming, Justin Beilby and Melanie Wakefield. Although no final formal version was adopted (see the brief and rather disappointing format in the Act itself) a number of studies were generated as result of this collaboration: an advance directive format proposal for South Australia Ashby, M. (1994). "A proposed advance directive format for South Australia." Australian Health Law Bulletin 2(7): 89-91.
Also a small separate publication of the views of general practitioners about living wills Ashby, M., M. Wakefield, et al. (1995). "General practitioners and living wills." British Medical Journal 310: 230.
A paper in a law periodical summarises the South Australian situation as seen by the author at the time. Ashby, M. (1994). "Law reform on death - over but not out." Australian Health Law Bulletin 2(7): 81-85.

[62] Part 3, division 2- the care of people who are dying. This section will be considered further in chapter 6.3. It gives indemnity to practitioners who administer treatment to relieve pain or distress 'even though an incidental effect of the treatment is to hasten the death of the patient.' It also deals with causation specifically in the context of palliative

2.3 Victoria

In the mid-1980s considerable community interest in end of life issues was mainly generated by the dying process of a former water-ski champion, John McEwan, who had been rendered quadriplegic in a diving accident.[63] It was widely felt that his common law right to refuse medical treatment had been overridden, and that medical paternalism was preventing people from rejecting medical treatment and hence dying 'with dignity'. The Social Development Committee of the Victorian Parliament was charged with the task of examining the issues. Its first report set out the terms of reference, which focussed on whether there was a right to die, definitions of death and treatment abatement. Of the ten thoughtful and wide-ranging contributions which made up the discussion paper, none was by a palliative care specialist.[64] However, the inquiry went on to hear evidence about palliative care from experts, and alarming public and professional evidence about the limited access to it in Victoria at that time. The inquiry recommended legislation to 'clarify and protect' the common law right to refuse medical treatment, and the creation of an offence of medical trespass, rather than a right to die. The emphasis shifted from euthanasia to palliative care, and the second and final report included a Health Department discussion paper (with recommendations) on palliative care.[65]

The resulting legislation, the *Medical Treatment Act* 1988 (Victoria) (MTA), is unique in that it focuses on a refusal of treatment certificate for a current condition. Subsequent legislation provided for the appointment of an agent, and alternate agent, to issue a certificate on the person's behalf

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interventions and treatment abatement, and included a saving provision to exclude euthanasia.

[63] Tonti-Filippini, N. (1992). "Some refusals of medical treatment which changed the law in Victoria." Medical Journal of Australia 157: 277- 279.

[64] Parliament of Victoria. Social Development Committee (1986). First report on inquiry into options for dying with dignity. Incorporating a discussion paper: a range of views on options for dying with dignity. Melbourne.

[65] Parliament of Victoria. Social Development Committee (1987). Inquiry into options for dying with dignity. Melbourne.

should he/she become incompetent.[66] MTA distinguished between medical treatment in general and palliative care:

> (2) This Act does not apply to palliative care and does not affect any right, power or duty which a medical practitioner or any other person has in relation to palliative care.

Palliative care was defined as including:

> (a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or
> (b) the reasonable provision of food and water.

It seems hard to see how this distinction is defensible, in that palliative care comprises medical treatment like any other, and the limitations of characterising treatments have already been exposed in the extraordinary/ordinary debate. The distinction is not required in order to achieve the objective set out in the preamble: namely, to 'ensure that dying patients receive maximum relief from pain and suffering'. There seems little doubt that the wording was constructed in support of palliative care. [67] Presumably, the statute does not remove a person's common law right

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[66] In the state of Victoria, under the *Medical Treatment Act* 1988, a person can issue a refusal of treatment certificate for a "current condition". *The Enduring Power of Attorney (Medical Treatment) Act* 1990 (EPA) together with the *Medical Treatment (Agents) Act* 1992 (MTAA) enable an adult person of sound mind to appoint an agent (or alternate agent) who can refuse medical treatment for a 'current condition' on behalf of the patient when he or she becomes incompetent. See Mendelson, D. (1992). "The Medical Treatment (Enduring Power of Attorney) Act and assisted suicide: the legal position in Victoria." Bioethics News 12(1): 34-39. for the full text of the Act, see Appendix 28.

[67] *Consent to Medical Treatment and Palliative Care Act* 1995 (SA) also retained the distinction between palliative care and medical treatment generally. An agent is not authorised to refuse 'the natural provision or natural administration of food and water; or the administration of drugs to relieve pain or distress.' The reason for this is that the select committee felt that it required such a level of will and self-determination that no agent could or should exercise this power on someone else's behalf. See Bailey-Harris, R. (1992). The Consent to Medical Treatment and Palliative Care Bill 1992: a legal appraisal. Death and dying SA 1992. L. F. Wray. Adelaide, Dietrich Bonhoeffer International Institute for Bioethical Studies Inc.

Danuta Mendelson also believes that the drafting was intended to promote palliative care, and develops this point at length Mendelson, D. (1993). "Medico-Legal Aspects of the 'Right to Die' Legislation in Australia." Melbourne University Law Review 19: 112-152.

Mendelson has subsequently written: 'I have interpreted this provision as having an objective of ensuring that the concept of palliative care encompasses a wider range of

to reject any treatment, palliative or not.[68] The clause on food and water, in particular, has generated significant confusion, but the Act has never been tested in case law, and the extent of its influence on clinical practice is questionable, although it may have reinforced defensive attitudes towards treatment abatement decision-making. However, it may also have been an attempt to placate those who might have argued that medically assisted hydration and nutrition can never be abated, especially by an agent.[69]

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treatments than what was regarded as the traditional care for the dying. Defining palliative care in terms of medical treatment was important at the time, ie, before proper development of palliative medicine in Victoria, however, the unfortunate consequence of the statutory definition is the apparent distinction between palliative care and any other medical treatment.'(personal communication).

[68] Danuta Mendelson comments further:

'I think the situation is a little more complicated. The Act is called "Medical Treatment Act" and s3, which defines "medical treatment", expressly excludes "palliative care", as do Schedule 1 and Schedule 3, which were amended in 1994. The formula is identical in both Schedules: "The refusal of palliative care is not covered by the Medical Treatment Act 1988". In both Schedules, the respective Refusal of Treatment Certificates contain provisions for refusal of medical treatment but "instructions as to palliative care" (again, the latter amended in 1994). The implication, according to the rules of statutory interpretation, is that under the statute the patient can give instruction about the kind of palliative care he/she wishes to receive, but cannot refuse it outright.

Section 4 titled "Other legal rights not affected" is ambiguous. Subsection (1), which is directed to patients, states that "This Act does not affect any right of a person under any other law to refuse medical treatment." It suggests that the patient still has the common law right to refuse medical treatment. The question is, whether the legislature meant "not affect any right of a person under any other law to refuse medical treatment" as defined under MTA, or *any/all* medical treatment, including palliative care. I would suggest that they meant only the former, because s.4(2), amended in 1994, is specific to palliative care, it says: "This Act does not apply to palliative care and does not affect any right, power or duty which a registered medical practitioner or any other person has in relation to palliative care."

This provision is specific to palliative care and statutorily vests in the medical practitioner or any other person "right, power or duty" which these persons have "in relation to palliative care". I am not sure what exactly these rights, powers or duties are, but the golden rule of interpretation would suggest positive duties of treatment rather than negative obligation to withhold treatment from a refusing patient. It seems to me that if the legislature wished to preserve the common law right to refuse palliative care (not that such right has been specifically affirmed by common law courts), it would have said so clearly and unambiguously.' (Mendelson, personal communication).

[69] Some hold the view that abatement of nutrition and fluids should only be at the express direction of a competent patient, and never by any form of agency or advance directive. Few would go as far as Justice Scalia of the US Supreme Court and assert that all treatment abatements by competent persons constitute suicide, per Annas. Annas, G. J. (1996). "The promised end-constitutional aspects of physician-assisted suicide." New England Journal of Medicine 335: 683-687.

The legislators addressed causation with regard to treatment abatement by the provision for statutory protection to doctors who comply with their patients' treatment refusals, but despite the scope of the preamble,[70] did not seek to deal with causation and palliative care interventions, and indeed appear to have specifically excluded it.

2.4 Queensland 1995-1998

Concerns about causation and palliative care by health practitioners and the public, led to palliative care being addressed in the 1995 revision of Queensland's criminal code. The Final Report of the Criminal Code Review Committee included the following provision:

> s69. Palliative Care
> A person is not criminally responsible if he or she gives such palliative care as is reasonable in the circumstances, for the control or elimination of a person's pain and suffering even if such care shortens that persons life, unless the patient refuses such care.

Scott points out that the wording that was incorporated into the proposed revised code on this matter, in Section 82, *Criminal Code Bill* 1995 (Qld), is much wider in its application, and allows for a person to be absolved of all criminal responsibility where the medical treatment (including pain relief) was "reasonable, having regard to the patient's state at the time and all the

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[70] The preamble of the *Medical Treatment Act* 1988 sets out the objectives of its principal provision, namely refusal of treatment, but the six objects range far more widely, and encompass strongly supportive statements about palliative care, pain and symptom relief:
'Preamble.
The Parliament recognises that it is desirable-
(a) to give protection to the patient's right to refuse unwanted medical treatment;
(b) to give protection to medical practitioners who act in good faith in accordance with a patient's express wishes;
(c) to recognise the difficult circumstances that face medical practitioners in advising patients and providing guidance in relation to treatment options;
(d) to state clearly the way in which a patient can signify his or her wishes in regard to medical care;
(e) to encourage community and professional understanding of the changing focus of treatment from cure to pain relief for terminally-ill patients;
(f) to ensure that dying patients receive maximum relief from pain and suffering.'

circumstances" and was "for that patient's benefit".[71] However, these proposed provisions were not enacted.

Public and professional surveys undertaken by Cartwright and colleagues as part of background research for legislation for agency and advance directives, in the *Powers of Attorney Act 1998* (Queensland), also revealed major concerns about palliative care.[72]

2.5 New South Wales 1993

New South Wales has not enacted legislation in this field, but the state's health department did promulgate interim guidelines in 1993.[73] These are mainly concerned with process, and focus on decision-making, patient autonomy, cardio-pulmonary resuscitation and advance directives. There is a small section on palliative treatment and double effect.[74]

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[71] Scott, R. (1995). "When is medical treatment for abortion, pain relief or euthanasia actionable?" Queensland Law Society Journal 25: 449-468. At 455.

[72] Extensive community and professional consultation showed that general practitioners expressed high levels of educational need in palliative care, specialists gave higher than expected rates of concern about addiction with opioids, and nurses reported very substantial dissatisfaction with analgesic orders in palliative care. Steinberg, M., M. H. Parker, et al. (1996). Report to the General Practice Evaluation Programme of the Department of Human Services. End of life decision-making: perspectives of general practitioners and patients. Brisbane, Department of Social and Preventative Medicine. The University of Queensland Medical School.
Steinberg, M. A., C. M. Cartwright, et al. (1996). Report to the Research and Development Grants Advisory Committee of the Department of Human Services and Health. Healthy ageing, healthy dying: community and health professional perspectives on end-of-life decision-making. Brisbane, Department of Social and Preventative Medicine. The University of Queensland Medical School. See also quotes from evidence in chapter 3.

[73] NSW Health (1993). Dying with dignity: interim guidelines on management. Sydney, Health Department, New South Wales Government.

[74] The NSW guidelines, in a section entitled 'Drugs which ameliorate symptoms but present a risk of shortening life' state that: 'In general, when correctly prescribed, drugs which ameliorate symptoms, should not present a risk of shortening life. In rare instances, there may be circumstances where large doses of drugs are required to provide adequate sedation for terminal agitation, pain relief or other severe uncontrollable symptoms.'

The following general principles should apply when an Attending Medical Officer prescribes drugs, such as benzodiazepines, major tranquillisers or opioids, which ameliorate symptoms but present a risk of shortening life. The Attending Medical Officer and the patient/advocate must have:
1. Considered the full range of foreseeable effects
2. Knowingly accepted whatever risk of death is entailed and
3. Found the risk to be justified in the light of the symptoms being experienced by the patient.'

2.6 Northern Territory and Commonwealth 1988, and 1996-1997[75]

The Northern Territory was the only jurisdiction in Australia, after South Australia, to pass NDA/living will legislation, with the *Natural Death Act* 1988 (NT). The act was based on the South Australian model, but in addition it allowed the person to specify which extraordinary measures they wished to reject in the event of a future terminal illness. In this the Territory legislators were moving more towards an advance directive format, a trend which was already well underway in the USA by the time the legislation was passed. It had been recognised there (as was the case in South Australia subsequently), that the NDA 'living will' generation of instruments was too narrow in application and not specific enough in terms of which treatments or interventions are to be abated.

In July 1996 the *Rights of the Terminally Ill Act* (RTI) of the Northern Territory came into force, being the first such statute successfully enacted in the world. RTI had been passed by the Legislative Assembly by a margin of 15-10 after a legislative passage of only four months. This included a Select Committee and forty-nine amendments during the Committee stage. In September 1996, the Liberal member for the federal seat of Menzies in Victoria introduced a private member's bill (*the Euthanasia Laws Bill 1996*) into the House of Representatives to override this act. It was passed by the House but was referred by the Senate Selection of Bills Committee to one of its standing committees: the Senate Legal and Constitutional Legislation Committee.

This parliamentary enquiry received a record 12,577 submissions, the large majority (93.3%) of which were interpreted as being against euthanasia. This is a startling result from a country which expresses 70-80% support for euthanasia in opinion polls, and suggests an orchestrated anti-euthanasia submission campaign. The Committee made no recommendation to the Senate because the matters were the subject of a private member's bill and hence, of a conscience vote. However, a

[75] For the author's discussion of this legislation, see Ashby, M. (1995). "Hard Cases, Causation and Care of the Dying." Journal of Law and Medicine 3(2): 152-160.

majority of senators supported the bill and advised that the Commonwealth parliament had the requisite legal powers to override RTI. Minority reports against the bill were filed by several senators, including the only medical practitioner on the committee, Dr Bob Brown, Australian Greens Senator for Tasmania. He argued that palliative care and euthanasia lie on a moral or clinical 'choice' spectrum, and hence euthanasia is not different in kind in a moral or clinical sense from palliative care.[76] The Senate passed the Bill and it was given royal assent in March 1997.

It is worthy of note that palliative care is listed merely as one of a series of arguments against euthanasia (as did also the Canadian Senate).[77] However, in the report's summary it is stated that: 'Both sides of this debate recognise the fundamental importance of effective and available palliative care'.[78]

The continued federal funding for palliative care was the subject of questions in both houses and a motion in the Senate during the passage of the *Euthanasia Laws Act*. RTI therefore ceased to operate after a few months.[79]

2.7 Conclusion

This survey of public policy and legal deliberations on end of life issues in Australia shows that there has been steady activity in various jurisdictions over the past two decades. The approach in each state and territory has

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[76] Roger Hunt, palliative care physician in South Australia Hunt, R. (1994). Palliative care: the rhetoric-reality gap. Willing to listen, wanting to die. H. Kuhse. Melbourne, Penguin: 115-137. Also Russel Ogden writing about AIDS in British Columbia, Canada, have both agreed with this position. Ogden, R. (1994). "Palliative care and euthanasia: a continuum of care." Journal of Palliative Care 10: 82-85.

[77] See Chapter 3.2.2, pp 59-66.

[78] Parliament of the Commonwealth of Australia. Senate Legal and Constitutional Legislation Committee (1997). Consideration of Legislation Referred to the Committee. Euthanasia Laws Bill 1996. Canberra, Senate Printing Unit, Department of the Senate, Parliament House.

[79] Kissane, D. W., A. Street, et al. (1998). "Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia." Lancet 352: 1097-102.

been different, but a number of themes emerge. The legislative approaches are summarised in table one. South Australia, Victoria, Queensland and the Northern Territory have been both proactive and innovative in this area. The ACT has enacted legislation that is modelled on that of Victoria. Tasmania and Western Australia explored the Victorian model, but no legislation was passed. The Victorian model is unusual and narrow in application. Both the distinction between palliative care and other medical treatment, and inclusion of nutrition and hydration provision in the palliative care definition are problematical and limiting. NSW has rejected the legislative approach so far, and instead has promulgated guidelines, as has Tasmania.

In all these legislative initiatives, public policy has primarily concerned itself with treatment abatement, agents and directives, and has followed a pattern similar to the USA, that is commencing with provision for living wills in natural death acts, proceeding to provision for the appointment of substitute health care decision making agents and advance directives. The notable exception was, of course, the *Rights of the Terminally Ill Act* (RTI) of the Northern Territory. Whatever the instrument, take-up rate and hence utility have been very low, no matter how much publicity and public education was attempted. In South Australia, for instance, this has been extensive, although press coverage appeared to evaporate once the contentious aspects of the debate were resolved in the parliamentary debate. It seems that public opinion in favour of such instruments, which has always been high, is not matched by public use of them. And none of the pieces of legislation discussed here has yet been the subject of case law, indicating that either use is low, or the fears articulated during their enactment have proved groundless, or a combination of both. Furthermore, no prosecution has ever been initiated for appropriate pain and symptom relief or treatment abatement decisions. This would appear to lend some weight to the aphorism 'if it ain't broke, don't fix it', which would without doubt have widespread support amongst the medical profession, many of whom believe that these matters should be entrusted to the privacy and trust of the doctor-patient relationship. However, too much negative evidence about experiences of poor care and decision-

making at the end of life was heard in all the above proceedings for that relationship, critical though it is, to be the sole determinant of what should and should not be done. It may be that the symbolic and educational value of the instruments enacted in Australia over the past two decades will continue to outweigh their practical use. Perhaps this is a desirable outcome, whereby parliaments and the law make their contribution to the social movement for change in the care of dying people.

Legislative activity now seems to have slowed up, the last being another select committee in South Australia, which did not recommend to parliament that legislation to allow for euthanasia be introduced,[80] and a report of the Community Development Committee of the House of Assembly, Parliament of Tasmania.[81] Euthanasia has been the main initial issue in the public policy deliberations, but the focus has invariably shifted to palliative care, even if this public attention has not always been accompanied by the level of resource allocation to match some of the rhetoric. It is, however, unhelpful and unreasonable to castigate the political world for not understanding or caring about these issues. In fact the level of political interest has been high and the compassion real.[82]

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[80] Parliament of South Australia (1996). Inquiry into the Voluntary Euthanasia Bill 1996: Twelfth Report of the Social Development Committee. Parliamentary Paper 186, Adelaide. The Quirke *Bill* in 1996, and the Levy *Bill* in 1999 (the latter giving rise to the Social Issues Committee) both had the same result.

[81] Parliament of Tasmania. Community Development Committee. House of Assembly (1998). Report on the need for legislation on voluntary euthanasia. 1998 (No 3), Hobart.

[82] Health ministers such as Jennifer Cashmore, Don Hopgood and Martyn Evans, Michael Armitage and Diana Laidlaw in South Australia, and Rob Knowles in Victoria, stand out for their support, enthusiasm and genuinely deep understanding and concern for palliative care. All the select committees have impressed with their care including, for instance, willingness to visit the terminally ill and listen to them and their families.

Many of the barriers to good care and decision-making with dying people lie just as much within the professions and health system itself as with policy makers, fuelled by the diversity of wider community attitudes and expectations.

2.8 Table

Australian Legislation And Guidelines On Death And Dying Issues

STATE	YEAR	TITLE	TYPE OF LEGAL INSTRUMENT	COMMENT(S)
South Australia	1983	Natural Death Act	Living Will	Over 18, sound mind Future terminal illness No extraordinary measures
Northern Territory	1988	Natural Death Act	Living Will	As above, can specify extraordinary measures you do not want
Victoria	1988	Medical Treatment Act (MTA)	Refusal of Treatment Certificate	Refuse treatment of current condition
Victoria	1990	Medical Treatment (Enduring Power of Attorney) Act (EPA)	Enduring Power of Attorney	
Tasmania	1990	Medical Treatment and Natural Death Bill (failed)	Refusal of Treatment Certificate	Victorian Model
Western Australia	1991	Report on Medical Treatment for the Dying Law Reform Commission of WA Project No 84	Refusal of Treatment Certificate (Victorian Model)	Recommends - 1. Enduring power of attorney 2. Appointment of Guardian 3. Substituted judgements first, then best interests 4. Palliative care and cause of death 5. Definition of death None implemented yet
Victoria	1992	Medical Treatment (Agents) Act (MTAA)	Alternate agent	Appointment of a substitute for first agent

STATE	YEAR	TITLE	TYPE OF LEGAL INSTRUMENT	COMMENT(S)
Queensland	1992	Final Report Criminal Code Review Committee	Criminal Code Revision	Palliative Care not a cause of death Schedule 3, Section 69
NSW	1993	Dying with Dignity (NSW Dept of Health)	Interim Guidelines on Management	Guidelines for use in NSW hospitals re care of dying, advance directives, advocates and resuscitation
ACT	1993	Voluntary and Natural Death Bill Private Members Bill (Michael Moore) withdrawn	Legislation of Physician Assisted Suicide and Medical Aid in Dying	1. Withdrawal or refusal of treatment 2. Power of Attorney 3. VAE (including by proxy)
Victoria	1993	Medical Treatment (Assistance to the Dying) Bill	A proposal to legalise medical assistance for the terminally ill who wish to end their own lives	Public Launch (Kuhse and Syme) of Private Member's Bill - no member has yet adopted it
ACT	1994	Medical Treatment Bill - Draft	Refusal of Treatment Certificate and Medical Power of Attorney	Victorian Model Promotion of pain control
South Australia	1995	Consent to Medical Treatment and Palliative Care Act	- Medical Power of Attorney - Advance directive - Non-culpability clause for palliative care treatment	First known statutory endorsement of so-called 'directive' of double effect in palliative care
Northern Territory	1996	Rights of Terminally Ill Act	Provision for assistance to die	World's first 'euthanasia' legislation. Overridden 1997
Tasmania	1996	Dying with Dignity	Guidelines on the care and management of people who are dying	Modelled on NSW Guidelines (as above)
Commonwealth	1997	Euthanasia Laws Act	Forbids Northern Territory to legislate for euthanasia	Over-rides Rights of the Terminally Ill Act, Northern Territory
Queensland	1998	Powers of Attorney Act	- Appoint one or more agents - Advance directive	

CHAPTER 3
PALLIATIVE MEDICINE IN PUBLIC POLICY AND THE LAW:
PART 2: INTERNATIONAL

3.1 The United Kingdom

The jurisdiction of England and Wales [83] has tended to avoid the passage of legislation on end of life issues, preferring to rely on the common law, case law and the doctor-patient relationship. There was no serious attempt to put in place living will or advance directive legislation until recently, although such directives have been deemed to be lawful by a senior judge, but the degree to which they are binding has not been tested. The country has been the birthplace of the hospice and palliative care movement, and, in contrast to the United States, has adopted a non-legalistic, practical and pragmatic approach to such matters. However, two cases in particular, in the 1990's generated widespread public interest and concern, resulting in a parliamentary enquiry.

3.1.1 Bland

The case of Anthony Bland brought end of life issues into the public eye in Britain in 1993 when the House of Lords (sitting in its role as the highest appeal court in England and Wales) decided that artificial hydration and alimentation might lawfully be ceased.[84] Bland was a victim of the Hillsborough football ground disaster in 1989, and as a result of crush injuries received, was in a persistent vegetative state (PVS). Despite acknowledging that death would ensue, the Law Lords reasoned that there was a distinction between acts and omissions, that the cause of death was the underlying condition, that his best interests were not served by continuing his

[83] The United Kingdom has three separate jurisdictions: England and Wales, Scotland, and Northern Ireland. For the purposes of this chapter, all references will be to England and Wales.

[84] *Airedale NHS Trust v Bland.* [1993] 1 ALL ER 821-896.

nasogastric tube sustenance (which was considered to be medical treatment like any other, and not different in kind), and that there was no duty to continue it in this particular case. There was agreement with the decision by the family, the hospital, the inferior courts who considered the case, and a large proportion of the British public, although public 'right to life' protests were made up to, and at the time of his death. Throughout the case, the judges involved showed great humanity towards the family, and humility in their role, both in terms of not wishing to intrude into clinical practice, and requesting parliament to consider the whole area of end of life decision-making. Ultimately many saw this as a right outcome, but disputed the reasoning, in particular the notion that such treatment abatement decisions are distinguishable from euthanasia. The Law Lords were adamant that their holding did not create a precedent for euthanasia. The judgment is long, complex and scholarly, and most of the assumptions have subsequently been examined and challenged.[85] The case revealed the intellectual fragility of such decisions, with particular regard to agency and causation. Although the case did not specifically address palliative care, it did comment extensively on it, and some aspects of the judgments are relevant to it.[86]

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[85] Mendelson, D. (1995). "Jurisprudential aspects of withdrawal of life support systems from incompetent patients in Australia." Australian Law Journal 69: 267-275.
Collins, D. (1994). "Prescribing limits to life-prolonging treatment." New Zealand Law Journal: 246-251.
Singer, P. (1994). Rethinking life and death. Melbourne, Text.
Dworkin, R. (1993). Life's Dominion. An argument about abortion and euthanasia. London, Harper Collins. Gerber, P. (1994). "Withdrawing treatment from patients in a persistent vegetative state." Medical Journal of Australia 161: 715-717.
I am indebted to Michael Freeman, Professor of Law, University College, London, for giving me access to his unpublished paper "Death's Dominion", in which the best interests test is supported, but the active-passive distinction is not.

[86] See for example Lord Goff: 'A doctor may, when caring for a patient who is, for example, dying of cancer, lawfully administer pain killing drugs despite the fact that he knows that an incidental effect of that application will be to abbreviate the patient's life. Such a decision may properly be made as part of the care of the living patient, in his best interests; and, on this basis, the treatment will be lawful. Moreover, where the doctor's treatment of his patient is lawful, the patient's death will be regarded in law as exclusively caused by the injury or disease to which his condition is attributable.' *Airedale NHS Trust v Bland* [1993] 1 All ER at 868.

3.1.2 *Cox*

In 1992, Dr Nigel Cox, a rheumatologist at the Royal Hampshire County Hospital in Winchester, UK, administered a lethal dose of potassium chloride to a Mrs Lilian Boyes, who was dying of advanced rheumatoid arthritis with multiple complications, and for whom he had been caring for 13 years.[87] He was convicted of attempted murder, but given a suspended sentence and was required by the General Medical Council to undergo palliative care training.[88] The case received widespread publicity, and once again there was substantial public support for the doctor and his action. Pamela Ferguson (academic lawyer at the University of Dundee) compares the Cox case to that of Anthony Bland, and a Scottish persistent vegetative state abatement case (Janet Johnstone), and concludes that it is 'ironic' that Mrs Boyes was the only patient who requested assistance to die, but her doctor was convicted of attempted murder.[89]

3.1.3 *House of Lords, Select Committee on Medical Ethics*

Parliament did indeed take up the challenge of the courts, with the appointment of the House of Lords Select Committee on Medical Ethics in March 1993.[90] It recognised that the nature of medical practice had changed substantially as a result of demographics, technical progress, and changes in public expectations, notably concerning autonomy. The Committee recommended that there be no change to the law to permit euthanasia or 'mercy killing'. They strongly endorsed patients' rights to refuse treatment, and

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[87] For a similar case in Halifax, Nova Scotia, Canada, see Robb. Robb, N. (1997). "Death in a Halifax hospital: a murder case highlights a profession's divisions." Can Med Association Journal 157(6): 757-762.

[88] Dyer, C. (1992). "Rheumatologist convicted of attempted murder." British Medical Journal 305: 731.

[89] Ferguson, P. R. (1997). "Causing death or allowing to die? Developments in the law." Journal of Medical Ethics 23: 368-72.

[90] House of Lords (1994). Report of the Select Committee on Medical Ethics. London, HMSO. Full details: House of Lords. Report of Select Committee on Medical Ethics. Volume I - Report (HL Paper 21-I); Volume II - Oral Evidence (HL Paper 21-II); Volume III - Written Evidence (HL Paper 21 - III) (HMSO, London, 1994).

supported advance directives and a new judicial forum with the power to make medical decisions for incompetent persons, both of these last two issues being taken up by the present British government in a new report by the Lord Chancellor's Department.[91] Palliative care was also strongly supported, and the doctrine of double effect was accepted as a sound ethical basis for pain and symptom relief:

> Double effect is not in our view a reason for withholding treatment that would give relief, as long as the doctor acts in accordance with responsible medical practice with the object of relieving pain or distress, and without intention to kill. [92]

3.2 Canada

3.2.1 Rodriguez

It was the case of the late Sue Rodriguez,[93] a young woman from British Columbia with motor neurone disease, which has probably done more than any other single event to bring the issue of euthanasia, and thereby palliative care to the attention of Canadians.[94] Her quest to have medical assistance to end her life led to a court case which resulted in the narrow rejection (5-4) of her appeal to the Supreme Court of Canada. It was a very public

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[91] The Lord Chancellor's Department (1997). Who decides? Making decisions on behalf of mentally incapacitated adults. London, HMSO., Dyer, C. (1998). "Living wills put on statutory footing." British Medical Journal 316: 9.

[92] The wording is interesting in that double effect is surely being argued here to be *the* reason why palliative treatment is ethical (see chapter 6 for further discussion of double effect as it is usually applied to palliative care).

[93] *Rodriguez v British Columbia* (Attorney General). [1993] 3 SCR 607.

[94] Ashby, M. (1997). The Rodriguez case and care of the dying. Canada-Australia: towards a second century of partnership. K. Burridge, L. Foster and G. Turcotte. Toronto, Carleton University Press.
Birnie, L. H. and S. Rodriguez (1994). Uncommon will: the death and life of Sue Rodriguez. Toronto, Macmillan Canada.
Keyserlingk, E. W. (1994). "Assisted suicide, causality and the Supreme Court of Canada." McGill Law Journal 39: 708-718.
Somerville, M. A. (1994). "Death talk in Canada: the Rodriguez Case." McGill Law Journal 602: 602-617.

dying process, with extensive media coverage, an authorised biography, a film, and both political and academic analysis during her life and afterwards. She was 44 years old when she finally died at her home in February 1994, allegedly with the assistance of an (unnamed) medical practitioner, in the presence of her prominent friend and supporter, Svend Robinson MP.

The case was constructed around a claim that Sue Rodriguez's Charter rights under the Canadian Charter of Rights and Freedoms were infringed by the Canadian Criminal Code prohibition of assistance to commit suicide.[95] The majorities in the three courts which considered her case argued that a blanket prohibition was appropriate and proportionate to prevent the harms that would be caused (to other members of society) if it were removed. They supported the doctrine of double effect as the major ethical underpinning of the distinction between palliative care and euthanasia. Claims of discrimination on the basis of her inability to kill herself without assistance did not prevail. Both chief justices (MacEachern CJ and Lamer CJ) involved dissented in her favour and laid down a series of safeguarding conditions which should be met before her request could be granted. This case gave rise to a wide-ranging Senate enquiry into end of life issues,[96] which is considered in some detail below.

3.2.2 Latimer

In 1995 another prominent and tragic case of so-called mercy killing was unfolding in the province of Saskatchewan. Robert Latimer killed his severely handicapped daughter Tracy by carbon monoxide poisoning. At his trial he entered a defence of necessity, because of her intractable severe pain, although there was disagreement about the quality of her pain management. He was

[95] Australian states, (and the constituent states of the United States) have their own criminal codes, whereas in Canada the criminal code is federal.

[96] Parliament of Canada (1995). Of Life and Death: Report of Special Senate Committee on euthanasia and assisted suicide. Ottawa, Minister of Supply and Services Canada.

convicted of second degree murder, the Supreme Court required a retrial due to jury irregularities, and he was convicted again, and sentenced to the minimum statutory sentence for this crime, confirmed again on appeal, which provoked heated public debate.[97]

3.2.3 *Canadian Senate Report*

The Canadian Senate report made recommendations under six chapter headings: palliative care, pain control and sedation practices, withholding and withdrawal of life-sustaining treatment, advance directives, assisted suicide, and finally euthanasia.[98]

3.2.3.1 Palliative care

The committee heard substantial evidence concerning the present state of palliative care in Canada, with strong endorsement of what was being done already, but concerns about lack of coverage of services. It recommended that provinces make palliative care: 'A top priority in the restructuring of the health care system'.

It also specifically endorsed better training and research and the promulgation of guidelines and standards. However, the report expresses initial surprise that palliative care emerged as such an important practical issue at all:

> The Committee began its hearings with the expectation that the large majority of its time would be spent on the ethical, social, legal and medical issues that have come to be associated with assisted suicide and euthanasia. However, at the outset of the hearings, it became apparent that a major and unanticipated issue was the question of alternatives to assisted suicide and euthanasia.[99]

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[97] Schneider, C. E. (1998). "Hard cases." Hastings Center Report 28(2): 24-6.

[98] Parliament of Canada (1995). Of Life and Death: Report of Special Senate Committee on euthanasia and assisted suicide. Ottawa, Minister of Supply and Services Canada.

[99] Ibid, p17.

These words are highly significant, as they suggest that for this group of senators, which included a prominent medical practitioner, the departure point in public policy concerning death and dying was the necessity for euthanasia, without any initial consideration of palliative care. It was not that palliative care was failing, rather that its role was either unknown or underestimated. The final report included a whole appendix on palliative care services which had not originally been scheduled.

3.2.3.2 Pain control and sedation practices

The Minister of Justice and Attorney General of Canada, the Honourable Allan Rock stated that palliative care practice was legal and that the distinction between palliative care and euthanasia is 'relatively clear' in law:

> The Criminal Code does not require futile treatment, nor does it require capable patients to accept treatment which they do not want. Similarly, necessary palliative care which is carried out in accordance with generally accepted medical practice is not prohibited by the Code whether or not this treatment results in the death of the patient.[100]

He then goes on to make this alarmist statement about morphine and causation, albeit with regard to professional and public perception rather than the law itself:

> When is it permissible to keep prescribing morphine when you know within the next six hours it will cause death? The underlying disease will not kill the person, however the treatment for the pain will. At present, that is shrouded in obscurity.[101]

[100] Ibid, p 26.

[101] Ibid, p 27.

Witnesses seemed united in their agreement on the need for proper pain and symptom management, and on how uneven this was due to lack of knowledge and fears of causing death or inducing addiction. One of the most influential palliative care physicians in Canada, Neil MacDonald, addressed the assumption that morphine can cause the death of patients, by pointing out that tolerance occurs to the respiratory depressant effects of the drug. Nevertheless, the committee decided to operate on the assumption that palliative interventions may shorten life, and to recommend legislation to clarify the practice: 'of providing treatment for the purpose of alleviating suffering that may shorten life'.

The majorities in both appellate courts in Rodriguez, and on the Senate Select Committee, therefore maintained that a moral and legal distinction between palliative care and euthanasia could be upheld on the basis of double effect and intention, along much the same lines set out by the Law Reform Commission in 1982.[102] Mr Justice Sopinka, writing for the majority in *Rodriguez* states:

> The administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes active contribution to death by any standard. However, the distinction drawn here is based upon intention - in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause death....In my view distinctions based upon intent are important, and in fact, form the basis of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear. [103]

[102] Law Reform Commission of Canada (1982). Protection of life: euthanasia, aiding suicide and cessation of treatment. Ottawa, Minister of Supply and Services Canada.

[103] *Rodriguez v British Columbia* (Attorney General). [1993] 3 SCR 607.

3.2.3.3 Total sedation

This term was defined by the Canadian Committee as: 'the practice of rendering a person totally unconscious through the administration of drugs without potentially shortening that person's life'.[104]

The witnesses quoted in the report offered a consensus that the practice was widespread, and an accepted part of palliative care. There were some concerns expressed about the possibility of a fine line existing between total sedation practices and voluntary active euthanasia, presumably based on causation. However, the definition expresses a certainty which cannot be defended clinically: namely, that such practices at least have the *potential* to influence the timing of death.[105]

As with most facets of its deliberations, the committee noted an absence of empirical data and guidelines and called for these to be produced.

3.2.3.4 Withholding and Withdrawal of Life-sustaining Treatment

The Committee recognised uncertainty in law concerning treatment abatement, which had previously been raised by the Law Reform Commission of Canada in 1982, but no legislative action ensued. The landmark *Nancy B* case[106] in the Quebec Superior Court clearly asserted the right of a

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[104] Parliament of Canada, op cit p33.

[105] In clinical terms it is important to specify the circumstances in which such sedation is deployed. It is one thing to use sedatives during the last few days or hours of a person's life for the comfort and dignity of a person who has terminal restlessness. This is part of normal palliative care practice world-wide. It is another to sedate a person, who is not dying, possibly to the point of coma, for an indefinite period, as a means of relieving symptoms which have not responded to the specific measures which are normally effective for the condition in question. This is not a part of accepted palliative care practice, and it would be hard to suggest that this is distinguishable from euthanasia in a forensic causal sense (see chapters 5 and 6), unless it is temporary treatment, such as the parallel with heavy sedation occasionally used for severe fitting, or when a person is being ventilated on an intensive care unit.

[106] *Nancy B v Hôtel-Dieu de Québec* (1992), 86 DLR (4th) 385.

person to reject medical treatment, even if this would result in her death. The Committee received some evidence from proponents of an absolute sanctity of life position that no life support measure, including artificial hydration and alimentation, could be abated, but these views did not prevail. The Committee accepted the views that there was no moral distinction between withholding or withdrawing treatment and that artificial hydration and alimentation constituted medical treatment like any other. They took a narrow definition of futility[107] as needing to be absolute (completely ineffective), but this did not include treatment that may be effective but whose results are deemed undesirable. If futility can be shown, treatment abatement may prevail even for a competent person against their wishes. The importance of competence assessment was underlined, substitute decision making was endorsed and those provinces which had not passed advance directive legislation were urged to do so.

3.2.3.5 Assisted suicide and euthanasia

These were considered in separate sections of the report. A majority of the Committee favoured the status quo of both remaining illegal. However, they did not preclude allowing assistance in suicide in future if more information were available to show that it was needed. With regard to euthanasia, they recommended that while it should remain a criminal offence, if elements of compassion and mercy could be demonstrated, for either voluntary or non-voluntary euthanasia, then a less severe penalty than the mandatory life sentence required by the Criminal code for murder in Canada should apply.

Minority recommendations were made by three (of the seven) senators on the committee to allow assistance in

[107] See chapter 1.3 for further consideration of the controversial topic of futility.

suicide and by two of those to allow euthanasia in certain highly regulated circumstances. Mullens has pointed out the significance of Senator Wilbert Keon, an eminent cardiothoracic surgeon from Ottawa, changing from opposition to qualified support for physician-assisted suicide, as a result of the hearings. He was apparently swayed by the poignant testimony of witnesses seeking this avenue for their relatives.[108]

3.3 USA

In 1997, the Supreme Court of the United States in a unanimous decision (9-0), decided that state legislation prohibiting physician-assisted suicide was constitutional.[109] Mendelson has pointed out that the court's decision-making was grounded in Anglo-American common-law tradition which has historically disapproved of both suicide and assisted suicide.[110] Although at first sight this might seem to lay the matter to rest, commentators have argued that the judgments are less decisive than they appear, and still leave the way open for a different conclusion in future.[111] Justice Sandra Day O'Connor indicated that, if, in a future scenario, a satisfactory way of relieving suffering (viz terminal sedation) could be demonstrated to be unavailable, then medical assistance to die might be

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[108] Mullens, A. (1996). Timely death. Considering our last rights. Toronto, Alfred A Knopf.

[109] *Vacco v Quill*. 117 S.Ct. 2293 (1997) and *Washington v Glucksberg*. 117 S.Ct. 2258 (1997).

[110] Mendelson, D. (1997). "Quill, Glucksberg and palliative care - does alleviation of pain necessarily hasten death?" Journal of Law and Medicine 5: 110-113.

[111] Kleinman, A. (1997). "Intimations of solidarity? The popular culture responds to assisted suicide." Hastings Center Report 27: 34-36.
Capron, A. M. (1997). "Death and the court." Hastings Center Report 27: 25-29.
Coope, C. M. (1997). ""Death with dignity"." Hastings Center Report 5(27): 37-38.
Kaveny, M. C. (1997). "Assisted suicide, the Supreme Court, and the constitutional function of the law." Hastings Center Report 27: 29-34.
Dworkin, R. (1996). Sex, death, and the courts. New York Review of Books. XLIII: 44-50.
Dworkin, R. (1997). Assisted suicide: what the court really said. New York Review of Books. XLIV: 40-44.
Dworkin, R., T. Nagel, et al. (1997). Assisted suicide: the philosopher's brief. New York Review of Books. XLIV: 41-47.

permissible.[112] Orentlicher has argued that by endorsing terminal sedation they are allowing a form of euthanasia which is less preferable than physician-assisted suicide because it can be applied to incompetent patients without their consent.[113] The Court recognised the importance of palliative care and the need to remove any (state) impediments to its delivery, eg excessive drug regulatory bureaucracy and funding barriers.[114] Patrick Wall wrote a strong editorial in the world's pre-eminent specialist pain journal concerning the disturbing causal inferences made by the justices of the Supreme Court with regard to pain control.[115]

Voters in the state of Oregon voted against the repeal of the *Death with Dignity Act* in November 1997, thereby rendering physician-assisted suicide legal in that state.[116] Subsequent experience in Oregon appears to have been favourable although interpretations of reports vary,[117] and there are bills before the US Congress which seek to obstruct the practice of physician-assisted suicide, and thereby to override state legislation.[118] The massive SUPPORT study on end of life care in the USA also provides more indirect evidence of a high level of causal anxiety, as well as poor symptom control,[119] and a recent article about 'slow codes', where doctors

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[112] Burt, R. A. (1997). "The Supreme Court speaks: not assisted suicide but a constitutional right to palliative care." New England Journal of Medicine 337: 1234-1236.

[113] Orentlicher, D. (1997). "The Supreme Court and physician-assisted suicide: rejecting assisted suicide but embracing euthanasia." New England Journal of Medicine 337: 1236-1239.

[114] Burt, R. A. (1997). "The Supreme Court speaks: not assisted suicide but a constitutional right to palliative care." New England Journal of Medicine 337: 1234-1236.

[115] Wall, P. D. (1997). "The generation of yet another myth on the use of narcotics." Pain 73: 121-122.

[116] Woolfrey, J. (1998). "What happens now? Oregon and physician-assisted suicide." Hastings Center Report 28(3): 9-17.

[117] Chin, A. E., K. Hedberg, et al. (1999). "Legalized physician-assisted suicide in Oregon - the first year's experience." New England Journal of Medicine 340: 577-83.
Foley, K. and H. Hendin (1999). "The Oregon report: don't ask don't tell." Hastings Center Report 29(3): 37-42.

[118] Angell, M. (1999). "Caring for the dying - congressional mischief." New England Journal of Medicine 341(25): 1923-1925.

[119] Teno, J. M. (1999). "Lessons learned and not learned from the SUPPORT project." Palliative Medicine 13: 91-3.

and nurses 'go through the motions' of resuscitation for patients with little or no prospect of recovery, reveals further disturbing evidence of a causal concern leading to poor care and decision-making at the end of life, in this case, that it is seen to be better to be doing something than nothing, even though the attempt is futile. [120]

3.4 New Zealand

New Zealand has not sought to legislate in this area, but like all similar countries, has had to consider euthanasia,[121] and has had two notable legal cases which have brought end of life issues to the fore in public debate. Both were treatment abatement cases, one of a patient with Guillain-Barré syndrome,[122] the other concerning the abatement of renal dialysis.[123]

3.5 Conclusion

From the above review of the international scene, and the Australian experience outlined in the preceding chapter, it can be seen that a number of themes emerge:

- Public pressure for the legalisation of euthanasia is an international phenomenon. By and large, courts and parliaments have been more cautious, and have turned to palliative care as the avenue for the public policy response to community concern about the process of dying.

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[120] Billings, J. A. and S. D. Block (1996). "Slow euthanasia." Journal of Palliatve Care 12: 21-30.

[121] New Zealand Medical Association (1996). Report on euthanasia. Wellington, New Zealand Medical Association.

[122] *Auckland Area Health Authority v Attorney-General.* (1993) 1 NZLR 235-256.

[123] *Shortland v Northland Health Limited* (the *Rau Williams* case), David Collins, personal communication. Collins, D. (1999). Medical futility and rationing health resources. Festchrift fur Erwin Deutsch, Carl Heymans Verlag.

- Euthanasia is permitted in the Netherlands (although important the Netherlands experience is not within the scope of this thesis) and the state of Oregon, and was for a brief time also in the Northern Territory of Australia, but legislative initiatives elsewhere have so far failed.

- A number of influential legal cases concerning end of life decisions have come to superior courts, with parliamentary inquiries resulting in two countries (UK and Canada). Most of these are treatment abatement cases for non-dying persons who have permanent and very severe neurological damage. (*Nancy B, Auckland Area Health Authority,* and *Bland*). Only *Rodriguez* has sought prospective permission for assistance to die. A number of cases of unlawful 'mercy' killing cases have been brought (eg, *Cox*) but only one (*Latimer* in Canada) has resulted in serious custodial sanction.

- No cases have been brought which challenge internationally-accepted standards of palliative care practice.

- Of great importance for the ensuing consideration of causation in palliative care (see chapter 6), in most of the above political and legal deliberations, treatment abatement and palliative interventions have been assumed to cause death, but are allowed, as the public policy imperative is to relieve suffering and avoid prolongation of the process of dying.

- The distinction between palliative care and euthanasia has been based on intention, with recourse, despite robust challenges, to the so-called *doctrine of double effect*, which was invoked in the important common law case on this issue, *R v Adams*, (see chapters 4 and 6) which has been cited in nearly all the deliberations discussed in the first two chapters.

CHAPTER 4
OPIOIDS, SEDATIVES AND CAUSATION

4.1 Introduction

This chapter will examine the causal inferences which arise from discussions about the use of opioids and sedatives in palliative medicine. In all the judgments and parliamentary reports studied,[124] and in the reasoning cited in many leading legal cases,[125] it will be shown the usual conclusion has been that palliative care interventions and treatment abatement decisions may indeed constitute a cause of death, and this is largely based on assumptions about opioid use.

4.2 Prevailing professional attitudes

In a 1995 survey of specialist Victorian nurses, some respondents expressed views about causation in their practice which are concerning:

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[124] Parliament of Victoria. Social Development Committee (1987). Inquiry into options for dying with dignity. Melbourne.
Parliament of South Australia (1991). First Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliamentary Paper No 164, Adelaide.
Parliament of South Australia (1991). Second Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliamentary Paper No 185, Adelaide.
Parliament of South Australia (1992). Final Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Adelaide, Parliament of South Australia.
Parliament of South Australia (1996). Inquiry into the Voluntary Euthanasia Bill 1996: Twelfth Report of the Social Development Committee. Parliamentary Paper 186, Adelaide.
Parliament of the Commonwealth of Australia. Senate Legal and Constitutional Legislation Committee (1997). Consideration of Legislation Referred to the Committee. Euthanasia Laws Bill 1996. Canberra, Senate Printing Unit, Department of the Senate, Parliament House.
House of Lords (1994). Report of the Select Committee on Medical Ethics. London, HMSO.
Parliament of Canada (1995). Of Life and Death: Report of Special Senate Committee on euthanasia and assisted suicide. Ottawa, Minister of Supply and Services Canada.

[125] *R v Adams.* [1957] Crim LR 365; *Airedale NHS Trust v Bland.* [1993] 1 ALL ER 821-896; *Rodriguez v British Columbia* (Attorney General). [1993] 3 SCR 607; *Vacco v Quill.* 117 S.Ct. 2293 (1997); *Washington v Glucksberg.* 117 S.Ct. 2258 (1997); *Auckland Area Health Authority v Attorney-General.* (1993) 1 NZLR 235-256; *R v Cox* [1992] 12 BMLR 38 (Ognall J's instruction to the jury); *R v Latimer* [1995] 126 DLR4 203; *Latimer v The Queen* [1997] 142 DLR4 577.

> Surprisingly, even within the palliative care and cancer nursing communities, myths exist about the power of morphine to lead to respiratory distress and death in narcotic-tolerant patients. Of further concern is that some respondents consider the routine escalation of morphine doses in response to increasing pain, as active euthanasia. The knowledge and attitudes of nurses about euthanasia, and the use of morphine in particular, requires further exploration.[126]

In evidence gathered by Colleen Cartwright in Queensland, in a series of studies conducted in 1995 about end of life decision-making (in particular about advance directives and euthanasia), a number of typical anecdotes of causal impediments to the care of the dying are identified. When questioning nursing home staff the following extracts are striking.

> *Doctors are fearful of the law* and so intervene medically when nature would be kinder. We keep elderly residents with no quality of life alive with assisted feeding and medication. It is a problem endemic in western society under the guise of modern medicine. I don't think God invented medicine. [127]

> GP's appear to be more and *more concerned about legal implications re medication dosage.* Some GP's and some nurses do not appear to have come to terms with their residents/patients (their own) mortality and the need to find the balance between adequate pain relief and life shortening doses. Some GP's and nurses are reluctant to commence morphine due to concerns about addiction or starting the "downward spiral. [128]

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[126] Aranda, S. and M. O'Connor (1995). "Euthanasia, nursing and care of the dying; rethinking Kuhse and Singer." Australian Nurses Journal 3(2): 18-21.

[127] These comments are quoted from field notes of research performed by Colleen Cartwright and co-workers in August 1995 interviewing health professionals for two major reports on end of life issues in Queensland. This first comment is numbered 3067. (Cartwright personal communication).
This work has generated two reports: Steinberg, M., M. H. Parker, et al. (1996). Report to the General Practice Evaluation Programme of the Department of Human Services. End of life decision-making: perspectives of general practitioners and patients. Brisbane, Department of Social and Preventative Medicine. The University of Queensland Medical School.
Steinberg, M. A., C. M. Cartwright, et al. (1996). Report to the Research and Development Grants Advisory Committee of the Department of Human Services and Health. Healthy ageing, healthy dying: community and health professional perspectives on end-of-life decision-making. Brisbane, Department of Social and Preventative Medicine. The University of Queensland Medical School.

[128] Ibid no 3059.

> I have been placed in this situation many times. Especially with large amounts of morphine (IMI). The first time occurred when I was a first year student nurse. The RN asked me to administer another dose of prn IMI morphine. I did so, and the patient died within 20 mins. The RN made the comment: *"that must have been just enough to send him off". I was horrified at the time. It is something I will never forget.* [129]
>
> The patient had been given a large amount of morphine but as the family sat with the patient over a number of hours and watched her pain persist they progressively became more frustrated and 'very pushy' in regards to the nursing staff not giving her enough. Although she was receiving large doses it was difficult to explain we didn't want to *give her too much in case she stopped breathing.* [130]

A hospital doctor gave this view of pain relief in hospital work:

> I have prescribed pain killers for years without support of senior medical staff and often against nursing staff opinions. *The law should protect me* but basically turns a blind eye without involving "public opinion". [131]

And in the community survey, this comment was made:

> From what I've been told in the nursing profession DNR and active euthanasia (*by way of morphine overdose*) of the terminally ill has been going on without patient consent for a long time. It is far better to have this issue discussed openly rather than carried out in secret. [132]

Margaret Brown, health social sciences researcher at the University of South Australia cites two representative quotes from recent research:

> Doctors and nurses can hasten death by medication. This is what is happening in hospices. Most people admitted (to hospices) 14 days before death – the treatment is bumped up – they know what is going to happen.

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[129] Ibid no 3094

[130] Ibid no 5223

[131] Ibid no 6232

[132] Ibid no 1010 F30-39

> ...and getting that across to doctors is very hard sometimes especially when they start using emotive terms like killing morphine doses and all the rest of it, you think well that's not my intention. [133]

Dr Ruth Redpath, in part of evidence from the perspective of a palliative care physician, a perspective which had not hitherto been heard by the Social Development Committee of the Victorian Parliament in 1986 [134], stated:

> For whatever reason, it is in-built in the hospital system that the dangerous drug cupboard, that was present long before the worry about drug addiction.....is locked at all times.....and [it] has been inculcated into everybody that morphine is dangerous.....The inhibitions that have built up about the danger of morphine have been present for a long time. It is something we must come to grips with.[135]

The Committee heard much evidence of poor pain control and the difficulties of care at the end of life, which led to an ongoing public policy effort to improve matters. All the above provides anecdotal evidence of causal concerns about treatment abatement and palliative care practice.

As has already been seen, there is also widespread anecdotal evidence that significant obstacles to the good care of dying people can be shown to arise from deeply entrenched myths that morphine causes addiction and death.[136] Countries like the United Kingdom and Australia have made

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[133] Margaret Brown personal communication, Advance Directive Study 1997 and current research on dying in an acute hospital setting.

[134] Redpath, personal communication.

[135] Parliament of Victoria. Social Development Committee (1987). Inquiry into options for dying with dignity. Melbourne.

[136] Reidenberg, M. M. (1996). "Barriers to controlling pain in patients with cancer." Lancet 347: 1278.
Zenz, M. and A. Willweber-Strumpf (1993). "Opiophobia and cancer pain in Europe." Lancet 341: 1075-6.
Somerville, M. A. (1994). Death of pain: pain, suffering and ethics. Progress in Pain Research and Management, Proceedings of the 7th World Congress on Pain, International Association for the Study of Pain. G. F. Gebhart, D. L. Hammond and T. S. Jensen. Seattle, Washington, IASP Press. **2:** 41-58.

substantial progress in palliative care provision, and there is good access to opioids for symptom relief, but bureaucratic hurdles still hinder care drug prescribing. In many other countries, access to morphine is still limited or non-existent, and there is still serious concern that in global terms, poor cancer pain control is commonly due, at least in part, to poor opioid access.[137] This is largely due to the regulation of opioid use by governments in order to control illicit drug use and its enormous attendant social and health problems.

In two surveys conducted in 1991 for a parliamentary select committee of the South Australian parliament, general practitioners showed minimal concern about addiction to pain-killing drugs, but over 80% of the community sample thought that addiction was a significant issue in palliative care. The public opinion survey asked a causal question concerning pain relief. This showed a wide divergence of views, and much uncertainty.[138] Unfortunately, no such question was asked in the general practitioner study.[139] But this and other work has shown both attitudinal and knowledge deficits amongst medical practitioners in cancer pain management,[140] although one study in the UK showed good reported practice amongst a sample of Scottish general practitioners.[141]

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[137] See Rita Carter's article; Carter, R. (1996). Give a drug a bad name. New Scientist. 6 April 1996: 14-15. The introduction reads: 'Morphine is the world's most effective painkiller, yet because of its reputation as a dangerous drug it is rarely prescribed even to terminally ill patients'. This is, of course, untrue, but nonetheless, the article highlighted the extent and depth of the negative attitudes and lack of knowledge about the safety and efficacy of opioids, even in the UK, where palliative care is well embedded.

[138] Asked if too many pain-killers shorten life, the results were (n=462): very true 11.7%, somewhat true 25%, not at all true 28%, don't know 35.3%. Ashby, M. and M. Wakefield (1993). "Attitudes to some aspects of death and dying, living wills and substituted health care decision-making in South Australia: a public opinion survey for a parliamentary select committee." Palliative Medicine 7: 273-282.

[139] Wakefield, M., J. Beilby, et al. (1993). "General practitioners and palliative care." Palliative Medicine 7: 117-126.

[140] Elliott, T. E., D. M. Murray, et al. (1995). "Physician knowledge and attitudes about cancer pain management: a survey from the Minnesota Cancer Pain Project." Journal of Pain and Symptom Management 10(494-504). Vainio, A. (1989). "Practising physicians' experiences of treating patients with cancer pain." Acta Oncologica 28: 177-82.

[141] Lang, C. C., P. H. G. Beardon, et al. (1992). "Drug management of pain caused by cancer: a study of general practitioners' treatment attitudes and practices." Palliative Medicine 6: 246-252.

However, there is still a question mark as to what extent surveys portray real practice, and patient attitudes have not received much attention in the literature.[142]

In a large retrospective case note review of 11,882 hospitalised inpatients at Boston University Medical Center, two physicians reported that only four patients showed evidence of addiction to opioids prescribed for pain.[143] Marie Fallon (Glasgow, Scotland) and colleagues conducted a prospective comparative study of mood and drug use in three groups of patients receiving opioids for: cancer pain, chronic non-malignant pain and drug dependence. They found significant differences in reasons for opioid use between the groups. Whilst cancer and chronic pain patients mainly took opioids to relieve pain, those with drug dependence used them for mood elevation and sleep (Fallon, personal communication). Although medical opinion is now clear that addiction is not an issue in cancer pain management and palliative care, opinion is divided about opioid use in non-malignant pain,[144] and patients and families in the wider community clearly still have a high level of concern about the potential for addiction.

Despite an extensive and sustained international campaign by the World Health Organisation,[145] many doctors still believe that they are causing or

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[142] Ward, S. E., N. Goldberg, et al. (1993). "Patient-related barriers to management of cancer pain." Pain 52: 319-324.

[143] Porter, J. and H. Jack (1980). "Addiction rare in patients treated with narcotics." New England Journal of Medicine 302(2): 123.

[144]For the prevailing views on the use of opioids for non-malignant pain, from the Australian Pain Society see a recent paper and editorial in the *Medical Journal of Australia*, Graziotti, P. and R. Goucke (1997). "The use of oral opioids in patients with chronic non-malignant pain." Medical Journal of Australia 167: 30-34.
Molloy, A., M. Nicholas, et al. (1997). "Role of opioids in chronic non-cancer pain." Medical Journal of Australia 167: 9-10. and in Canada, see website of Canadian Pain Society: Use of opioid analgesics for the treatment of chronic non-cancer pain – a consensus statement and guidelines from the Canadian Pain Society <www.pulsus.com/Pain/03_04/opio_ed.htm)> Accessed on 22nd February 2001.

[145] Stjernsward, J. and N. Teoh (1989). "The cancer pain relief programme of the World Health Organisation." Palliative Medicine 4: 1-3.
Twycross, R. (1994). Pain relief in advanced cancer. London, Churchill Livingstone.
Zech, D. F., S. Grond, et al. (1995). "Validation of World Health Organization Guidelines for cancer pain relief: a 10-year prospective study." Pain 63(1): 65-76.

hastening the death of their palliative care patients, despite a lack of any evidence to support this view.[146] Regulatory barriers abound in many countries,[147] with many still not allowing the use of opioids for pain management.[148] A recent event of note in the United States, which may represent a significant shift in public policy and attitude, has been the institution of disciplinary or legal sanction for doctors who fail to provide adequate analgesia.[149]

4.3 Justice Devlin's advice in *R v Adams*

These deep seated fears are based on the fact that opioids, used inappropriately, can cause respiratory depression, coma and death. In particular, the notion that there is agreement about a 'high' dose of an opioid drug such as morphine beyond which timing and possibly causation might be in question has permeated medicine, and hence, every legal deliberation on this issue since the 1957 instruction to the jury by (later) Lord Patrick Devlin in *R v Adams*:

> But that does not mean that a doctor who is aiding the sick and the dying has to calculate in minutes or even hours, and perhaps not in days or weeks, the effect on the patient's life of the medicines that he administers or else be in peril of a charge of murder. If the first purpose of

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Expert Working Group of the European Association for Palliative Care (1996). "Morphine in cancer pain: modes of administration." British Medical Journal 312: 823-826.
Twycross, R., J. Harcourt, et al. (1996). "A survey of pain in patients with advanced cancer." Journal of Pain and Symptom Management 12: 273-282.

[146] Ashby, M. (1997). "The fallacies of death causation in palliative care." Medical Journal of Australia 166: 176-177.
Simini, B. (1996). "Prescribing morphine for pain relief is unduly difficult in Italy." Lancet 347: 753.
Mendelson, D. (1997). "Quill, Glucksberg and palliative care - does alleviation of pain necessarily hasten death?" Journal of Law and Medicine 5: 110-113.

[147] Simini, B. (1996). "Prescribing morphine for pain relief is unduly difficult in Italy." Lancet 347: 753.

[148] See Cancer Pain Release (a publication of the WHO Collaborating Center for symptomatic evaluation in cancer care, Madison, Wisconsin, USA). Supplement to Volume 9 – Summer 1996, quoting International Narcotics Control Board report in 1996.International Narcotics Control Board (1996). Availability of opiates for medical needs. New York, United Nations.

[149] Charatan, F. (1999). "Doctor discipined for "grossly undertreating" pain." British Medical Journal 319: 728.

> medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life. This is not because there is a special defence for medical men but because no act is murder which does not cause death. We are not dealing here with the philosophical or technical cause, but with the commonsense cause. The cause of death is the illness or injury, and the proper medical treatment that is administered and that has an incidental effect on determining the exact moment of death is not the cause of death in any sensible use of the term. But ... no doctor, nor any man, no more in the case of the dying than of the healthy, has the right deliberately to cut the thread of life.[150]

It is clear that expert medical evidence, given forty years ago has been incorporated into legal deliberations and public policy formulations ever since. This trial specifically deals with the use of opioids in terminal care by a general practitioner in a case where the doctor's motives and intentions were in question, and the advice was based on medical opinion of that time, which held that morphine and heroin, even when used for pain relief, led to addiction, or death from respiratory depression. Double effect reasoning was employed to justify, and render lawful, the use of escalating morphine doses which might have the incidental effect of shortening the life of a dying person. Whilst the judgment is supportive of palliative care, and expresses the doctrine of double effect in law for the first time in this context (see chapter 6), much has changed in medicine, and society, since the expert evidence which would have informed that judgment in 1957. Modern palliative care experience has, of course, shown this causal assumption about morphine to be false. The title for Patrick Devlin's 1985 book as a result of the 1957 Bodkin Adams case: Easing The Passing,[151] is perhaps illustrative of the prevailing views on palliative care

[150] *R v Adams*, Central Criminal Court, London, 1957. Unreported but discussed in Palmer, Dr Adams' trial for murder, [1957] Crim LR 365. See also G. Williams, The Sanctity of Life and the Criminal Law, 1958, pp 288-90.

[151] Devlin, P. (1985). Easing the passing: The trial of Dr John Bodkin Adams. London, The Bodley Head.

at the time. The widespread use of the 'Brompton's Cocktail'[152] also shows that the view of dying was that rapidity of death and oblivion were the goals of palliative interventions, which were almost exclusively focused on terminal care. Palliative care has now expanded well beyond terminal care, and is seeing patients far earlier in the course of their illness. Until the last few hours or days of life, most patients wish to have optimal pain management with minimal side effects, in particular, they do not wish to be drowsy or cognitively impaired.[153]

4.4 Opioid use in palliative care

There is no clinical scientific evidence that morphine causes death, if used with appropriate skill to palliate symptoms. In particular, the respiratory depressant effects have been shown to be minimal, and it seems that the presence of pain acts as antagonist to respiratory depression and sedative effects of opioids.[154] However, like any class of drugs, the opioids are dangerous if used inappropriately. There is now a substantial body of clinical experience in palliative care about safe standards of practice, with particular regard to initial doses for 'opioid-naive' patients and subsequent dose titration according to the person's pain or symptom reporting. It is widely assumed that the morphine (or other opioid) *dose per se*, is the main determinant of whether the drug causes or hastens death. In fact there is no such determinative or threshold dose. What matters is the present dose in relation to the previous dose. Gradual dose escalation by a factor in the region of 50-100% of the previous dose is usual practice, although substantially higher increases can usually be well tolerated by patients who are not new to the drug (that is, they are no longer termed

[152] Named after the Brompton Hospital (a famous London postgraduate teaching hospital which specialises in chest diseases), the mixture usually contained heroin, cocaine and alcohol. It was very extensively used prior to the advent of the modern hospice/palliative care movement and its composition has varied from one institution to another over the years.

[153] Hanks, G. W. (1995). "Morphine sans morpheus." Lancet 346: 652-3.

[154] DuBose, R. A. and C. B. Berde (1997). Respiratory effects of opioids. IASP Newsletter: 3-5.

'opioid-naive'). It is therefore the size of the initial dose, and the rate of subsequent incremental dose increases which are important.

Cancer pain management with morphine is unusual compared to most other forms of drug treatment in that there are no predetermined dose ranges to achieve satisfactory pain control for adults or children. Most adults will achieve initial pain control with a daily dose in the range of 30 mg to 200 mg (per 24 hours, orally), but the range of doses is very wide. The accepted practice is to adjust the regular dose upwards according to the requirements to keep the pain under control, balanced against incidence of side effects.[155]

4.5 Terminal sedation

Sedative drugs are commonly used in terminal care (when death is believed to be imminent), in order to maintain comfort and dignity by alleviation of agitation, anxiety and so-called terminal restlessness. They are used proportionately to the patient's distress, and not to bring about death.[156] It is clear that there is a robust disagreement within medicine itself, about whether such treatment contributes to the cause of death, and even what the therapeutic goals are or should be. There are those who contend that, within accepted palliative care practice, patients are sedated, and death is thereby caused, either through central nervous system and respiratory depression, or dehydration and starvation. Billings and Block also contend that this is result of the use of morphine infusions.[157] In

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[155] Mercadante, S., G. Dardanoni, et al. (1997). "Monitoring of opioid therapy in advanced cancer pain patients." Journal of Pain and Symptom Management 13: 204-212.

[156] Ashby, M. (1997). "The fallacies of death causation in palliative care." Medical Journal of Australia 166: 176-177.
Mendelson, D. (1997). "Quill, Glucksberg and palliative care - does alleviation of pain necessarily hasten death?" Journal of Law and Medicine 5: 110-113.

[157] Billings, J. A. and S. D. Block (1996). "Slow euthanasia." Journal of Palliatve Care 12: 21-30.
Brody, H. (1996). "Commentary on Billings and Block's "slow euthanasia"." Journal of Palliative Care 12: 38-41.
Dickens, B. M. (1996). "Commentary on "slow euthanasia"." Journal of Palliative Care 12: 42-43.
Mount, B. (1996). "Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes." Journal of Palliative Care 12: 31-37.
Portenoy, R. K. (1996). "Morphine infusions at the end of life: the pitfalls in reasoning from anecdote." Journal of Palliative Care 12: 44-46.

Victoria, a prominent urologist, Dr Rodney Syme has challenged the state coroner to investigate his sedation of a patient as a cause of death.[158] Certainly, palliative care practitioners rarely use morphine for its sedative properties at any stage of an illness, especially when patients are trying to function as normally as possible, and sedation is usually unwelcome. In terminal care morphine may even aggravate terminal restlessness, probably due to metabolite accumulation.[159] In terminal care sedatives are titrated against agitation and distress, but occasionally also against another symptom (e.g. pain or shortness of breath) where other measures have failed and the patient may wish to be less aware of what they are going through. If patients are conscious and competent they are consulted about this and asked if they wish to be more sedated, but they are often unable to give this consent due to incompetence. It should also be noted that patients are usually unconscious and/or cognitively impaired, and therefore incompetent, at this stage. It is clearly not possible to state categorically that such sedation has no effect on time of death, but this is not really the important question, being superseded by the comfort and dignity of the person. The precise timing of death is unpredictable and verification of the relative causal contributions to that timing of disease, physiological and pharmacological factors is not usually measurable. Outside the setting of terminal care, so-called 'pharmacological oblivion' is not part of accepted palliative care practice, especially not as a way of ending a patient's life.

4.6 Conclusion

The Ontario coroner (Dr James Young, 1997) seems to have captured the essence of the basic underlying principles of therapeutic intervention in palliative medicine, in laying down four conditions which need to be satisfied for palliative care interventions to be legal in his jurisdiction. These conditions should be universally applicable:

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[158] Syme, R. (1999). "Rodney Syme: pharmacological oblivion contributes to and hastens patients' deaths." Monash Bioethics Review 18(2): 40-3.

[159] Ashby, M. A., B. Fleming, et al. (1997). "Plasma morphine and glucuronide (M3G and M6G) concentrations in hospice inpatients." Journal of Pain and Symptom Management 14: 157-167.

> (1) The care must be intended solely to relieve suffering; (2) it must be administered in response to suffering or signs of suffering; (3) it must [be] commensurate with that suffering; and (4) it cannot be a deliberate infliction of death. Documentation is required, and the doses must increase progressively.[160]

The intention is to relieve symptoms and suffering, not bring forward the time of death. Whilst this position is sustainable in the palliative phase, it is susceptible to challenge in the terminal phase, when death is imminent (hours or days away).[161] It should be acknowledged by practitioners that, as death approaches, abatement of life-sustaining treatment and terminal sedation may indeed alter the time of death, although this matter cannot be verified scientifically, one way or the other, in a particular case, or in general. There are serious limitations to the use of clinical studies in this area, and the causal question itself cannot be directly asked in any interventional study for obvious reasons. We cannot know when a particular patient would have died in the absence of palliative interventions or treatment abatement, particularly during the final dying process, and it would be unethical to design randomised controlled trials to find out.

In the absence of formal training in palliative care, doctors' attitudes and clinical behaviour are complex and variable, ranging from abrupt cessation of treatment, minimalist palliative care and treatment directed at bringing about a rapid dying process, to excessive caution about being seen to be instrumental in causing the death, particularly with regard to the provision of pain and symptom relief, cessation or non-initiation of artificial hydration and alimentation and cardio-pulmonary resuscitation.

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[160] Parliament of Canada (1995). Of Life and Death: Report of Special Senate Committee on euthanasia and assisted suicide. Ottawa, Minister of Supply and Services Canada. pp 26-7.
Lavery, J. V. and P. Singer (1997). "The "Supremes" decide on assisted suicide: what should a doctor do?" Canadian Medical Association Journal 157: 405-406.

[161] For a description of these three phases of illness and goals of care: curative, palliative and terminal, see Ashby, M. and B. Stoffell (1991). "Therapeutic ratio and defined phases: proposal of an ethical framework for palliative care." British Medical Journal 302: 1322-1324.

Whilst a doctor's intention may not always be easy to validate, evaluation of intention and motive are fundamental to legal analysis, and many would argue that intention also determines the moral character of medical interventions.

Whilst it is undoubtedly true that throughout history certain doctors have administered treatment to terminally ill patients with the covert or overt intention of shortening their lives, this is not the clinical or ethical position which is put forward by palliative care practitioners.[162] It is the central tenet of this thesis that death causation is a major factor influencing care and decision-making at end of life, however, causation alone cannot resolve the issues at stake. There has been a failure within medicine itself to deal with causation in this context. Anxieties about responsibility for causing death, and questionable assumptions by health care professionals and the public, concerning law and ethics, permeate practice and debate related to death and dying.

[162] Gilbert, J. and S. Kirkham (1999). "Double effect, double bind or double speak." Palliative Medicine 13: 365-366.

CHAPTER 5
TREATMENT ABATEMENT

5.1 Introduction

Even when death is manifestly approaching, or the quality of life is grossly compromised, including permanent absence of consciousness, the non-initiation or cessation of medical treatment gives rise to anxieties for doctors, nurses, patients and families, and causal factors are clearly to the fore. Here are two more quotes from Colleen Cartwright's work:

> A resident who made the decision not to prolong life by withholding nutrition and fluids was counselled by staff – GP, staff and relatives discussed the situation with her. Her faith was strong and her desire not to live was strong. Her wishes were agreed to – *staff and relatives found it very difficult* and all other aspects of care were accepted. *It took three weeks and was extremely difficult, staff required strong counselling after the death.* [163]
>
> As a student nurse I was asked to turn off a respirator – (this decision was made by a team of GP's). This left a lasting negative effect. [164]

Many doctors feel more comfortable with non-initiation than cessation, presumably because of the causal implications, and an underlying sense of reliance on the act versus omission distinction. [165] As a result of causal anxieties, it is common that treatment aimed at saving or prolonging life is often continued in clinical situations where the chances of benefit are slim, and treatment-related morbidity can be substantial without obvious gain. The duties and goals of medicine are overwhelmingly articulated in terms of cure.

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[163] See Cartwright (personal communication) op cit, ch 4.3, no 3082.

[164] Ibid no 3189

[165] See Beauchamp, T. and J. Childress (1994). Principles of biomedical ethics. New York, Oxford University Press. pp 196-200. For an important discussion of factors which influence life support withdrawal see a vignette-based survey of physicians.Christiakis, N. and D. A. Asch (1993). "Biases in how physicians choose to withdraw life support." Lancet 342: 642-646.

The term 'abatement' is taken from the title of an important 1989 book by Robert Weir, a bioethicist from the Medical College of Iowa, which gives a comprehensive historical account of legal and ethical deliberations on end of life decision-making in the United States up to that year.[166] The term, which is used throughout this thesis, encompasses both non-initiation and cessation of medical treatment. This appears to be an important distinction in clinical decision-making behaviour, but not in terms of outcome, where death can clearly result from both non-initiation and cessation of medical treatment. Neither does it appear to be a morally robust distinction, resting tenuously perhaps on the unsafe foundations of the acts/omissions distinction.

A number of legal reports and judgments have addressed the issue of treatment abatement and palliative care, by stating that there is no duty for doctors to provide medical treatment that does not benefit the patient, and hence any notion of causing death by failure to provide such treatment is nonsensical from the law's point of view. In 1982 the Canadian Law Reform Commission wrote:

> The law should recognise that the prolonging of life is not an absolute value in itself and that therefore a physician does not act illegally when he fails to take measures to achieve this end, if these measures are useless or contrary to the patient's wishes or interests, and: that the incapacity of a person to express his wishes is not sufficient a reason to oblige a physician to administer useless treatment for the purpose of prolonging life, and: that in the case of an unconscious or incompetent patient, a physician incurs no criminal responsibility by terminating treatment which has become useless.[167]

The major treatment abatement decisions that are taken in clinical practice are: the provision or non-provision of artificial nutrition and hydration, cardio-pulmonary resuscitation and life support interventions, notably artificial ventilation. This chapter will focus on the first of these as a major

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[166] Weir, R. F. (1989). Abating treatment with critically ill patients. Ethical and legal limits to the prolongation of life. New York, Oxford University Press.

[167] Law Reform Commission of Canada (1982). Protection of life: euthanasia, aiding suicide and cessation of treatment. Ottawa, Minister of Supply and Services Canada.

issue for palliative care, general medicine and aged care. It will be necessary to examine the ordinary/extraordinary distinction and see how the characterisation of treatments has fuelled a 'special case' status for the provision of nutrition and fluids (a moral 'bottom line' of what may be abated and what may not). It will also be seen that a 'moral equivalence' argument is made to equate the abatement of any medical treatment, regardless of clinical efficacy in the given circumstances, with voluntary active euthanasia. This will be challenged, and a clinical distinction will be made about the setting of such decisions between dying and non-dying persons. The English case of *Airedale NHS Trust v Bland* is one of the world's leading reference cases for legal and ethical aspects of treatment abatement in general and hydration and alimentation in particular and will hence be referred to substantially here.

5.2 The ordinary/extraordinary distinction

One historically influential approach to ethical reasoning (which is now appears to be waning) in treatment abatement decision making at the end of life, has been to characterise the treatments into those that are morally obligatory (termed 'ordinary'), and those which are not ('extraordinary'). It has its origins in the Catholic moral theological tradition. Kelly was the first to use the extraordinary/ordinary distinction to characterise specific treatments.[168] In this tradition, as reviewed by Cronin[169] and described by McCormack,[170] it is understood that it is up to individuals to decide, on the basis of proportionality, what constitutes ordinary and extraordinary treatment in their particular situation. The ordinary/extraordinary distinction was described in this way by Pope Pius XII in 1957:

> Natural reason and Christian morals agree that patients have a duty "to take the necessary treatment for the preservation

[168] Kelly, G. (1954). "Medico-moral problems." St Louis: The Catholic Hospital Association of US and Canada: 6-15.

[169] Cronin, D. (1989). Conserving human life. Doctoral dissertion (1958). Boston, The Pope John Center.

[170] McCormack, R. (1978). "The quality of life, the sanctity of life." Hastings Center Report 1: 30-36.

> of life and health", the Pope proceeded to declare: "Normally one is held to use only ordinary means – according to circumstances of persons, places, times and culture – that is to say, means that do not involve any grave burden for oneself or another." He went on to state, specifically in regard to the withholding or withdrawing of mechanical ventilation, that such acts of treatment abatement do not constitute cases of "direct disposal of the life of the patient, nor of euthanasia in any way", for any direct causation of death "would never be licit".[171]

Somerville[172] argues against the ordinary/extraordinary distinction on the grounds that it is not the treatments which tend to be characterised but the patients to whom they are applied, and subjective standards are applied under the masquerade of objectivity.

5.3 The *Bland* case

This prominent 1992 case in the United Kingdom[173] gave rise to one of the most profound legal and ethical analyses of treatment abatement in general, and artificial hydration and alimentation in particular. The House of Lords at appeal decided that the cause of death was the initial injury rather than the cessation of artificial hydration and alimentation, but this over-reliance on the underlying disease or injury as the cause of death has been disputed. Gerber has called it 'the logic of Alice in

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[171] Note the Pontiff's emphasis on proportionality, and causal inference in the last line. This quotation is taken from Weir, R. F. (1989). Abating treatment with critically ill patients. Ethical and legal limits to the prolongation of life. New York, Oxford University Press., Ch 6, p 221. He in turn has quoted it from Pope Pius XII: Pope Pius XII (1977). "The prolongation of life." Ethics in medicine. S. Reisner, A. Dyck and W. Curran. Cambridge, Mass, MIT Press. pp 502-3. See also Elizabeth Hepburn IBVM, Hepburn, E. (1996). Of life and death. An Australian guide to Catholic bioethics. Melbourne, Dove., and Pope Pius XII, 1958: The Pope Speaks.

[172] Advice to the Minister for Health, South Australia, Professor Margaret Somerville. Director, Centre for Medicine, Ethics and Law, McGill University, Montreal. Adelaide, 23rd December 1992. (unpublished) Professor Somerville also points out that the extraordinary/ordinary distinction, as employed in the original drafting of the Consent to Medical Treatment and Palliative Care Bill 1992, could lead to an interpretation that ordinary measures might include, for example, antibiotics and blood transfusions, which were often not appropriate in terminal care.

[173] *Airedale NHS Trust v Bland.* [1993] 1 ALL ER 821-896. For brief description of the case, see Ch3.1.1.

Wonderland'.[174] Collins writes that it is 'susceptible to penetrating intellectual assault'.[175] Singer reiterates the point that the clearly intended outcome of the decision to stop nasogastric feeding and hydration was to end the life of Tony Bland.[176] It therefore appears that there are situations in which it is agreed that the life of an incompetent non-dying and permanently unconscious and insensate person may be intentionally ended. This practice should be clearly differentiated from that of palliative care for persons who are dying, where the intention of all therapeutic interventions is to relieve symptoms. Although palliative care measures may be applied to a patient such as Tony Bland, despite the fact that he is no longer sensate,[177] the principles of palliative care practice do not underpin the decision to withdraw life sustaining measures in this type of situation.

The moral equivalence argument between acts and omissions which result in death, advanced by Rachels,[178] Singer and Kuhse[179] is an important insight. It is hard to refute Singer's predominantly consequentialist analysis of the Bland case,[180] and his conclusion that the courts sanctioned the ending of Tony Bland's life, because life-sustaining treatment was removed from a person who was permanently incompetent but not dying. For Singer the cause of death was the treatment abatement, not the underlying condition. At the time the case was considered, the decision

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[174] Gerber, P. (1994). "Withdrawing treatment from patients in a persistent vegetative state." Medical Journal of Australia 161: 715-717.

[175] Collins, D. (1994). "Prescribing limits to life-prolonging treatment." New Zealand Law Journal: 246-251.

[176] Kuhse, H. (1987). The sanctity of life doctrine in medicine: a critique. Oxford, Oxford University Press.
Singer, P. (1994). Rethinking life and death. Melbourne, Text.

[177] Although Bland was considered to have no functioning higher cerebral centres and hence it seems hard to argue that he could be in aware of pain or suffering, distress behaviour might still be treated with drugs, if only to preserve his dignity and comfort his family.

[178] Rachels, J. (1987). The end of life. Oxford, Oxford University Press.

[179] Kuhse, H. (1987). The sanctity of life doctrine in medicine: a critique. Oxford, Oxford University Press.

[180] Singer, P. (1994). Rethinking life and death. Melbourne, Text.

appeared to have wide public support, including by many who oppose the legalisation of voluntary active euthanasia. However, when this line of argument is mobilised to undermine properly negotiated treatment abatement for dying people it is problematical. Moral equivalence arguments based on outcome cannot ignore the assessment of clinical proportionality and appropriateness. The death is surely only caused if the treatment under consideration for abatement can be demonstrated to be (actually) clinically effective or life-sustaining in those circumstances, that the underlying condition is potentially reversible, and that there would therefore then be a demonstrable disruption of a pre-existing chain of causation were it abated.

For a competent patient who expresses a wish to reject any medical treatment whatsoever this has been clearly accepted as morally and legally permissible, and the issue is not controversial. Van der Maas[181] and Kuhse et al[182] rightly draw attention to situations in which patients were not consulted about medical decisions, but treatment abatement cannot be negotiated with incompetent dying people. Unfortunately, incompetence due to organic brain dysfunction is fairly common during the dying process and medical decisions do have to be taken. Although the Australian doctors in the survey conducted by Kuhse et al may be reflecting a degree of honest pragmatism, clearly this finding needs more exploration - with particular emphasis on transparency of process, negotiation and consultation.

The moral equivalence argument has not found widespread support amongst practising doctors, nurses and other health care professionals, who tend to maintain strong intuitive moral and clinical distinctions

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[181] Van der Maas, P. J., J. J. M. Van Delden, et al. (1991). "Euthanasia and other medical decisions concerning the end of life." Lancet 338: 669-674.
Van der Maas, P. J., J. J. M. Van Delden, et al. (1992). Euthanasia and other medical decisions concerning the end of life. Amsterdam, Elsevier.
Van der Maas, P. J., G. Van der Wal, et al. (1996). "Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995." New England Journal of Medicine 335(22): 1699-1705.

[182] Kuhse, H., P. Singer, et al. (1997). "End of life decisions in Australian medical practice." Medical Journal of Australia 166: 191-196.

between stopping absolutely or relatively futile medical treatment and giving a lethal injection. For the omission to be morally equivalent to the act of, say, giving a lethal injection, it is necessary for the omission to be of a treatment which is demonstrably still working to the patient's benefit in prolonging that person's life. In other words the moral equivalence argument cannot ignore the assessment of clinical proportionality and appropriateness. For a competent patient who expresses a wish to reject any medical treatment whatsoever this has been clearly accepted as morally and legally permissible, and the issue is not controversial. If the omission is made for an incompetent patient who is not in the process of dying, and the treatment to be omitted can be shown to be life sustaining in the circumstances, then the intention is to end that person's life.

Both Keyserlingk[183] and Collins[184] argue that act/omission distinctions should not be the principal determinative factor in assessing criminal or tort liability, and Collins particularly opposes the emphasis of this distinction in determining the legality of cessation of artificial hydration and alimentation in the *Bland* case. Although this leading case is not about palliative care per se, most aspects of death and dying were raised in the legal process, and it continues to be a valuable source of reference for the consideration of wider end of life issues. Mendelson[185] has pointed out that the reasoning in Bland was based not on causation, but on what constituted an ethically acceptable limit to the medical duty to continue treatment. It was shown to the court's satisfaction that it was not in Tony Bland's best interests to continue as he was in an irreversible persistent vegetative state, so the cessation of life-sustaining measures did not constitute a breach of duty to the patient as no such duty was found to exist in the circumstances. However, treatment abatement, with the intention of causing death, for incompetent, non-dying persons who are

[183] Keyserlingk, E. W. (1994). "Assisted suicide, causality and the Supreme Court of Canada." McGill Law Journal 39: 708-718.

[184] Collins, D. (1994). "Prescribing limits to life-prolonging treatment." New Zealand Law Journal: 246-251.

[185] Mendelson, D. (1995). "Jurisprudential aspects of withdrawal of life support systems from incompetent patients in Australia." Australian Law Journal 69: 267-275.

permanently unconscious and insensate should be clearly differentiated from palliative care abatement decisions in the terminal phase of an incurable illness where the treatment(s) are no longer effective.

Decisions such as the withdrawal of feeding in the Bland case (he was not 'dying', his condition was stable at the time of the decision) clearly need to be taken, and have very wide public support. However, treatment abatement decision-making for dying persons represents a different type of clinical situation, in which the cessation or non-initiation of medical treatment aimed at life prolongation is based on a commonsense recognition of relative or absolute futility. To call causation into question in these situations is unhelpful, as are arguments that all treatment omissions, no matter what the clinical circumstances, constitute 'passive' euthanasia. Nobody benefits from argument lines which categorise the cessation or non-initiation of treatment in the context of a person's dying process (even if the treatment is argued to be *potentially* life-prolonging) with the administration of (for example) potassium chloride to end a life. It is surely not the purpose or the duty of medicine to provide all treatments that have any potential to prolong life to all patients in all circumstances.

5.4 Hydration and alimentation at the end of life

There can be few more emotive subjects in medical practice than the provision of *medically administered nutrition and hydration* (MN&H) when a person can no longer feed and/or drink themselves.[186] It is especially common for health professionals, (especially junior doctors, nurses and dietitians, who are usually closest to the patients and their families) to be nervous about discontinuation or non-initiation of nutrition and hydration, even in clinical circumstances where it is clear that the patient's

[186] Much of the recent discussions of these issues in the literature refer to *artificial hydration and alimentation (AHA)*. The term 'artificial' is used in contrast to 'natural', on the basis of what means are required to deliver the fluid and nutrients. For reasons that will be set out later, the unambiguous and non-pejorative term adopted for such provision by Beauchamp and Childress, namely *medically administered nutrition and hydration (MN&H)*, is favoured in this exposition of the issues. Beauchamp, T. and J. Childress (1994). Principles of biomedical ethics. New York, Oxford University Press.

death is not far away. For carers, family and friends there is often anxiety that the person is 'starving' to death,[187] and that they are complicit in causing the death. With the exception of euthanasia, it is the aspect of decision-making at end of life which generates the most public debate and professional concern. Once again, the issue of causation is the key to these attitudes and apprehensions, although with food and drink there are also profound emotional and social meanings which come into play. Understanding and working-through of these issues is a common task for those who care for dying people, and an uneasy acquiescence to the non-provision of fluid and nutrition, with lingering doubts about ensuing responsibility for causing death is a frequent outcome.[188]

Decisions about whether to provide MN&H appear, for many, to constitute a special subset of treatment abatement decision making.[189] For instance, until the distinction between ordinary and extraordinary treatments itself became unfashionable,[190] MN&H was usually located in the category of so-called ordinary measures, which should be initiated and continued whatever the circumstances, unless the patient refuses. For a competent person this represents relatively little difficulty as their consent is both required and available. If the person is no longer able to take oral nutrition and fluid, and they do not wish to have these provided artificially then there the matter rests, regardless of what others have to say about the 'ordinariness' of the treatment. For an incompetent person the situation is more problematical, and there are those who would argue that MN&H cannot be morally or legally abated by anyone on behalf of an incompetent patient, particularly if sedated. In other words the provision of alimentation and hydration is a truly ordinary measure, with the means of delivery being irrelevant to the moral duty to provide them. Here, for

[187] For a rebuttal of the negative and cruel imagery, and the inappropriateness of applying it to the non-feeding of dying persons, see Ahronheim, J. C. and M. R. Gasner (1990). "The sloganism of starvation." Lancet 335: 278-279.

[188] Parkash, R. and F. Burge (1997). "The family's perspective on issues of hydration in terminal care." Journal of Palliative Care 13(4): 23-27.

[189] Beauchamp and Childress in Principles of Biomedical Ethics (Fourth Edition), chapter 4, Nonmaleficence, pp202-206. The distinction between so-called sustenance and medical technologies is refuted. Beauchamp, T. and J. Childress (1994). Principles of biomedical ethics. New York, Oxford University Press.

those who conceptualise the issues in this way, is a clear moral and legal 'bottom-line' of what can only be rejected in the most extreme circumstances: where provision is medically impossible or would cause undue distress.

Weir cites one of the most prolific and visible proponents of this position in the United States, Robert Barry OP.[191] Barry cites the amicus curiae brief of the New Jersey Catholic Conference in the Nancy Jobes case,[192] and policy statements of the Committee for Pro-Life Activities of the National Conference of Bishops as evidence for his position as the correct interpretation of the tradition. Food and fluids should be given to all patients unless it is medically impossible to provide them. The term 'assisted feeding' is adopted, and characterised as different to other medical treatment because death inevitably results from non-provision, less skilled expertise is required to carry it out (tubes become passive conduits), and it is natural. Assisted feeding is deemed to be always morally required as it provides an objective standard which can stand firm against other more subjective standards and tests that might be used in treatment abatement. There is also concern with the wider societal effects of individual refusal or abatement of MN&H. Ranaan Gillon refers to this position as vitalist,[193] where the imperative is to attempt to preserve life above all things, at all costs, and no matter what the circumstances, prospects, quality or realities of the situation.

There are significant tensions between those who hold strong views against nutrition and hydration abatement in most clinical situations, and those both inside and outside the palliative care world who take the opposite view. These are well illustrated by an exchange in the *Journal of*

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[191] Weir, R. F. (1989). Abating treatment with critically ill patients. Ethical and legal limits to the prolongation of life. New York, Oxford University Press.

[192] In re Jobes, 108 NJ. 394, 529 A.2nd 434 (1987)

[193] Gillon, R. (1993). "Persistent vegetative state and withdrawal of nutrition and hydration." Journal of Medical Ethics 19: 67-68.
Gillon, R. (1994). "Palliative care ethics: non-provision of artificial nutrition and hydration to terminally ill sedated patients." Journal of Medical Ethics 20: 131-132.

Medical Ethics, in which the author was engaged. In 1994, a British geriatrician, Gillian Craig,[194] raised serious concerns about the ethics and legality of the non-provision of MN&H,[195]) in palliative care. It seems likely that she was giving voice to more widespread concerns amongst health workers about the abatement of MN&H in hospital and residential care settings, particularly in aged care. Craig argued that the abatement of nutrition and hydration was widespread in hospice and palliative care, and dangerous because patients who may have a chance of recovery may appear to be terminally ill, do not receive MN&H, and die prematurely as a result. She was especially concerned that sedation renders patients unable to eat and drink when they might otherwise have done, and lived longer.

Dr Craig quoted from an article in which Ashby and Stoffell described an approach of three phases to a life-threatening incurable illness: curative, palliative and terminal, with different aims and levels of treatment-related morbidity being acceptable in each phase. In this work it was stated that in the terminal phase:

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[194] Craig's original article led to an exchange with Ashby and Stoffell in the *Journal of Medical Ethics* in 1994-5: Craig, G. M. (1994). "On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?" Journal of Medical Ethics 20: 139-143.
Ashby, M. and B. Stoffell (1995). "Artificial hydration and alimentation at the end of life: a reply to Craig." Journal of Medical Ethics 21(3): 135-140.
This lead to a further reply from Craig: Craig, G. M. (1996). "On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues." Journal of Medical Ethics 22: 147-153.

This exchange showed very pronounced differences in opinion about palliative care and non-provision of MH&N. Other contributions from the palliative care world were less confronting in their opposition to Craig's position, see Wilkes, E. (1994). "On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A commentary." Journal of Medical Ethics 20: 144-145. Wilkes advocates the occasional use of what he calls the 'homely' remedy of rectal tap water.

See also Dunlop, R., J. Ellershaw, et al. (1995). "On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A reply." Journal of Medical Ethics 21: 141-143.

In an editorial, the editor of the *Journal of Medical Ethics* (Dr Ranaan Gillon) identified an overriding concern about causation of death in this controversy. Gillon, R. (1994). "Palliative care ethics: non-provision of artificial nutrition and hydration to terminally ill sedated patients." Journal of Medical Ethics 20: 131-132.

[195] MN&H was referred to as artificial hydration and alimentation (AHA) throughout this exchange.

> No form of artificial hydration or alimentation is undertaken, all measures not required for comfort are withdrawn, and no treatment-related toxicity is acceptable.[196]

This framework was not proposed as a rigid and arbitrary 'policy', and it did not set out to make a virtue of death without artificial hydration (in particular), as in some situations it might even be necessary for comfort right up until the time of death. It has been agreed that the model excludes that as previously worded, and has been amended by the addition of the following:

> Artificial hydration may however be required in the terminal phase to satisfy thirst or other symptoms attributable to lack of fluid intake.[197]

Subcutaneous fluid infusion (hypodermoclysis) has gained considerable acceptance as a means of providing fluids in palliative care, when this indicated.[198] It is also not usual 'policy' (as suggested by Craig) in hospices to sedate patients in order to mask any proposed unpleasant effects of dehydration, but rather to alleviate suffering caused by acute organic brain syndromes (particularly where the underlying cause cannot be identified or reversed), so-called 'terminal restlessness' and emotional distress for which other non-medical interventions have failed. It is possibly true that sedation may contribute to the timing of an inevitable death. Dehydration can be a contributory cause of an acute organic brain syndrome,[199] but these common episodes of impaired brain function are

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[196] Ashby, M. and B. Stoffell (1991). "Therapeutic ratio and defined phases: proposal of an ethical framework for palliative care." British Medical Journal 302: 1322-1324.

[197] Ashby, M. and B. Stoffell (1995). "Artificial hydration and alimentation at the end of life: a reply to Craig." Journal of Medical Ethics 21(3): 135-140.

[198] Ashby, M., B. G. Fleming, et al. (1992). "Subcutaneous fluid infusion (hypodermoclysis) in palliative care: new role for an old trick." Medical Journal of Australia 156: 669.
Steiner, N. and E. Bruera (1998). "Methods of hydration in palliative care patients." Journal of Palliative Care 14(2): 6-13.

[199] Bruera, E., M. Legris, et al. (1990). "Hypodermoclysis for the administration of fluids and narcotic analgesics in patients with advanced cancer." Journal of Pain and Symptom Management 5: 218-220.
Fainsinger, R. and E. Bruera (1994). "The management of dehydration in terminally ill patients." Journal of Palliative Care 10: 55-59.

usually multifactorial, and rehydration alone appears to have a rather limited role in the improvement of cognitive function in dying patients.
In hospice and palliative care, hydration of the sedated patient is not instituted during the dying process, when they are unable to maintain oral intake, on the grounds that they may have a transiently reversible component to their overall dying process. Despite the fact that Craig also agrees that in the last few days of life the lack of food and drink will not contribute to death and artificial hydration would not be appropriate, it seems that the concerns are as much ethical and legal as clinical, and are based on a belief that medicine has a duty to prevent death, by not shortening life, at all costs. That Craig's real concern is causal, is clearly shown in the final paragraph of her article, where she writes that:

> At the end of the day there should not be the slightest grounds for suspicion that death was due to anything but the disease. Unless this can be guaranteed, the public's faith in doctors in general, and in the hospice movement in particular, will be ill founded.[200]

However, it is normal part of the dying process for there to be a gradual reduction, and eventual cessation of oral intake. In palliative care units food and drink, and assistance with eating and drinking is always available to satisfy a patient's thirst and hunger, but MN&H is not routinely used when oral intake ceases. All treatments which are not required for comfort are stopped when a person is dying, and MN&H, for example subcutaneous fluid infusion, is only used for symptomatic thirst or hunger which cannot be adequately treated by other means. Clinical experience shows no basis for believing that patients receiving palliative care are experiencing symptoms of starvation and dehydration, which would be lessened or abolished by the routine provision of MN&H. Such symptoms, especially poor appetite and lack of energy, are intrinsic effects of the underlying condition, and are usually resistant to any treatment.

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[200] Craig, G. M. (1994). "On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?" Journal of Medical Ethics 20: 139-143.

Families and health care professionals are nevertheless often uncomfortable with this practice. Although all therapeutic interventions should be for the benefit of the patient and not the carers, their emotional needs and ethical views must be considered, in order to resolve differences of opinion about what constitutes a duty of care for the dying person. Due regard is however required for the cultural and ethnic dimensions involved. Families who feel that they are neglecting their role and duty in the provision of nourishment will not appreciate having a quasi-ethical or legal discussion about treatment abatement. They are however much more likely to agree to a care plan which is gently worked out with them, where all parties agree the common value of the comfort, value and integrity of the person who is dying, and the absence of anyone's responsibility for that dying.

In those states which have a Criminal Code, such as Western Australia and Queensland,[201] the Code imposes a duty on certain individuals to prevent harm to others, and to provide what are sometimes referred to as the 'necessaries of life'.[202] It would seem that doctors and the provision of MN&H would certainly fall into that category, and in those jurisdictions, that there might be argued to be a greater imposition on practitioners to provide MN&H than in states where no such Code requirement exists. However, there has been no testing out of this in law, and it is to be hoped that the prevailing pragmatism and commonsense in Australia would hold.

Two Australian statutes have attempted to clarify the issue in the context of treatment refusal and the scope of medical powers of attorney. In both pieces of legislation, the 'reasonable' and 'natural' provision of food and water is required, and cannot be rejected by an agent on the person's

[201] Similar criminal code provisions also exist in Tasmania and New Zealand. However, no case law exists whereby these provisions have been tested out with regard to the issue of hydration and alimentation for dying or non-dying persons.

[202] For an excellent discussion of this issue, see a paper by the Hon David K Malcolm AC, Chief Justice of Western Australia, "Euthanasia and the Criminal Law: what will sever a causal link?", given at the Deakin University Symposium on Causation in Law and Medicine, 27th November 1999. He cites ss 285-287 at 290, Criminal Code (Qld), and ss 262-264 and 267, Criminal Code (WA).

(donor's) behalf. In the *Medical Treatment Act* (Vic) 1988, palliative care is defined as including:

> (a) the provision of *reasonable* medical procedures for the relief of pain, suffering and discomfort; or
> (b) the *reasonable* provision of food and water. (italics added)

Palliative care is differentiated from other forms of medical treatment, in that it cannot be rejected by an agent. This does not seem to be a defensible position, in that it is almost universally agreed that palliative care and medically assisted nutrition and hydration are medical treatments which should be subject to the same criteria of use and rejection as any others. It probably represents a well-intentioned attempt to promote palliative care, and to ensure that nutrition and alimentation could only be rejected by patients themselves and not their agents.

The wording in the *Consent to Medical Treatment and Palliative Care Act 1995* (SA) is as follows:

> (7) A medical power of attorney-.....(b) does not authorise the agent to refuse-....(i) the *natural provision* or *natural administration* of food and water,.... (italics added)

These terms are not defined, but artificial nutrition and hydration are included in the term 'life sustaining measures' which are defined as:

> Medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation, and includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation.

Such measures then may be abated by a medical practitioner responsible for the care of a person 'in the terminal phase of a terminal illness', 'in the absence of an express direction by the patient or the patient's representative to the contrary.'[203]

[203] This is interesting, does it mean that a patient or their agent can insist on such measures, regardless of the clinical circumstances?

One select committee member in South Australia stated that the committee took the view that it required a very special level of courage and strength to eschew food and water, even during the dying process, and no agent could be charged with this responsibility (Jennifer Cashmore, personal communication). It seems that it is important to reflect again on the meaning of the term 'natural' in this context. The 'natural' provision of food and water for oral intake is both a basic human need and a right, and no civilised person or health care institution could possibly argue for its non-provision or so-called withdrawal. The author has proposed the following operational definition:

> The provision of food and drink, to be taken voluntarily by mouth, to satisfy hunger or thirst, and may include physical assistance (if requested by the patient) from another person, but does not include the administration of fluids or nourishment via nasogastric tubing or an intravenous line.[204]

There is now a broad consensus that so-called 'artificial' provision of fluid and nutrition should be regarded as medical treatment, as encapsulated by Beauchamp and Childress' unambiguous term 'medically-administered nutrition and hydration' (MN&H). The techniques involved are medical treatments, requiring intrusion on the person and medical and nursing skill for insertion and maintenance, and carry associated unpleasant side effects and may even induce premature death. The introduction of a nasogastric tube is unpleasant and its continued presence is usually a source of discomfort and irritation, and regurgitation and inhalational (overspill) pneumonia are common when patients are weak and debilitated. Venous lines can cause infective complications, and neck lines are uncomfortable and potentially hazardous to insert. Tubes and lines also become blocked or dislodged, and their replacement can be unpleasant and distressing, particularly for conscious patients with cognitive impairment. For patients in whom there is a prospect of recovery all of these problems will be acceptable, but the same trade-offs seem disproportionate when applied to people who are dying.

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[204] Ashby, M. (1994). "Law reform on death - over but not out." Australian Health Law Bulletin 2(7): 81-85.

For a potentially reversible condition, and for people with incurable conditions who are not yet dying, MN&H is a medical treatment which must be offered. For incompetent persons with irreversible brain damage, the decision of cessation of MN&H should depend on any available evidence of prior wishes of the person, their concepts of personhood, their best interests, and not a preconceived position on the moral nature of MN&H. All the legal deliberations on MN&H have been for people in this latter category. The issue of MN&H abatement for dying persons has not been tested in the courts of the United Kingdom or Australia, and the most relevant recent legal deliberations are those in *Bland*.[205] Tony Bland was not dying, but was irrefutably in the persistent vegetative state (PVS) from which absolutely no prospect of recovery was deemed possible, with only one dissenting piece of medical evidence. For some this is not even a state of living.[206] The judgment of the House of Lords permitted the discontinuation of MN&H, which was acknowledged to be his life support, on the grounds that as it was not in his best interests, there was therefore no duty to continue this treatment. *Bland* cannot be used in direct extrapolation as dying people may well be sensate until the moment of death, and do have an interest in being alive. Nonetheless, the deliberative process of *Bland* has been helpful to all who study decision making at the end of life.

The question is whether the dying person's interests are served by the provision of MN&H, and this must surely be a decision based on comfort and quality of life, as reported by the patient. If these measures are requested, and can be demonstrated to be effective in achieving the stated aims, then they should not be unilaterally rejected by the attending physician. It seems that no court has deliberated on the issue of MN&H abatement for dying persons because there is no need to, most of the principles set out in *Bland* would apply to them also, and there is no established or accepted duty of care to maintain hydration and alimentation by whatever medical means available until death. Tony

[205] *Airedale NHS Trust v Bland.* [1993] 1 ALL ER 821-896

[206] The author is clear that in these circumstances, only the respect due to his dead body should be accorded (this is, nonetheless, no light imposition).

Bland did not consent to the insertion of his nasogastric tube, and this is also frequently the case for incompetent persons who are dying.

It can be seen that the non-initiation or continuation of MN&H cannot constitute a cause of death if there is no legal duty to provide it, and the cause remains the underlying condition which has led to the situation of absent oral intake, even if sedation is required for the palliation of another symptom, as an unnatural but necessary component of care in an otherwise natural dying process. There is no place for emotive language about killing patients, which suggests the ascendancy of causation over care, and of law over common sense and compassionate medical care.

A recent strategy in palliative medicine is to adopt a biomedical research approach, so that the question about MN&H is resolved not by ethical or legal argumentation or religious belief, but by clinical data concerning the influence of hydration on chest secretions, thirst, urinary output, biochemistry, cognitive function and drug handling. Although at first glance, this has wide appeal, in a recent review of six studies, all appear to measure something different and conclude something different, and end with the customary, but largely unhelpful, exhortation to do more rigorous research.[207] Biomedical data seem destined to fail as answers if the underlying issue is death causation rather than clinical comfort.

Abatement of MN&H is probably the most common decision at the end of life in health care facilities. For dying persons it seems to be medically and ethically uncontroversial, although emotional, cultural and social factors are significant and complex influences, and the practice is far from comfortable for many families and some health care professionals, especially nurses, and, for example in nursing homes.[208] The only refuge would appear to be a common understanding of the nature of 'normal'

[207] Viola, R., G. Wells, et al. (1997). "The effects of fluid status and fluid therapy on the dying: a systematic review." Journal of Palliative Care 13(4): 41-52.

[208] It is fairly common for patients (usually after stroke) to be fed by a percutaneous gastrostomy, and the presence of a functioning PEG may be a condition of transfer, and an indication for referral back to acute facilities.

human dying, and the 'naturalness' of the cessation of oral intake as life comes to an end. The major legal deliberations internationally have been concerned with abatement for people who are not dying, but have irreversible brain damage resulting in permanent coma or PVS, but there has been no Australian equivalent of *Bland* or *Quinlan*, and the whole matter remains untested in Australian jurisdictions. In the absence of case law or statute, the practice is still a daily one in Australian health care facilities, based on clinical assessment, patient best interests, prior known wishes and wide consultation. It is possible that this pragmatic and casuistic approach is adequate. Unease and uncertainty nevertheless still permeate the whole issue, fuelled by vitalist or 'right to life' activists who adopt an extreme position not shared by most of the community, but their influence on public policy cannot be underestimated.[209]

5.5 Conclusion

In conclusion, the approach which is described here is the dominant one in modern palliative care practice, and is accepted in the mainstream of contemporary ethical discourse,[210] as presented by Beauchamp and Childress who find:

> No reason to believe that medically administered nutrition and hydration is always an essential part of palliative care or that it necessarily constitutes, on balance, a beneficial medical treatment.[211]

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[209] Gillon, R. (1993). "Persistent vegetative state and withdrawal of nutrition and hydration." Journal of Medical Ethics 19:67-68.

[210] See the British Medical Association's landmark guidance booklet British Medical Association (1999). Withholding and withdrawing life-prolonging medical treatment. London, BMJ Books.
See also Ranaan Gillon's 1999 editorial in the *Journal of Medical Ethics*, for support for this position, and three salient articles in that same issue which look at various aspects of what they term ANH (artificial nutrition and hydration) issue:
Gillon, R. (1999). "End-of-life decisions." Journal of Medical Ethics 25: 435-6.
Brockman, B. (1999). "Food refusal in prisoners: a communication or a method of self-killing? The role of the psychiatrist and resulting ethical challenges." Journal of Medical Ethics 25: 451-6.
McHaffie, H. E., M. Cuttini, et al. (1999). "Withholding/withdrawing treatment from neonates: legislation and official guidelines." Journal of Medical Ethics 25: 440-6.

[211] Beauchamp, T. and J. Childress (1994). Principles of biomedical ethics. New York, Oxford University Press.

Treatment abatement in palliative care practice is based on the notion of the inevitability of death and the framework of recognising that the dying process is underway and futile treatments aimed at prolonging survival when this is no longer a realistic goal, are not required, and should not be offered or continued. Inevitably, it is understandable that there will be occasions where patients and/or families wish to continue such treatments and cling to life no matter what, and sensitive supportive negotiation is required to avoid unnecessary patient morbidity and waste of resources which could be better directed to appropriate palliative care. Abatement in this setting does not bring causation into question.

Abatement decisions concerning life support interventions for non-dying persons who are permanently unconscious or very severely brain-damaged do need to be made, but the forensic causal argument is different. A moral equivalence argument based on causation and outcome can be made, i.e. death is indeed caused by the treatment abatement. No matter what arguments are put, it would appear that public policy and the law in most countries considered here have explicitly or implicitly allowed such decisions in public policy and the law for many years without invoking causation or legal sanction.[212]

[212] There have been disturbing recent moves in the UK parliament to legislate against abatement of the provision of fluids and nutrition, together with claims in the press that the aged are being neglected and deaths caused by such abatement decisions.

CHAPTER 6
LEGAL CAUSATION AND PALLIATIVE CARE

6.1 Causation in law and medicine

Legal causation, as it applies to death causation and palliative care, will be considered at some length for the following reasons. Firstly, despite showing disdain for what they might see as incursion of the law into clinical matters,[213] health care professionals shape their clinical practice according to what they perceive to be the requirements of the law, and these perceptions are often false.[214] Secondly, legal deliberations have formed an important part of the societal discourse on these issues. Thirdly, the law has had an important influence on public policy. Legal cases and proposed legislation have led to four of the most influential parliamentary reports considered in this thesis, and courts have requested the involvement of the legislature in addressing the issues. Lastly, there are some important distinctions about causation in the law and medicine (and science) which require elucidation. [215]

Dialogue between medicine and the law is hampered by the fact that the term causation in medicine and science is usually employed in a narrow empirical sense. This is a term which itself has a complex and interesting history,[216] but taken here to mean the facts or data pertaining to a given situation, and their relationship to one another. Causation is a complex notion in the law, and it might be reasonably argued that it is a misnomer

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[213] Interestingly, a view shared by the Law Lords in *Bland*, which would perhaps surprise many doctors.

[214] Although surveys which have examined reports of end of life care would indicate that there is a wide range of clinical behaviour by doctors, with some prepared to state that they break the law by assisting patients to die.

[215] The philosophical literature on this complex topic will not be addressed. This is not to suggest that it is unimportant, but rather it is not directly relevant to the regulation of clinical practice.

[216] See Williams, R. (1985). Keywords: a vocabulary of culture and society. New York, Oxford University Press., pp 115-117, for an account of the various meanings of the word 'empirical'.

in that context.[217] Legal causation is established by courts looking at the chain of events in a case, and then attempting to attribute legal liability. In legal usage the term therefore encompasses the facts *and* determination of legal liability.[218]

Most people without a legal background, and hence most health care practitioners, will have a narrow medical view of causation, which approximates to the 'but-for' test of causation. In fact the law, particularly in Australia, recognises the multifactorial nature of causation, and does not use the "but-for" test as the sole legal standard for ascertaining or apportioning legal responsibility,[219] which is over-arched or controlled by the test of common sense and experience:

> In law ... problems of causation arise in the context of ascertaining or apportioning legal responsibility for a given occurrence ... Thus, at law a person may be responsible for damage when his or her wrongful conduct is one of a number of conditions sufficient to produce that damage. [220]

Jane Stapleton has suggested that causation in legal analysis sometimes masks more important public policy considerations which may be the true issues at stake in given cases:

> Causation is not a scientific concept at all. Rather, it is a term we sometimes use to answer one question about a transition that has happened in the world and sometimes to answer a quite different question about such transition. These two questions are:
>
> 1. How did the transition come about? This is a factual question about history, though there may be value choices about how we should frame it, and

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[217] Danuta Mendelson, personal communication.

[218] Mendelson D. Torts. Sydney Butterworths, 1997. Chapter 13.

[219] "The 'but-for' test in law asks whether the damage or harm would have occurred but for the (plaintiff's) wrongful act, and serves to eliminate matters which could not have been the causes of the (plaintiff's) damage (synonyms include *conditio sine qua non*, literally 'the cause without which', 'proximate cause' and 'real effective cause').

[220] Mendelson, D. (1993). "Medico-Legal Aspects of the 'Right to Die' Legislation in Australia." Melbourne University Law Review 19: 112-152.

> 2. Of all the myriad of factors that came together to produce the transition which ones seem, in our individual opinions, to be important for the particular purpose at hand?
>
> Courts would make themselves clearer to scientists and other citizens if they explicitly distinguished between [these] two questions that can be asked about a transition. In particular, when courts are presented with cases where the substance of the dispute is about how to fill evidentiary gaps in relation to past facts or about weight to put on agreed facts, courts should recognise the case as one about competing views of legal responsibility, refuse to accept a formulation of the case as one about 'causation' and 'causal test' and instead insist that the parties argue directly about the issues of policy and principle relevant to the question of responsibility.[221]

It would surely simplify matters considerably if causation in the medico-legal context were to be understood to be a two-step analysis. The first step consists of consideration of the facts of a given case, and forensic data are clearly usually to the fore here. The second step consists of the evaluation of legal liability and culpability. Whatever the technique of legal analysis to be applied, it is important that the facts are clearly presented, and distinguished from any public policy imperatives involved.

As has been seen, the medical facts on which Devlin's judgment in *R v Adams* were based, are not consistent with modern palliative care practice and knowledge. It can be shown that in jurisdictions which follow the English common law tradition (e.g. Australia, New Zealand, Canada, the USA, and of course, England and Wales), the leading reference case is still *R v Adams*, and, in particular, the famous passage on causation quoted above.[222] As has been seen, in all the judgments and parliamentary reports studied,[223] and in the reasoning cited in many prominent legal cases,[224] it

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[221] Stapleton, J. (1999). Philosophical, scientific and legal approaches to causation. Symposium: Causation in Law and Medicine, Deakin University, Geelong.

[222] See chapter 4.3.

[223] Parliament of Victoria. Social Development Committee (1987). Inquiry into options for dying with dignity. Melbourne.

has been concluded that palliative care interventions and treatment abatement decisions may indeed constitute a cause of death. However, such practice is allowed in law, in the context of a terminal illness, because of almost universal agreement that public policy should support the imperative to relieve suffering and avoid prolongation of the process of dying. Whilst legal endorsement of accepted standards of palliative care practice is a good outcome for the care of those at the end of life, these causal assumptions concerning palliative interventions and treatment abatement decisions have been shown to be based on out of date medical evidence, and deep-seated beliefs about opioid use in particular for which there is little or no basis in the modern palliative care experience.

Although there has been no known case where this experience itself has been put to the test as such, *R v Adams* is always quoted in judicial and parliamentary deliberations concerning end of life issues. Absent any prosecutions of medical practitioners, except where intention is clearly in question,[225] academic lawyers and parliamentary enquiries have continued to take the view that prosecution is at least theoretically possible, and

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Parliament of South Australia (1991). First Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliamentary Paper No 164, Adelaide.
Parliament of South Australia (1991). Second Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliamentary Paper No 185, Adelaide.
Parliament of South Australia (1996). Inquiry into the Voluntary Euthanasia Bill 1996: Twelfth Report of the Social Development Committee. Parliamentary Paper 186, Adelaide.
Parliament of Tasmania. Community Development Committee. House of Assembly (1998). Report on the need for legislation on voluntary euthanasia. 1998 (No 3), Hobart.
Parliament of the Commonwealth of Australia. Senate Legal and Constitutional Legislation Committee (1997). Consideration of Legislation Referred to the Committee. Euthanasia Laws Bill 1996. Canberra, Senate Printing Unit, Department of the Senate, Parliament House.
House of Lords (1994). Report of the Select Committee on Medical Ethics. London, HMSO.
Parliament of Canada (1995). Of Life and Death: Report of Special Senate Committee on euthanasia and assisted suicide. Ottawa, Minister of Supply and Services Canada.

[224] *R v Adams*. [1957] Crim LR 365; *Airedale NHS Trust v Bland*. [1993] 1 ALL ER 821-896; *Rodriguez v British Columbia* (Attorney General). [1993] 3 SCR 607; *Vacco v Quill*. 117 S.Ct. 2293 (1997); *Washington v Glucksberg*. 117 S.Ct. 2258 (1997); *Auckland Area Health Authority v Attorney-General*. (1993) 1 NZLR 235-256; *R v Cox* [1992] 12 BMLR 38 (Ognall J's instruction to the jury); *R v Latimer* [1995] 126 DLR4 203; *Latimer v The Queen* [1997] 142 DLR4 577.

[225] See *R v Cox* (1992) 12 BMLR 38.

various legal mechanisms have been put forward to allow lawful palliative care.

The Australian Attorney General's Department gave this (confusing) legal advice to the Senate enquiry about the meaning of the term 'intentional killing' in the Euthanasia Laws Bill, and whether the passage of the bill would generate legal 'uncertainty' about end of life decisions:

> The Attorney-General's Department noted that English cases refer to a rule that a doctor caring for a dying patient may lawfully administer pain-killing drugs despite the fact that he or she knows that an incidental effect of doing so will be to shorten the patient's life. The Department said "it is uncertain whether the rule as stated is part of the law in all common law jurisdictions in Australia...[and a] degree of further uncertainty exists as to code jurisdictions..." The Department said if the rule were to be adopted [in Australia], "which seems probable as to general principle, if uncertain as to reasoning and detail", many uncertainties remain on matters of significant detail. [226]

6.2 Legal reasoning

6.2.1 Somerville on causation and palliative medicine

Margaret Somerville has drawn attention to the difficulties which are encountered when those outside the law attempt to grapple with legal causation and apply it to end of life issues.[227] She points out the important but nuanced distinctions between causation in the criminal and tort (civil responsibility) law. In criminal law, for causal analysis to be relevant, there would need to be conduct which would constitute a crime, *actus rea*, together with the *mens rea*, criminal intent, and the 'but-for' test is not always applied. She writes:

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[226] Parliament of the Commonwealth of Australia. Senate Legal and Constitutional Legislation Committee (1997). Consideration of Legislation Referred to the Committee. Euthanasia Laws Bill 1996. Canberra, Senate Printing Unit, Department of the Senate, Parliament House. at 29

[227] Somerville, M. (1997). "Euthanasia by confusion." University of New South Wales Law Journal 20(3): 550-575.

> When multiple causes are present, there is a value judgement involved in choosing which formulation of the 'but-for' test predominates in establishing causation-in-fact, and whether none of the causal factors, one, more than one, or all of them, each of which could attract legal liability, count as relevant in establishing criminal liability. [228]

Somerville points out the distinction between cause-in-fact and cause-in-law (causa causans) and its lesser emphasis in criminal compared to tort law. She cites this example:

> In a situation where one has a duty not to continue to treat the patient with artificial life support because the patient has refused this or because it is medically futile, then it is inappropriate to formulate the test of causation (even if it were relevant to assess causation, itself, which it is not if the act of withdrawing treatment is legal) in terms of whether the cause of death was the withdrawal of the treatment. The physician cannot have a legal obligation both to withdraw the treatment and not withdraw it and we must choose which of these duties predominates in a given situation. If the former, then the relevant test of cause of the patient's death is 'but for' the patient's underlying condition would the patient have died; if the latter, 'but for' turning off the respirator would the patient have died. [229]

Looking at withdrawal of life support, another approach is to see it as a situation of multiple causation, but here Somerville notes that courts, *from the point of view of causation,* (her italics), where the act is legal, turning off a respirator for example, was not the cause of death, and death resulted from "natural causes". Judges adopt this line of reasoning she speculates:

> To avoid any possibility that they could be seen as setting a precedent to the effect that lethal injections would be legally acceptable. [230]

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[228] Ibid p 564.

[229] Idem.

[230] Ibid, p 565.

In the law of torts, tests for causation-in-law are of 'varying degrees of stringency', and are of two sorts, 'reasonable forseeability' (a prospective test) and 'substantive cause' (a retrospective test). So with a treatment withdrawal decision, death may be foreseeable, but not the 'substantive' cause of death. In tort cases, Somerville also points out that judges will sometimes attempt to determine the *proximity* or *remoteness* of the damage from the cause, another way of looking at foreseeability.

The last test analysed by Somerville is that of *public policy*, which can be mobilised in tort law to provide immunity from legal liability, but not to impose it, and also has a special role in the criminal law to:

> Characterise acts to which consent of the person affected by such acts may function as a defence. For instance, the intentional infliction of bodily harm, beyond a certain very limited degree, will be held to be contrary to public policy and, therefore at common law the consent of the person suffering that harm will not be a defence to such an act. [231]

Lastly, Somerville addresses the public policy stance on the importance of the provision of pain and symptom relief, albeit with the causal assumption about pain relief and death risk:

> This raises the issue of how necessary pain relief treatment given with the primary intention of relieving pain that could or will shorten life should be prima facie characterised from a public policy perspective. Just as the intent to relieve pain and not to kill justifies, through the doctrine of double effect, the administration of such treatment, likewise this same intent legitimates this treatment from a public policy perspective and, therefore, it can be given with the consent of the patient. Indeed, it should be considered contrary to public

[231] Ibid, p 567.

> policy to fail to offer fully adequate pain relief treatment to persons who need this. [232]

6.2.2 *Other legal reasoning: Casswell, Skegg, Giesen, Keyserlingk, Otlowski*

In a 1987 paper on a criminal law reform, by the Law Reform Commission of Canada, it was proposed that criminal liability not be attached to the administration of life-shortening palliative care 'appropriate to the circumstances'.[233] In a commentary on this David Casswell (an academic lawyer in Victoria, BC, at the time) urged more specific criteria (terminal illness, pain and suffering). In his paper he agrees with Devlin's instruction to the jury on causation in *R v Adams*, however he goes on to state that:

> It is difficult, however, to support as a generalized proposition his Lordship's reasoning that palliative care which has the "incidental effect of determining the exact moment of death, or may have, is not the cause of death in any sensible use of the term." If a factual causal connection between the administration of palliative care and the patient's death is proved and if the physician subjectively knew that the palliative care he or she was about to administer would likely be life-shortening, it would seem that causation would be established. Further, two causes may operate together, with each legally being a cause of an event. In the present context both the patient's illness and the physician's administration of life-shortening palliative care would be the causes of the patient's death.[234]

Casswell continues that Devlin's 'absence of causal analysis' in the case has led to reasoning by others that there was an absence of intent, or that the act was justified by necessity (to relieve pain).

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[232] Ibid p 568.

[233] Law Reform Commission of Canada (1987). Report 30: Recodifying Criminal Law. Ottawa, Minister of Supply and Services Canada.

[234] Casswell, D. (1990). "Rejecting criminal liability for life-shortening palliative care." Journal of Contemporary Health Law and Policy 6: 127-145. Casswell refers extensively to works by the eminant jurist Glanville Williams: G. Williams (1958) The Sanctity of Life and the Criminal Law, pp288-290, and G. Williams Textbook of Criminal Law (2nd ed. 1983).

Peter Skegg (Faculty of Law, Otago University, Dunedin, New Zealand) has written that there is a theoretical possibility that the administration of pain-killing drugs which hasten death might lead to a prosecution of homicide in a New Zealand court, although no such thing has ever happened, and criminal liability would not be established, provided that intention is clear. Reliance on causation is thought to be preferable to a defence of necessity, as these do not have a very successful track record in English courts. It is also of note that Skegg states that the principle of double effect has no track record or standing in legal analysis, despite the fact that courts and parliaments have endorsed it.[235]

Margaret Otlowski (Law, University of Tasmania) is also troubled by Devlin J's instruction to the jury in *R v Adams*[236] and concurs with Williams that it rests on the legal doctrine of causation. She argues that application of strict common law principles to pain and symptom relief in terminal care may lead to the drug(s) being found to cause death rather than the underlying disease (the reverse finding to that in *R v Adams*). She writes:

> The prevailing assumptions regarding ... this practice are irreconciliable with established criminal law principles and ... the law is clearly being manipulated in order to sanction what is widely regarded as legitimate medical practice. Clearly, doctors must be able to administer lawfully the necessary palliative drugs to relieve their patients' pain and other symptoms but it is argued that a more satisfactory basis for the legal exception needs to be developed. [237]

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[235] Skegg, P. (1984). Drugs hastening death. Law, Ethics and Medicine: Studies in Medical law. Oxford, Clarendon Press: 121-139.
Skegg, P. (1995). "Pain-killing drugs and the law of homicide." Otago Bioethics Report 4(3): 8-10.

[236] *R v Adams*, Central Criminal Court, London, 1957. Unreported but discussed in Palmer, Dr Adams' trial for murder, [1957] Crim LR 365. See also G. Williams, The Sanctity of Life and the Criminal Law, 1958, pp 288-90.

[237] Otlowski, M. F. A. (1997). Voluntary euthanasia and the common law. Oxford, Oxford University Press. See p181.

Giesen (Professor of Comparative Law, Free University of Berlin) also highlights the legal uncertainty as to the jurisprudential basis for allowing the administration of analgesics which might shorten life:

> The Principle of double effect is a way to resolve the dilemma of the conflicting duties springing from the principles of nonmaleficence (not to kill) and beneficence (to relieve pain) which cannot be observed simultaneously. This in effect is not only the ethical, but also the legal position, although it is not quite clear what the exact legal reasoning is: a lack of guilt, justification on reasons of necessity or missing causation.[238]

Keyserlingk,[239] in an argument against decriminalisation of assisted suicide based on an analysis of Rodriguez, proposes a move away from standard and 'but-for' causality of death approaches in legal analysis. Instead he favours the adoption of what he terms a normative causality approach, and what courts more commonly term the 'common sense' and 'experience' test of causation. Causality is divided into three categories: standard, empirical and normative.

Standard causality entails the characterisation of treatments (eg ordinary v extraordinary) in order to allow abatement. Cause of death is usually ascribed to the underlying disease rather than the decision or intervention in question. Any therapeutic intervention in palliative or terminal care may potentially affect the timing of death, but the cause remains the underlying condition from which the person is dying. Lord Goff appears to be articulating Keyserlingk's standard causality category in *Bland.*

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[238] Giesen, D. (1990). Law and moral dilemmas affecting life and death. Law and ethical dilemmas at life's end. Strasbourg, Council of Europe.

[239] Keyserlingk, E. W. (1994). "Assisted suicide, causality and the Supreme Court of Canada." McGill Law Journal 39: 708-718.

> As I see it, the doctor's decision whether or not to take any step must (subject to his patient's ability to give or withhold his consent) be made in the best interests of the patient. It is this principle too which, in my opinion, underlies the established rule that a doctor may, when caring for a patient who is, for example, dying of cancer, lawfully administer painkilling drugs despite the fact that he knows that an incidental effect of that application will be to abbreviate the patient's life. Such a decision may properly be made as part of the care of the living patient, in his best interests; and, on this basis, the treatment will be lawful. Moreover, where the doctor's treatment of his patient is lawful, the patient's death will be regarded in law as exclusively caused by the injury or disease to which his condition is attributable. [240]

'But-for' or empirical causality relies on the scientific cause (the facts of the case). Normative causality allows a more comprehensive analysis including normative considerations and empirical data:

> [This] position emphasises not simple scientific causality, the cause-in-fact of a death, but normative or legal causality as well. This more nuanced and comprehensive analysis holds that empirical, scientific or "but-for" causality cannot alone account for what distinguishes assisted suicide from voluntary euthanasia, or what distinguishes both from withdrawal of life support or appropriate pain control resulting in death.[241]

This normative, or common sense and experience approach allows the 'but-for' cause of death to be overridden if a society (via its legal or parliamentary institutions) decides that the intervention or non-intervention in question should not be viewed as a cause of death in law, which appears to be the case in the matter of opioids and pain relief and putative potential life-shortening.

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[240] *Airedale NHS Trust v Bland.* [1993] 1 All ER at 868.

[241] Keyserlingk, E. W. (1994). "Assisted suicide, causality and the Supreme Court of Canada." McGill Law Journal 39: 708-718.

6.3 Australian statutes

Rather than fashioning holdings or ethical arguments to fit the outcome desired, it is at least worth asking whether it would be preferable to state public policy clearly, where necessary by statute, as has been done in South Australia. Double effect was put into statute law for the first time, with regard to the care of dying persons, with the *Consent to Medical Treatment and Palliative Care Act, 1995*. In Division 2 of this act, entitled 'The Care of People Who Are Dying', there is a non-culpability clause which specifically states that medical treatment for the relief of pain or distress, and the non-application or discontinuance of life sustaining measures (for people who are dying) does not constitute *an intervening cause of death* (*novus actus interveniens*, ie a cause that breaks a pre-existing chain of causation).[242]

A saving provision was inserted stating that the act does not allow euthanasia.[243]

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[242] *Consent to Medical Treatment and Palliative Care Act* 1995 (SA):

DIVISION 2 - THE CARE OF PEOPLE WHO ARE DYING

17. (1) A medical practitioner responsible for the treatment and care in the terminal phase of a terminal illness, or a person participating in the treatment and care of the patient under the medical practitioner's supervision, incurs no civil or criminal liability by administering medical treatment with the intention of relieving pain or distress -
    (a) with the consent of the patient or of patient's representative; and
    (b) in good faith and without negligence; and
    (c) in accordance with proper professional standards of palliative care,
    even though an incidental effect of the treatment is to hasten the death of the patient.

(2) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, is, in the absence of an express direction by the patient or the patient's representative to the contrary, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state.

(3) For the purposes of the law of the State -
    (a) the administration of medical treatment for the relief of pain or distress in accordance with subsection (1) does not constitute cause[1] of death; and
    (e) the non-application or discontinuance of life sustaining measures in accordance with subsection (2) does not constitute a cause[1] of death.

[1]A novus actus interveniens ie a cause that breaks a pre-existing chain of causation.

[243] For a detailed legal analysis of the original Bill's provisions, see: Advice to the Minister for Health, South Australia, Professor Margaret Somerville. Director, Centre for Medicine, Ethics and Law, McGill University, Montreal. Adelaide, 23rd December 1992.

The parliamentary select committee from which this piece of legislation emerged heard wide-ranging evidence, including assertions by palliative care physicians that death was not caused by palliative interventions and treatment abatement. Nonetheless, they heard sufficient professional and community concern about this issue to take the same view as the Canadian Senate, namely that it was important to be specific in law, in order to prevent false perceptions of what the law had to say in this area from obstructing appropriate care of dying people. The House of Lords also endorsed double effect but did not recommend any legislation.

The objects sections of the four Australian state and territory acts of parliament which have been passed over the last decade on matters related to death and dying all have significant comment to make about the issue of proper pain and symptom control,[244] but only the South Australian act specifically articulates and codifies the principle of double effect in this context. This is not to suggest that there have been prosecutions of doctors for treatment abatement decisions or palliative interventions, which there have not, nor to propose legal remedies for clinical problems. Rather, if the law specifically articulates, in statute, the priorities and parameters it sets for the care of dying people and differentiates palliative care from euthanasia, this sends a powerful

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(unpublished). Professor Somerville, raised a number of legal concerns about the proposed provisions. Courts rather than the medical profession are the final arbiters as to what constitutes acceptable standards of medical practice (in Australia since *Rogers v Whittaker*); the meaning of 'without negligence'(would this be present if there were breach of the legal standard of care, even though the tort of negligence would not be established in the absence of damage to the patient?) and 'in good faith'(did this render practitioners who would not be liable for private law damages liable because of the Bill's immunity provision, or does it refer to a state of mind, viz, an absence of 'mens rea'?) Somerville's advice would appear to have led to the saving provision being inserted into the Act, as she advised that Division 2 could be read to allow for voluntary euthanasia. She also questioned the meaning of the terms 'terminal illness' and 'moribund state'.

[244] Eg. *Medical Treatment Act* 1988 (Victoria).
Preamble.
(e) to encourage community and professional understanding of the changing focus of treatment from cure to pain relief for terminally-ill patients;
(f) to ensure that dying patients receive maximum relief from pain and suffering.

Consent to Medical Treatment and Palliative Care Act 1995 (South Australia)
(c) to allow for the provision of palliative care, in accordance with proper standards, to people who are dying and to protect them from medical treatment that is intrusive, burdensome and futile.

message to practitioners and their teachers which may fundamentally influence such care for the better. This holds even if the causal assumption about opioids and causation is inflated and unsubstantiated.[245]

6.4 Double Effect

As has been seen, the doctrine of double effect is the foundation stone of most of the ethical and legal reasoning on end of life issues upon which the present international status quo in public policy has been built. Its adoption in legal reasoning is particularly striking in view of the fact that it is not a recognised legal doctrine, and is not, therefore, found in any other area of legal reasoning. It also would appear to have no identifiable basis in medical practice or science.

The doctrine has its origins in medieval Roman Catholic moral theology, and can be traced back to the writings of Thomas Aquinas. Young has shown three accounts of it:[246]

> New Catholic Encyclopaedia: the doctrine consists of four conditions that must obtain in order for an action that one can foresee will have a good effect and a bad effect to be morally permissible:
>
> 1. the act itself must be morally good or at least morally indifferent;
> 2. the agent may not positively will the bad effect but may merely permit it. (If he could obtain the good effect without the bad effect, he should do so);
> 3. the good effect must be produced directly by the action, not by the bad effect. Otherwise, the agent would be using a bad means to a good end, which is never allowed;
> 4. the good effect must be sufficiently desirable to compensate for the allowing of the bad effect."[247]

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[245] This 'educational' role for the law is noteworthy.

[246] I am indebted to Professor Robert Young, Professor of Philosophy, Latrobe University, to quote from his paper given in the Philosophy Department of Melbourne University on 17th March 2000, entitled 'Palliative Care and the Doctrine of Double Effect'. He points out that Australian, American, British and World Medical Associations have all made policy statements which incorporate double effect reasoning to allow palliative care and forbid euthanasia.

[247] New Catholic Encyclopaedia, 1967.

> Joseph Mangan:[248] A person may licitly perform an action that he foresees will produce a good and a bad effect provided that four conditions are verified at one and the same time:
> - that the action in itself from its very object be good or at least indifferent;
> - that the good effect and not the evil effect be intended;
> - that the good effect be not produced by means of the evil effect;
> - that there be a proportionately grave reason for permitting the evil act.
>
> Joseph Boyle:[249] It is permissible to bring about harms which it would be absolutely impermissible to bring about intentionally, provided:
> 2. the harms are not intended, but brought about as side effects; and
> 3. there are sufficiently serious moral reasons for doing what brings about such harms.

Pope Pius XII was posed the following question at the Congress of Anesthesiologists in 1957,

> Is the suppression of pain and consciousness by the use of narcotics [.....] permitted by religion and morality to the doctor and the patient (even at the approach of death and if one foresees that the use of narcotics will shorten life)?

He replied:

> If no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties.

The emphasis on a distinction between physical and moral consequences is important, and Pope Pius shows the strength of the religious basis of the doctrine's formulation and application.

McCabe gives an account of how the doctrine, in strict keeping with its moral theology tradition, is applied to palliative care:

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[248] Mangan, J. (1949). Theological Studies 10: 41-61.

[249] Boyle, J. (1991). Journal of Medicine and Philosophy 16: 475-494.

> In palliative care, the intent is to relieve pain and not to directly cause the death of the patient. Consequently, palliative care is ethically acceptable because any unintended effects are physical and not moral. The act of palliation has two effects, alleviating pain and, in the light of recent medical literature, "possible" respiratory depression. The latter effect is not intended because the terminally [ill] patient's pain is "alleviated" by the palliation and not by his or her death. Given that, by definition, the terminally ill have a fatal pathology, the level of palliation may be titrated to effect. More positively, this principle is not a "legalistic formula" but provides an aid for discerning the ethical and moral validity of an action.[250]

The doctrine is deployed as a technique of attempting to show that human agency is not casual of death in a range of medical contexts, because such agency is prohibited by religion, the determination of the mode and timing of death resting exclusively with God. It should be seen that natural death, in the forensic sense of death from natural causes, can also suit this purpose neatly, for nature read God (see chapter 1). The usual end of life scenarios in question are: opioid analgesia, terminal sedation, treatment abatement (for both dying and non-dying persons) and the administration of non-analgesic drugs with lethal intent in terminal care. Each will be considered briefly in turn.

Opioid analgesia

Double effect, as employed in *R v Adams*, is not required as death due to opioid toxicity is not being defended as part of palliative care practice. Morphine does not cause death if used appropriately, according to accepted standards of palliative care practice (see Ontario coroner's principles), only if the initial dose or dose escalation is too steep. The only exceptions to this would be where the dose is elevated (significantly) above the accepted dose range, due to medical negligence, or an intent to end the person's life.

Terminal sedation

[250] McCabe, M. J. (1997). "Ethical issues in pain management." The Hospice Journal 12(2): 25-32.

When sedative drugs are used in terminal care (where the person is imminently dying) to treat signs of emotional distress and/or physical restlessness, the intent is clear, but the determinant of causal contribution to timing of an otherwise imminent death is not possible in this situation. The sedation is given to relieve an objective symptom. The law would not apply a causal analysis here. Medicine, however, cannot empirically define the causal contribution which the drug might make, in a multifactorial causal model, to the actual timing of death. Few would even argue that it is important to do so in a particular case, unless relatives wish to be reassured that the drugs are not responsible for the patient's state, in which case, the drugs may be temporarily ceased or doses reduced to show that their comatose state and deteriorating condition is due to the dying process and disease rather than the drugs.

Treatment abatement

When a person is dying cessation of futile treatment does not make a causal contribution to the person's death, as the treatment in question is no longer effective in controlling the disease or pathological process, and is therefore not of itself life-sustaining.

For a person who is not dying, abatement of treatment which may be life-sustaining may cause death, as there is no other defensible intended transition apart from death. For example, in *Bland*, Tony Bland was not dying when his nasogastric tube was removed, but he died after the cessation of the sustenance being provided by it. In order to make this course of action ethical and legal, there has to be a public policy acknowledgement that there are times when death is caused by treatment abatement for non-dying persons. One way of describing this is to find (in law) that death is due to the underlying condition, ie a healthy person does not die if they have tube feeding ceased. This is true, but the feeding was keeping him alive, and 'but-for' its removal he would continue to live on in his persistent vegetative state. Neither a causal analysis (medical or legal) nor the doctrine are helpful or necessary here. Abatement of life-sustaining medical treatment is necessary here to end the life of a person who is irreversibly unconscious. The law would usually find that there

was no duty to continue the tube feeding (as in *Bland*), that medicine and the underlying condition has put him in this position, and his interests are not served by continuing treatment, as nothing can restore consciousness.

Administration of a non-analgesic drug with lethal intent

In *R v Cox*,[251] a lethal injection of potassium chloride was given by a doctor to end the life of patient who was suffering from poorly controlled pain. The defence was that the drug was being used to relieve pain. However, there is no role for invoking double effect here as the drug is not an analgesic, it abolishes pain by ending the person's life, the intention to do so is implicit and usually explicit in these situations, although the outcome, if the patient desires it, will not necessarily be unwelcome.

In none of the above situations is the doctrine of double effect helpful in elucidating the medical, ethical or legal aspects of particular situations, with the possible exception of terminal sedation, where the causal contribution of the sedative drug(s) is usually unverifiable, and probably by common assent, the least important.

Palliative care practitioners in general are very attached to double effect as a way of describing what they do, at least in an ethical sense.[252] However, a small number of them have started to question this. Jessica Corner, a prominent palliative care nurse, in commenting on the recent Annie Lindsell case in the UK, has made a plea for palliative care to recognise that there may be times when death is an intended outcome.[253] Quill and co-authors have argued that patient self determination is more important than doctor's intentions as a guide to action in end of life decision making.[254] This view has been shared by a South Australian palliative care

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[251] *R v Cox* [1992] 12 BMLR 38.

[252] Gilbert, J. and S. Kirkham (1999). "Double effect, double bind or double speak." Palliative Medicine 13: 365-366. Dunphy, K. (1998). "Sedation and the smoking gun: double effect on trial." Progress in Palliative Care 6(6): 209-12.

[253] Corner, J. (1997). "More openness needed in palliative care." British Medical Journal 315: 1242.

[254] Quill, T. (1997). "The rule of double effect - a critique of its role in end-of-life decision-making." New England Journal of Medicine 337: 1768-1771.

specialist (Roger Hunt),[255] and another in Quebec (Marcel Boisvert).[256] Quill et al write:

> For clinicians and others who believe in an absolute prohibition against actions that intentionally cause death, the rule of double effect may be useful as a way of justifying adequate pain relief and other palliative measures for dying patients. But the rule is not a necessary means to that important end. Furthermore the rule's absolute prohibitions, unrealistic characterisation of physicians' intentions, and failure to account for patients' wishes make it problematic in many circumstances. In keeping with the traditions of medicine and broader society, we believe that physicians' care of their dying patients is properly guided and justified by patients' informed consent, the degree of suffering, and the absence of less harmful alternatives to the treatment contemplated.[257]

The doctrine of double effect has been subjected to penetrating intellectual assault by certain influential philosophers, and its role in formulating the moral basis of palliative care must be questioned. Singer has suggested that it is a 'figleaf' used to hide decisions whose intention and outcome is to end life. In the *Bland* case, he makes the self-evident case that the intended outcome of the court's decision was Anthony Bland's death.[258] Young has argued that the distinction between what a practitioner intends, as opposed to merely foreseeing, is not a sufficiently robust ethical basis for determining what is permissible in the care of the terminally ill, and that death for those who seek it is not a bad outcome.

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[255] Hunt, R. (1994). Palliative care: the rhetoric-reality gap. Willing to listen, wanting to die. H. Kuhse. Melbourne, Penguin: 115-137.
Hunt, R. (1998). "A critique of the principle of double effect in palliative care." Progress in Palliative Care 6(6): 213-215.
Gilbert, J. and S. Kirkham (1999). "Double effect, double bind or double speak." Palliative Medicine 13: 365-366.
Hunt, R. (1999). "Taking responsibility for affecting the time of death." Palliative Medicine 13: 439-441.

[256] Mullens, A. (1996). Timely death. Considering our last rights. Toronto, Alfred A Knopf.

[257] Quill, T. (1997). "The rule of double effect - a critique of its role in end-of-life decision-making." New England Journal of Medicine 337: 1768-1771.

[258] Singer, P. (1994). Rethinking life and death. Melbourne, Text.

Cavanaugh[259] concludes that double effect, as applied to palliative care, has wider acceptance than Catholic moral theology. This may be so because, (a) this theological defence of causation is accepted by many palliative care and other health care practitioners, and has been transmitted in evidence to courts and parliaments, or (b) because the causal formulations used in double effect evaluations are also the basis for prospective discussions of transitions which may result from proposed medical or surgical treatments in everyday clinical practice.

This second proposition should be examined further. Causal formulations form the basis of all discussions with patients (and/or families if the patient is incompetent) where consent to medical treatment is sought. These may sound or look as if they are dependent on the doctrine of double effect, but can function independently of it, i.e. detached from the moral and theological history, and all value judgements about the moral character of interventions, abatements or outcomes (viz, good versus bad or evil) are set aside. They then can be seen merely as a way of talking about how you start from point A, with the intention of effecting a transition to point B, an altered state of affairs, but may end up at point C, which transition could be foreseen or unforeseen, wanted or unwanted, but unintended.[260] Stated intention, and accuracy of clinical information (especially the probability of the causal inferences) are the only two requirements of such discussions. Any pretence of this being a justificatory doctrine is thus abandoned. Any effect of medical treatment can be beneficial or not (ie, the effect in question is termed an 'adverse' or 'side' effect),[261] intended or unintended, foreseen or unforeseen, and any combination of these, although you at least have to foresee an event to intend it. In addition, proportionality relevant to the particular case, has to be taken into account. As seen in Chapter One, the ratio of adverse

[259] Cavanaugh, T. A. (1996). "The ethics of death-hastening or death-causing palliative analgesic adminstration to the terminally ill." Journal of Pain and Symptom Management 12: 248-254.

[260] For this use of the word 'transition' with regard to causation, see Stapleton, op cit.

[261] Note the language employed here by doctors: side effects, adverse effects, unwanted effects, treatment-related toxicity, all refer to the same phenomenon.

effects to wanted effects should be the key element in any discussion with patients in which they decide whether a treatment is to proceed or not.

For example, when a surgeon proposes removal of a potentially lethal brain clot, and the goal of the intervention is to cure the patient, even in the best surgical hands there is a chance that the patient will not survive the procedure. This contingency is foreseen,[262] and indeed discussion of it should be a normal part of informed consent, but it is certainly unintended and non-beneficial (and hence unwanted).[263]

6.5 Conclusion

There is almost universal support for the relief of pain and suffering, and avoidance of prolongation of the process of dying. Public policy and the law has, without known exception, endorsed these common sense principles. There is also wide support for the cessation of life-sustaining measures in certain non-dying persons, where it is clear that the intention is to bring about death, as for instance those in a permanent and irreversible coma, or the persistent vegetative state, such as in the case of Anthony Bland.[264] However, there is deep division in societies about whether assisted suicide and euthanasia[265] should be made legal, and the fundamental question is causal. Those who advocate such changes often cite accepted palliative care practice in support of their position, on causal and consequentialist grounds. The line of argument runs something like this: "If you agree with the administration of opioids and sedatives, or

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[262] It is safe to say that wanted or beneficial effects of treatment are almost always foreseeable, ie the potential beneficial properties of treatment are usually known (there may be rare exceptions), whereas abherrant, idiosyncratic or very rare complications or hazards of treatments may occur 'out of the blue'.

[263] Death, however, is not always a non-beneficial or unwanted outcome, indeed the reverse would be argued by persons seeking assistance to die, and those who campaign for them. For a representative account of these views, see Julia Anaf, citing Hunt and Kuhse in "The doctrine of 'double effect' and its limitations.' The VE Bulletin, July 2000, pp7-9. (this publication is the official newsletter of the South Australian Voluntary Euthanasia Society – SAVES).

[264] *Airedale NHS Trust v Bland.* [1993] 1 All ER 821.

[265] Defined by the peak body Palliative Care Australia as 'the deliberate action to terminate life by someone other than, and at the request of, the patient concerned' 1995.

treatment abatement which even have the *potential* to alter the timing, *and therefore the cause*, of death, how could you disagree with the administration of a lethal injection which has the expressed intention of causing death?" It is clear that all criminal codes forbid causing death, and natural death has a forensic meaning of death absent human agency. Double effect is invoked to allow pain and symptom relief, which is assumed to cause death by dose escalation. Treatment abatement is allowed for dying and non-dying persons by a range of legal reasoning: usually either death due to underlying disease (Keyserlingk's standard causality) or absence of duty (and hence no breach can be demonstrated because there was no duty in the first place).

Keyserlingk's argument, that narrow empirical causality, applied in the setting of terminal care, cannot alone account for the distinction between accepted palliative care practice and euthanasia seems to accord well with palliative care practice and professional intuitions. It is both false and unhelpful to see pain and symptom relief which is appropriately and skilfully administered and monitored, together with the abatement of futile treatment in the context of a person's dying process, as causing death. Self-willed and planned death, with or without third party assistance, surely has better arguments in its favour anyway. Public opinion polls show consistent support (in many western countries) of at least three quarters of the population, so the prevailing view would appear to be strongly permissive of death being explicitly caused in the setting of a terminal illness. However, only a tiny fraction of the population, at present, ever receive such assistance even where it is an option, and the remaining quarter or so need reassurance that causation is not in question without their knowledge. Empirical verification of that reassurance is not possible in all situations, so intention remains decisive.

Despite the complexities of legal causation, and the obvious ensuing differences in the way that health workers and lawyers apply causal analysis in practice, it is important for all who work with dying people and their families to be familiar with the works of legal authorities such as Somerville and Mendelson. They show that neither criminal nor civil law

apply bare empirical (or but-for) causality to cases of treatment abatement or palliative intervention, and that practitioners who relieve suffering according to prevailing standards of palliative care practice, such as those laid down by the Ontario coroner (see above), or who abate futile treatment, need have no concern about potential legal sanction. This is the status quo in most jurisdictions,[266] and represents a way of proceeding in end of life care upon which nearly all can agree, whatever the ethical or religious beliefs held. However, in the experience of caring and being cared for, both intention and honesty are decisive. Palliative care must be clear about its intentions, and accept that there are some occasions when the process of death is hastened, either unknowingly or knowingly.[267] Far from subverting its practice, this acknowledgement might liberate it from wider claims of ambiguity on causal issues. There is a defensible canon of palliative care practice standards, which on the basis of the Ontario coroner's principles, is clearly distinguished from euthanasia, and makes no attempt to hide its intentions in double effect, and in no way constitutes an argument against euthanasia. By maintaining this distinction, confidence in palliative care is also maintained, for patients and families who are opposed to euthanasia this is essential and understood, and for those who favour it, honesty is fundamental. Lastly, the doctrine of double effect is neither a necessary nor helpful justificatory principle in palliative care and end of life decision-making.

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[266] Exceptions are where law has been enacted to allow euthanasia: the Netherlands, Oregon and for a brief time, the Northern Territory of Australia.

[267] See Corner, J. (1997). "More openness needed in palliative care." British Medical Journal 315: 1242.

CONCLUSION

This thesis has examined the way palliative care and related end-of-life issues have been analysed in medicine, ethics and law. This is a complex ongoing conversation between three major disciplines on the one hand, and the public and their policy-makers on the other. Two major assumptions have been identified which inhibit the delivery of timely and appropriate palliative care: the law's assumption that pain relief really does entail a real danger of causing death, and medicine's tendency to think solely in terms of empirical causality. The major conclusions of this study are listed below.

1. Evidence of widespread concerns about death causation, and specifically the potential for legal or professional sanction, have been expressed to bodies charged with public policy formulation on end of life issues. These concerns are still frequently expressed by health professionals, and have the capacity to impede the provision of optimal palliative care, and appropriate decision-making, at the end of life.

2. Natural death is often used in a forensic sense to mean death absent human agency. It is now widely held, particularly by many medical practitioners, that a significant proportion of deaths are orchestrated, in that they are caused, in part or wholly, by medical decisions and interventions. These deaths are not, therefore, viewed by many as being natural in the sense of the cause being the underlying disease, but rather due to the medical decision and/or palliative intervention.

3. Causation is an important analytical and reflective component of the process of determining whether palliative care is ethical and legal. But public policy, medical ethics and the law should recognise that causative analysis need not be applied to the care of persons at the end of life, unless for medical treatment purposes, or

in a legal or disciplinary setting, where negligence or criminality is suspected.

4. Differentiation between palliative care and euthanasia is necessary because intended outcomes of treatment need to be explicit and clearly communicated to patients, families and professional colleagues. Palliative care must be lawful, and applicable to all persons, whatever their views, beliefs, and wishes with regard to death causation.

5. The palliative care causal position is that life is neither intentionally shortened nor prolonged. The intention component is a matter of integrity and experience, but the forensic empirical causal claim cannot be scientifically defended in all cases during the course of terminal care, ie, the last hours of life, and the law does not require practitioners to do so. Drugs used for sedation may alter the timing of death, but they are administered with the object of improving comfort and dignity.

6. In all the principal reports, judgments and parliamentary committee proceedings which have considered these issues in the five countries considered, it has been assumed that palliative care interventions and treatment abatement decisions may indeed constitute a cause of death. However, this is allowed in law due to the public policy imperative to relieve pain and suffering and avoid prolongation of the dying process.

7. This causal assumption can be traced back to a famous passage of Justice Devlin's instructions to the jury in the case of *R v Adams* in 1957. This case specifically deals with the use of heroin in terminal care in circumstances where motive and intention were in question. Devlin's instruction was based on medical opinion of that time, which held that morphine and heroin, even when used for pain relief, led to addiction and/or death from respiratory depression. Double effect reasoning was employed to justify, and render lawful,

the use of escalating morphine doses which might have the incidental effect of shortening the life of a dying person. Modern palliative care practice shows this causal assumption about morphine to be false.

8. The doctrine of double effect has been endorsed as a justificatory principle for interventions at the end of life in all the medical, legal and public policy deliberations studied. The explicit purpose has been to clarify causation, and attempt to remove any implication of human agency in death causation, and thereby to differentiate legally and ethically acceptable palliative care practice from euthanasia. It has been extensively deployed to situations involving interventions and/or abatement decisions for both dying and non-dying persons. The doctrine is neither a reliable nor necessary justificatory principle in palliative medicine. Trenchant critiques of it have been mounted by certain philosophers and some palliative care specialists, it is not a robust legal doctrine, and it has no basis in scientific medicine.

9. Health professionals usually have a narrow empirical view of causation, and they should be made aware that the law takes a common sense and multifactorial view, and indeed will often not even apply a causal analysis, focussing more on legality of actions and presence or absence of duties instead. Clarification of what law and ethics really say about death causation in the setting of the care of dying people will show that causal anxiety is largely misplaced, inflated and inappropriate. There is no basis for fear of legal sanction by health professionals when dealing with dying persons if the prevailing standards of palliative care are adhered to.

10. Provision of artificial hydration and alimentation is widely held in ethics, law, and public policy, to be medical treatment like any other, and there is no medical, ethical or legal requirement for these to be administered to dying persons, unless indicated for comfort.

11. If the position of neither hastening nor prolonging the process of dying is not always sustainable on empirical grounds, neither is the assumption that the use of opioids and sedatives in palliative, and terminal care, and treatment abatement for dying persons cause death. Neither the doctrine of double effect nor empirical causality can account for a distinction between palliative care and euthanasia, alone or in combination. This must remain a matter of professional integrity, matched with appropriate attitudes, knowledge and skill.[268]

12. The clinical pharmacology component of palliative medicine consists of the appropriate and explicit intentional use of drugs for symptom relief, with constant response monitoring, and does not bring causation into question. (The so-called Ontario coroner's principles).

13. Abatement of burdensome and purposeless treatment during the process of dying does not constitute a cause of death, and is an integral component of palliative care practice. Treatment related toxicity is diminished or abolished and the process of dying is not prolonged. Nonetheless, in certain treatment abatement decisions concerning non-dying persons (eg *Bland*) death is the intended outcome of treatment abatement. However justified, this is not a part of palliative care practice.

14. Natural death as death due exclusively to natural causes is not a sustainable concept in modern medicine, nor is it a necessary one, unless required as part of a patient's religious beliefs. But a broader conception of natural death is useful, in terms of improving care and decision-making at the end of life, when understood in an existential sense, embracing the inevitability of death, patient autonomy and dignity. And acceptance that death is natural in the

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[268] Australia and New Zealand Society of Palliative Medicine. Australasian Undergraduate Medical Palliative Care Curriculum. Melbourne, undated (printed at Monash University 1997).

> sense of recognition of the inevitable is necessary, as modern medicine and those who turn to it for help often expect too much of it.

In both contemporary public and professional attitudes and behaviour in medical matters, there is still a strong prevailing medical preoccupation with 'buying time', suggesting a belief that doctors are responsible for death unless they do all possible to sustain life in all circumstances. Medicine is misrepresented when its sole aim is seen as universal curative competence. This transient illusion is at best an understandable extrapolation from some of the century's more striking successes. No law demands that curative measures must be administered irrespective of the therapeutic ratio or biographical setting of the patient. In Justice Thomas' fine words, natural death may have partly lost its meaning, but certainly not its significance:

> It may be deferred, but it need not be postponed indefinitely.[269]

This is the important point.

The sobering challenge for late twentieth century medicine is to embrace those practical limitations which have some claim to be seen as natural limits on the appropriateness of interventions. This implies no barrier to the true spirit of research, nor a nihilistic denial of the power of science. The claim is that medicine should be engaged in a more honest dialectic with its place in life and its role in our collective confrontation with our nature, inclusive of death.

In care and decision-making at the end of life it is argued that the deliberative processes and discourse should move away from almost exclusive focus on human agency and death causation, important though this is, and embrace non-obstruction of the dying process and self

[269] *Auckland Area Health Board v Attorney-General* [1993] 1 New Zealand LR at 253.

determination as well.[270] So natural death is seen as having a composite meaning, which embraces both forensic and existential senses. And in the final analysis all would surely agree that there is more to a 'good' or 'good enough' death[271] than causality. Ronald Dworkin gives a timely reminder of the need for tolerance and humanity to permeate all these deliberations, be they theoretical or clinical. That somehow the way we approach our deaths and those of our fellow human beings is an important ingredient in individual and collective constructs of human dignity:

> But if people retain the self-consciousness and self-respect that is the greatest achievement of our species, they will let neither science nor nature simply take its course, but will struggle to express, in the laws they make as citizens and the choice they make as people, the best understanding they can reach of why human life is sacred, and the proper place of freedom in its dominion.[272]

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[270] Stoffell, B. and M. A. Ashby (1997). On natural death and palliative care. Health care law and ethics. L. Shotton. Katoomba, Social Science Press: 163-178.

[271] This terminology is taken from the work of the English child psychotherapist D.W.Winnicott (1896-1971). See Winnicott, D. W. (1986). Home is where we start from. London, Penguin. For reflections on the good and good-enough death in hospice and palliative care, see the following:McNamara, B., C. Waddell, et al. (1994). "The institutionalization of the good death." Social Science and Medicine 39: 1501-1508.
McNamara, B., C. Waddell, et al. (1995). "Threats to the good death: the cultural context of stress and coping among hospice nurses." Sociology of Health and Illness 17: 222-243.
Hart, B., P. Sainsbury, et al. (1998). "Whose dying? A sociological critique of the 'good death'." Mortality 3(1): 65-77.

[272] Dworkin, R. (1993). Life's Dominion. An argument about abortion and euthanasia. London, Harper Collins., p241.

Postscript

This work begs the question of the author's views about the legalisation of voluntary active euthanasia. My own political worldview is imbued with the British liberal democratic tradition. I have no political, theological or ethical objection to euthanasia per se. However, I doubt that, in any of the legal formulations in which it has been hitherto proposed, voluntary euthanasia or physician-assisted suicide will be applicable to most people and their clinical situations towards the end of their lives. This applies especially to those that are most feared by many, such as permanent and progressive loss of mental and physical function, and independence (especially, for example, dementia). Although the sole requirement for third party assistance to die should be the consent of a competent autonomous person, the family and social context cannot be ignored. Where 'natural causes' are seen to be overridden, I believe that near-ideal conditions of patient consent and family consensus are required. This would certainly not be the case for a large proportion of the community. Public support for euthanasia stands at more than three quarters of the population. This author also believes that it is necessary to distinguish between palliative care and euthanasia, in order to reassure the other quarter that causation will not be in question. Present evidence also shows that of the three quarters who express support for euthanasia, many will not take up the option when the time comes. I therefore do not oppose its legalisation, but do not advocate it either. The status quo is workable, even if the reasoning which is mobilised to support present practice parameters sometimes seems convoluted and inconsistent, and frustrating for those that believe that voluntary euthanasia should be legal.

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APPENDICES

Journal Articles

1. Ashby MA, Stoffell B.
   Therapeutic ratio and defined phases: proposal of an ethical frame work for palliative care.
   British Medical Journal 1991, 302:1322-1324

2. Wakefield M, Ashby MA.
   Attitudes of surviving relatives to terminal care in South Australia.
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3. Wakefield M, Beilby J, Ashby MA.
   General practitioners and palliative care.
   Palliative Medicine 1993, 7:117-126

4. Ashby MA, Wakefield M.
   Attitudes to some aspects of death and dying, living wills and substituted health care decision making in South Australia: public opinion survey for a parliamentary select committee.
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   Law reform on death - over but not out.
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   A proposed advance directive format for South Australia.
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8. Komesaroff P, Lickiss JN, Parker M, Ashby MA.
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9. Ashby MA, Stoffell B.
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15. Excerpt from First Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliament of South Australia. Adelaide: August 1991.

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26. Natural Death Act, 1983 (South Australia).

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29. Craig G
On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?
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JOURNAL ARTICLES

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Therapeutic ratio and defined phases: proposal of ethical framework for palliative care

Michael Ashby, Brian Stoffell

> I cannot define an elephant but I know one when I see one.[1]

The everyday practice of oncology and palliative care raises complex moral issues. Examples include: When should radical curative treatment be stopped—or rejected from the outset as an option? Do measures for the relief of symptoms shorten life? When should active drug treatments—for example, antibiotics and steroids—be stopped? (Similar questions can be asked about support of physiological systems: blood transfusion, ventilation, renal dialysis, intravenous hydration and nutrition.) What steps should be taken when food and drink can no longer be taken by mouth? How should we deal with differences of opinion about management arising among patient, family, and carers? What is the relation between euthanasia and palliative care? We propose to examine these questions in a framework that divides the therapeutic interaction into three phases or modes: curative, palliative, and terminal.

Risk-benefit analysis or the therapeutic ratio is widely used in pharmacology and oncology to describe the ratio of risk of unwanted side effects (treatment related toxicity, morbidity, or mortality) to desired effect. Without determining the therapeutic ratio well reasoned or informed clinical decisions cannot be made as most proposed actions will have both desired and unwanted outcomes.

The probability of expected effects or end points may be defined by either the doctor or the patient. There may well be congruence or disagreement between these points of view. Mitchell discussed this observer variation with regard to the prevention of postoperative pulmonary emboli, for which some studies had shown an improvement in the radiological end points, but the only question the patients were interested in was whether they would die of a pulmonary embolus.[2] Similarly, with the treatment of cancer a tumour response may or may not be translated into a survival advantage or better control of symptoms for the patient.[3,4] Observer variations among patients, carers, and staff; differential goal setting; and problems of evaluation are all well documented.[5-7] In our model all treatments that are thought to offer partial responses are classed as palliative, and it requires that the partial response must also have some favourable influence on symptom control or quality of life. The table summarises the three phases or modes.

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Priorities in three modes of treatment of incurable disease

Mode	Supremacy	Survival	Toxicity	Measures to support physiological systems	Artificial hydration and alimentation
Curative	Survival	Prolong	May be high	Yes	Yes
Palliative	Quality and value of life	No	Low	Maybe (for quality only)	Maybe (for quality only)
Terminal	Quality and value of life	No	None	No	No

Curative, palliative, and terminal modes

The curative mode is the phase of therapeutic intervention in the natural course of a disease in which cure or durable complete remission is a realistic expectation. Prolongation of life and survival are the aims, and a high rate of treatment related toxicity and morbidity, and even a low level of mortality, may be acceptable. Comfort is a secondary issue; when a comfort measure conflicts with survival the supremacy of survival is the dominant theme.

The palliative mode is a phase in the natural course of a disease in which curative treatment is not expected to prolong life. Alternatively, the gain in weeks or months that might reasonably be expected may be seen to be outweighed in quality or value by the intensity or duration of the treatment related toxicity, morbidity, or risk of mortality. Therapeutic endeavours or investigations are directed at the supremacy of comfort, symptom relief, and general wellbeing. The level of

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toxicity acceptable in this mode is consequently lower than in the curative mode.

The terminal mode is the phase in which death seems inevitable and imminent. There is clinical evidence of the final part of the dying process with poor appetite, weight loss, recumbency, lassitude, failure of physiological systems, and progression of the disease. The process of anticipatory grief may have commenced for both patient and family. The intake of food and fluid decreases, and although both are always available (that is—they are never withdrawn), no form of artificial hydration or alimentation is undertaken. All measures not required for comfort are withdrawn, and no treatment related toxicity is acceptable.

Transitions

The transition from one mode to another may be either painful and problematic or smooth—the last being more likely when the issues of death and dying have been faced. A precise point of transition may not always occur, in particular in some haematologic malignancies and AIDS, in which "active" treatment may continue until very soon before death.

Patients must be given the chance to acknowledge which mode of treatment they are in. Nevertheless, the patient's social context of family and friends will loom large in many decisions. Differences of opinion among patients, families, friends, and carers will usually be resolved by discussion and, if necessary, by case conferences. Families may be counselled that withholding the truth causes emotional pain for most patients.[8-10] Matters take a different turn when the patient is no longer competent. In this case the next of kin are usually consulted, although in exceptional circumstances an agency such as a guardianship board may be required. The palliative and terminal care for geriatric and psychogeriatric patients may be especially difficult.[11]

We do not use the terms, "ordinary" measures or "extraordinary" measures—a distinction that marks off measures taken to be morally obligatory from those that may be legitimately abandoned.[12,13] We think this distinction is irrelevant as we are seeking to present a framework within which all plausible measures are weighed in terms of their impact on the patient's interests. A person's interest will sometimes be met by the curative mode and sometimes by the palliative mode, when comfort measures hold sway. In neither case are we relying on any secondary notion of prolongation of life.

Discussion

Two barriers stand out in the delivery of palliative care. The first is the frank acknowledgment of the clinical realities of palliative care; the second is a misconception about the relation between palliative care and euthanasia.

Clinicians and relatives still often fear that if patients are confronted with the full clinical reality they will give up the ghost and so do much worse than would be the case if they were in good spirits. This fear is exacerbated by myths such as that morphine is addictive or synonymous with "the end" and that palliation is at best a very poor second best for clinicians who are deeply imbued with the curative model of care. Cassidy explained that life is seen by many people as a series of minor losses escalating toward death at the end of a terminal illness and that death is often attended by conspiracies of silence, alienation, selective attention, and false reassurances.[4]

Patients and their families are all too often willing coconspirators with their doctors and carers to try treatments whatever the odds and the toxicity. Yet few—given full information—would argue that death should be defied at all costs. That the support of one failed physiological system after another during the dying process is unacceptable has been shown by the protracted deaths of three famous twentieth century heads of state—the Tito-Franco-Hirohito paradigm. Death denying attitudes with unrealistic expectation of medicine by both doctors and their patients are common sources of distress for patients with incurable cancer.

Relatives are usually unfamiliar with the features of the normal dying process. Reassurance may be needed that dying people usually want only enough food and drink to keep them comfortable—and frequent mouth care. The myths of terminal dehydration and starvation should be dispelled.[14,15] Attempts to artificially hydrate and feed the dying, particularly insertion of nasogastric tubes, are likely to add to distress rather than relieve it.

Euthanasia is an issue often raised in the context of palliative care. Though the linkage is understandable and the debate which connects them fruitful, there are two serious conceptual errors to be avoided. The first of these two mistakes is evident in those who believe—quite correctly—that improvements in palliative care may reduce the numbers of those who wish to avoid further suffering by a quick death. From this empirical assumption it is falsely inferred that the moral case for active voluntary euthanasia lapses. Improvements in palliative care are one thing; how someone chooses to use their availability is quite another.

The second error is somewhat more complex. The achievement of comfort and symptom control is the dominant concern of the terminal mode of care, and, just as we accept a level of morbidity in the curative mode, so should a risk of premature death be recognised as a possibility attendant on palliation. There is, however, no evidence that the skilled and appropriate delivery of palliative care measures (in particular the use of opioid analgesics and anxiolytic drugs) shorten life, and the natural course of unrelieved suffering must surely be unfavourable by comparison. Within the terminal mode we operate with a therapeutic ratio that balances symptom relief against a risk of death; we do not seek death—even a good or easy death—as a means of achieving relief. To seek an easy death through analgesia would be active (voluntary or non-voluntary) euthanasia.

Moving into the terminal mode implies that further therapeutic measures that do not address palliative issues will cease, and this decision is based on a judgment about clinical effectiveness. Hence in the terminal mode most therapeutic measures are likely to be useless. This recognition and the clinical judgments on which it is based are not usefully equated with what Rachels and others refer to as "passive euthanasia." In Rachels's formulation "Passive euthanasia" . . . simply means refraining from doing anything to keep the patient alive."[13]

To withhold an effective treatment because death is sought is to act in order to realise an end, much as to give a lethal injection would be. However, to withhold an ineffective treatment because it would have little chance of working is simply avoiding the futile.

Increasingly often therapeutic decision making is being assessed on the basis of cost-benefit analysis.[16-18] This is due to escalating costs of health care and increased demand in most developed countries. We believe that our first endeavour should be to examine individual intention to treat issues on the basis of the therapeutic ratio, as outlined, and not on cost. This approach should lead to a reduction in inappropriate use of precious resources to treat patients with curative intent when the mode is palliative. A clearer idea of which treatments are curative, palliative, or experimental in a given clinical setting would lead to both

better patient care and savings.[17] This aspect should be addressed firstly on the basis of asking the question "Is the therapeutic ratio favourable and realistically constructed for this patient and this proposed treatment?" and not "Is it more cost effective to treat this patient than another patient?"

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APPENDIX 2

Original Article

Attitudes of Surviving Relatives to Terminal Care in South Australia

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Abstract

To provide evidence concerning caregivers' perceptions and experiences of terminal care service delivery in South Australia for a State Parliamentary Select Committee on the Law and Practice Relating to Death and Dying, a structured interview was conducted with surviving caregivers 1 year or more after the death of a family member. One hundred caregivers of deceased patients from metropolitan Adelaide were identified from the South Australian Central Cancer Registry. The study included caregivers of patients who died at home (N=18) or in a public hospital (N=27), hospice (N=22), private hospital (N=19), or a nursing home (N=14). Home-care services were rated as good to excellent in most cases. The main sources of dissatisfaction were delays in gaining access to medical care and lack of practical help, such as showering or lifting. In most cases, the institutional care provided to terminally ill patients was judged by relatives as being good to excellent. Relatives expressed greater levels of satisfaction with hospice care, probably reflecting the higher staff ratios available at these institutions. Most caregivers considered that the place of death was the right place for the patient to have died. Home deaths were characterized by the patient having expressed a wish to die at home, whereas institutional care was sought because it was perceived that there would be better control of problematic symptoms in the terminal phase of care. Access to medical care, especially in public and private hospitals, was a concern for a significant percentage of caregivers. Lack of communication about the patient's progress and a perceived degree of insensitivity on the part of doctors was also a problem for some caregivers reporting on care at these institutions. Nearly one-third of caregivers volunteered that they were unhappy with the way in which doctors had communicated the nature of the patient's terminal condition, believing either that the news should not have been given or that it had been given inappropriately. These data demonstrate that the public values palliative care and hospice care, especially compassion, good relationships and communication, access to 24-hr medical and nursing care support, and sound practical backup with equipment and services. Adequate funding for the provision of such services needs to be addressed, particularly as numbers of cancer deaths increase. The difficulties of breaking bad news are highlighted, and should be noted by medical educators. J Pain Symptom Manage *1993;8:529–538.*

Key Words

Cancer, home care services, patient satisfaction, place of death, quality of health care, and terminal care

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Introduction

In late 1990, a Select Committee of the House of Assembly of the Parliament of the State of South Australia was established on the Law and Practice Relating to Death and Dying. The Committee considered that there was a need to investigate the views and experiences of surviving caregivers regarding the terminal care provided to their loved ones. The membership and terms of reference of the Select Committee are set out in Appendix 1, and the first and second interim reports have now been tabled.[1,2]

Although the degree of involvement of relatives in the terminal care experience may vary, the principal caregivers are usually close family members. Families are, therefore, in a position to observe the care received by patients and are usually active participants in their care. Where similar studies have been conducted, they have been helpful in providing a consumer perspective for the planning of palliative and terminal care services.[3–8] The aims of the present study were the following:

1. To determine overall levels of satisfaction of surviving relatives with terminal care, and to examine differences according to place of death.
2. To determine the extent of use of services for terminally ill patients.
3. To identify problems encountered in the period of terminal care, particularly in relation to
   (a) Access to palliative care,
   (b) Communication, particularly concerning medical progress,
   (c) Institutional care, and
   (d) Home-care services.

Methods

Sampling Procedure

The South Australian Cancer Registry was used to select a random sample of case record numbers of patients aged at least 20 yr who died from cancer in the Adelaide metropolitan area approximately 12–15 mo prior to the proposed interview period. For deaths occurring in institutions, a random sample of 40 patients was selected for each category of place of death (public hospital, private hospital, hospice, and nursing home). Following ethics approval from each of the institutions, access to patient case notes was obtained. A patient death was then excluded from the study if death was found to have occurred under active treatment, or if the diagnosis of cancer did not occur until autopsy. The name, address, and telephone number of the contact person listed in the case notes (usually a relative or close friend) was extracted, and a standard approach letter seeking the involvement of the relative in the study was then sent from the institution. Telephone follow-up 1 wk later was undertaken by one of two nurses with palliative care experience, and if the caregiver agreed to be involved in the study, an appointment was made for the interviewer to travel to the caregiver's home to conduct the interview.

By reference to the case notes and Central Cancer Registry data, information was collated for each patient on the type of cancer responsible for the patient's death, the time between diagnosis and death, the period of terminal care (when active treatment ceased), and the length of the final admission, as well as other patient details such as age, gender, and country of birth.

For cancer deaths occurring at home, a random sample of 80 of these deaths was selected from Royal District Nursing Society (RDNS) records. Due to the differing ethics requirements of RDNS, telephone contact to recruit caregivers to the study was not permitted. The more passive form of postal recruitment was considered likely to yield a much lower response rate and consequently the sample to be selected was increased from 40 to 80. Access to the case notes of each patient was obtained and a letter seeking the relative's involvement in the study was sent with a reply paid envelope by RDNS to the relative. Those caregivers who did not wish to participate were asked to ignore the letter. Caregivers were assured that they should be forthright in their assessment of RDNS services, and that their responses would be forwarded directly to the research team without perusal by RDNS staff. Those who indicated that they wished to participate received a phone call to arrange a time for interview in their own home.

Interview Procedure

Interviews were conducted by one of two nurses with palliative care experience (one

male and one female) in the relatives' own homes. The first section of the questionnaire explored whether the patient's condition had been explained to both the relative and the patient, and the extent to which they were aware that the patient was dying. Caregivers were also asked to indicate which of a list of symptoms commonly experienced by cancer patients were encountered, whether they were severe, and whether the treatment seemed to help. The second section dealt with perceptions of satisfaction with palliative care service delivery, and the questionnaire was adapted according to whether death occurred at home or in an institution.

Data Analysis

Where cell sizes were of sufficient magnitude to enable statistical analysis, comparisons between proportions were undertaken using the Fisher's exact test.

South Australian Domiciliary Care Agencies

An explanation of the role of these agencies (RDNS, Domiciliary Care, and Meals on Wheels) is contained in Appendix 2.

Results

Response Rates

Table 1 details exclusions and nonrespondents, by place of death, for the 233 cases randomly selected to comprise the sample. Overall, a total of 100 interviews were undertaken, this being 56% of those cases eligible for interview. Most nonresponses were due to being unable to make contact with the caregiver (34%), rather than refusal to participate (11%). Those who refused were not significantly different from those who participated with respect to patient's country of birth, age, gender, or cancer site. A significantly higher response rate was obtained for institutional deaths (63%), compared with home deaths (37%), reflecting the less direct method used to approach caregivers of those who died at home ($P = 0.003$).

Sample Characteristics

Of the 100 deceased patients, 53% were male and 47% were female. Nearly 71% were Australian born, with a further 16% having migrated from other English-speaking countries, and 13% originating from non-English-speaking countries. The mean age of patients at death was 68 yr (SD = 13 yr); this varied according to place of death, with those dying at home having a mean age of 61 yr (SD = 11 yr), which was lower than for those dying in nursing homes (mean, 79 yr, SD = 8 yr).

Overall, the mean number of months between diagnosis and death was 20 mo, although this varied widely (SD = 29 mo). For institutional deaths, the mean length of the final admission was 23 days (SD = 45 days). Public hospitals had a lower mean length of final admission (10 days; SD = 8 days), when compared with hospices (mean, 23 days, SD = 48 days) and private hospitals (mean, 23 days, SD = 43 days) and nursing homes (mean, 58 days, SD = 78 days).

The primary site of the cancer in the 100 cases under study is presented in Table 2. For each gender, there was no significant difference in the distribution of cancer sites when compared with all cancer deaths reported to the South Australian Cancer Registry in 1990.

Of the caregivers interviewed, most were close relatives. Just under half were spouses (48%), followed in frequency by daughters (18%), sons (16%), a parent (1%), or other relatives (11%). In addition, 6% of interviews were undertaken with a close friend of the deceased. Caregivers were significantly more likely to be spouses when the death occurred at home ($P = 0.02$) and significantly more likely to be sons or daughters when the death took place in a nursing home ($P = 0.002$). This was consistent with the differences in age distribution of those dying at these sites.

Awareness of Dying

Overall, 80% of respondents indicated that a doctor or nurse had explained to them the nature of the terminal condition, and 83% thought that a doctor or nurse had explained to the patient their condition. There were no differences in this regard by place of death.

In 66% of cases, respondents believed themselves to be fully aware that the patient was dying, with a further 16% being partly aware, 14% being unaware, and 4% being unsure. However, caregivers of patients who died in a nursing home were significantly less likely to be fully aware than other respondents, with nearly two-thirds indicating they were only partly aware. With respect to the patients themselves,

Table 1
Reasons for Exclusion and Nonresponse by Place of Death

	Public hospital	Hospice	Private hospital	Nursing home	Home	Total
No. selected	40	40	40	40	80	240
Exclusion for institutional reasons[a]	—	—	5	8	31	44
Exclusion for specified reasons	2	2	7	5	—	16
No. posted	38	38	28	27	49	180
Not able to contact[b]	5	12	3	10	31	61
Refused	6	4	6	3	—	19
Interviewed	27	22	19	14	18	100

[a]"Exclusion for institutional reasons" includes case notes not located, institution no longer operational, or institutional approval to access case notes not given.
[b]In the case of home deaths, "not able to contact" means no reply was forthcoming from the letter posted to the relatives having changed address; in others, relatives would have exercised the option to ignore the letter.

58% were reportedly fully aware they were dying, 14% were partly aware, 19% were said to be unaware, and in 9% of cases the relative was unsure as to what the patient had thought. No significant differences were apparent according to place of death.

Although the interview did not specifically seek further information about the breaking of bad news, many caregivers harbored sufficiently strong feelings about this issue to spontaneously describe their experiences in some detail. In all, 31% of caregivers related that they were unhappy with the way in which the news had been broken. Over half of these cases, 19% of the total, described instances where they perceived that news about the patient's condition and prognosis had been given insensitively. Some relatives, however, felt that the breaking of bad news had been done extremely well, and 9% of caregivers spontaneously expressed how much they appreciated the honesty and sensitivity of the doctors involved.

Table 2
Primary Site of Cancer in Cases Under Study

Site of primary cancer	No.
Lung	28
Colon	12
Other gastrointestinal	16
Breast	5
Hematologic	9
Brain	4
Prostate	5
Unknown	13
Other	8
Total	100

Symptom Control

Table 3 summarizes data relating to the reported prevalence and severity of symptoms, and extent to which symptoms were relieved by treatment. Treatment for pain, difficulty breathing, and trouble sleeping were relatively effective, as judged by the percentage of severe cases where treatment was reported to have helped ameliorate these symptoms. Treatment for commonly experienced symptoms, however, such as loss of appetite, weakness, and weight loss, were reported as being relatively ineffective.

Notably 73% of patients were reported to have suffered pain during the last month of life. Of these patients, 77% were rated as suffering severe pain. Among those with severe pain, 75% were reported as receiving benefit from pain control treatment.

Care at Home

Time Spent at Home in the Final Month of Life

Of the 18 patients who died at home, 10 (56%) had spent all of the final month of life at home, four (22%) had spent two-thirds or more, three (17%) had spent about half, and one (6%) had spent one-third or less at home. Of the 82 patients in the sample who died in an institution, 34 (41%) spent no time at home in the final month of life. However, 14 patients (17%) had spent one-third or less of the last month at home, 12 (15%) had spent approximately half of the time at home, and 23 (28%) had spent two-thirds or more at home. Feed-

Table 3
Reported Prevalence and Severity of Symptoms and Extent to Which Treatment Was Perceived to Have Helped

Symptom	Experienced? % of all cases	Severe? % of those experienced	Treatment helped? % of severe cases
Weakness	87	75	3
Loss of appetite	83	69	11
Weight loss	80	71	0
Pain	73	77	75
Constipation	58	78	42
Difficulty breathing	53	60	63
Trouble sleeping	48	21	62
Nausea/vomiting	42	50	43
Cough	42	33	14
Confusion	42	38	0
Fluid retention	40	63	40
Other	26	77	25

back from respondents regarding home care is also presented for the 48 patients who spent some time at home before being admitted to an institution to die.

Use and Appraisal of Home-Care Services

All patients who died at home made use of general practitioner (GP) and RDNS services, 14 (78%) used Domiciliary Care, and 10 (56%) a palliative care nurse. A small minority used additional home nursing (11%), private home help (11%), and Meals on Wheels (6%). In general, these home-care services were rated as good to excellent, but some of those using GPs (22%) and RDNS (11%) rated the service as fair.

Of the 48 patients in the institutional death group who spent some time at home during the final month of life, 31 (65%) had used a GP, 23 (47%) had used RDNS, 17 (35%) had used Domiciliary Care, and 13 (27%) made use of a palliative care nurse. Smaller numbers of patients had used private home help (19%), additional home nursing (10%), and Meals on Wheels (4%). Generally, respondents rated these services as good to excellent. However, 16% of those who had used GPs rated the service as poor to fair, as did 9% of those using RDNS and 6% of those using Domiciliary Care. Access to services, or delay in initiating assistance, was perceived as a problem in 17% of cases (three of 18 home and eight of 48 institutional deaths). Lack of knowledge of availability of services, and particularly of night and weekend on-call backup, was the most frequently stated cause. In both the home death and institutional subsamples, around 30% of respondents wished that they had had more assistance with practical caring tasks such as showering and lifting, as well as respite care.

Among those reporting on home deaths, 61% required access to additional help at night and 50% needed help during the weekend. Most respondents had no trouble gaining help at these times. Among the institutional subsample, 13 (27%) required access to additional help during the night and during the weekend. Of these, four (31%) reported having trouble getting access to adequate help during the night, and seven (54%) of those who needed help to care for patients during the weekend had trouble obtaining this help.

Institutional Care

Most patients who died in public hospitals, hospices, and private hospitals were admitted directly from home (93%, 68%, and 63% respectively), although admission from another institution was most common in the case of patients who died in nursing homes (64%).

Overall Satisfaction with Care

Respondents were asked to rate the quality of care received at the institution where the patient died on a four-point scale labeled excellent, good, fair and poor. Table 4 shows that the vast majority of respondents rated institutional care as being good to excellent.

Table 4
Rating of Quality of Care Provided According to Place of Patient's Death

Rating of care	% Public hospital (*N*=26)	% Hospice (*N*=22)	Private hospital (*N*=19)	% Nursing home (*N*=14)
Excellent	46	95	84	43
Good	42	5	11	57
Fair	12	—	5	—
Poor	—	—	—	—

Those reporting on terminal care received at a hospice were significantly more likely to rate it as excellent than those commenting on care received at other sites ($P = 0.001$).

Although a rating of fair was given by one in eight respondents involved in public hospital care and one in 20 of those reporting on private hospital care, the ratings for these institutions were not significantly different from those given at hospices or nursing homes.

Satisfaction with Doctors

Those receiving hospice care were significantly more likely than those at other sites to report that they were always able to get access to a doctor ($P < 0.001$) during the final admission (82% at hospice versus 52% public hospital, 33% private hospital, and 23% nursing home). Those reporting on nursing home care were significantly less likely to always be able to get access to a doctor ($P = 0.03$). Access to doctors at public and private hospitals was significantly more likely to be perceived by respondents as inadequate, when compared with that applying for hospice care ($P < 0.03$).

Of the doctors that were accessible, respondents reporting on hospice care were significantly more likely to be very satisfied with their care, compared with those at other sites (95% at hospice versus 31% public hospital, 58% private hospital, and 71% nursing home) ($P < 0.009$). Level of satisfaction with care by doctors was lowest at public hospitals, and there was a greater proportion of respondents who were dissatisfied with such care at public and private hospitals ($P = 0.009$). In most cases of dissatisfaction, respondents reported that there was insufficient explanation given by doctors, or that they perceived the doctors to be uncaring or insensitive.

Satisfaction with Nurses

At all sites of care, most respondents (more than 81%) rated nurses as always accessible and were very satisfied (more than 73%) with the care they gave. There were no significant differences between sites.

Information About Patient's Progress

More than half the respondents reported that they felt sufficiently informed about the patient's condition and progress at each site (85% at hospice, 71% nursing home, 63% private hospital, and 52% public hospital). There were significantly more of those reporting on hospice care who reported feeling informed in this regard ($P = 0.04$) and significantly fewer of those receiving public hospital care who felt this way ($P = 0.05$).

Significantly more of those reporting on hospice care felt sufficiently informed that the patient's death was imminent than respondents at other sites (82% at hospice, 58% private hospital, 54% public hospital, and 43% nursing home).

Satisfaction with Place of Death

Overall, most respondents felt that the place of death was the right place for the patient to die (Table 5). Very few respondents were unsure about this matter. Respondents reporting on public hospital care, however, were significantly less likely to consider that this site was the right place for the death, when compared with respondents for all other sites ($P = 0.02$).

When asked why the respective site was considered the right place to die, the prime reason given by those involved in home deaths was that the patient had expressed a wish to die at home (all cases except one) and, in most cases (78%), the respondent had wanted this also.

By comparison, satisfaction with place of death for institutional death related mainly to the need for control of symptoms (relatives were able to nominate more than one reason). A total of 53 respondents (65%) believed that

Table 5
Extent to Which Respondents Felt the Place of Death Was the Right Place for the Patient to Die

Institution right place to die	% Public hospital (*N*=27)	% Hospice (*N*=22)	% Private hospital (*N*=19)	% Nursing home (*N*=14)	% Home (*N*=18)
Yes	70	91	84	93	94
No	26	9	16	—	—
Unsure	4	—	—	7	6

the patient was too sick to be cared for at home and, in 23 cases (28%), the respondents reported that they were unable to cope with the patient's care at home. In only 12 cases (15%) did the respondent report that the patient had expressed a wish to die in the institution, and in only five (6%) cases did the respondent wish for the patient to die at that site. Respondents who believed that the place of death was the wrong place for the patient to die did so mostly because of a belief that the patient had not wanted to die there.

Discussion

Although the survey achieved a response rate of only 56%, explicit refusal was infrequent and those caregivers who refused were not significantly different from those who participated with respect to patient's country of birth, age, gender, and cancer site. Moreover, the distribution of primary cancer sites for those cases involved in the study was the same as indicated by the State Cancer Registry for all cancer deaths in South Australia. Cases involved in the study were, therefore, likely to be fairly representative of all cancer deaths occurring at each of the five different places of death.

Most of the exclusions from the randomly selected sample of patients were due to practical reasons, and particularly applied to caregivers of patients who died at home. The recruitment of this group of relatives was further compromised by a lower response rate, owing to the less direct approach used to make contact. A response rate of approximately 37% is not unexpected, however, where there is no opportunity for active follow-up.[9] However, comments were also available on terminal care at home for those patients who died in institutions but had spent variable periods at home during the final month of their lives.

It is acknowledged that the use of caregivers as informants may have introduced some degree of bias. As Addington-Hall and colleagues[6] point out, caregivers of patients who died at home would have been likely to have provided more of the patients' care than those of patients who died in an institution, and may thus have been more aware of symptoms and unmet needs. An additional point is that caregivers' perceptions may have differed from those of patients in general. Prior research has shown, for example, that caregivers rate patients as having more pain than patients themselves report.[10] These factors should be borne in mind when interpreting the results of the present study.

Awareness of the impending death and the breaking of bad news yielded some ambivalent, and at times angry, reactions. While veracity is an important guiding ethical principle in modern health care and communication, it is clear that many caregivers felt that either the news should not have been given or that the way it was given was inappropriate. Some caregivers clearly admitted to a level of denial and selective recall. Differences in levels of knowledge and the withholding of information between the patient and family members may also have contributed to reports of lingering anxiety and anger. Although there may be an element of hostility to the breaker of bad news that lasts long after the event, it seems clear that this remains an area in which more research and educational effort are required.

Perceptions of rates of symptom control were surprisingly good for pain (75%), difficulty breathing (63%), nausea/vomiting (43%), constipation (42%), and sleep difficulties (62%). It is important to note, however, that some of the most common symptoms of loss of appetite, weight loss, and weakness are virtually untreatable; cough and confusion also did poorly. Although rates of pain control were high, it is still troubling that 25% of patients with severe pain did not appear to have their pain controlled, according to relatives' perceptions.

Many positive responses came from the reports of death at home, or domiciliary palliative care, with home-care services being rated as good to excellent in most cases. However, a minority of those who used general practitioners and community nursing facilities expressed some degree of dissatisfaction with care. Access to a general practitioner was sometimes a problem, due to delays or occasional perceived unwillingness to make a home visit. Lack of practical help with caring was cited as a problem by those dissatisfied with other home-care services. Delays in accessing care caused considerable distress among caregivers, although these were uncommon.

To optimize the care of dying patients at home, families not only need to know what services are available early on, but require rapid responses to crises to meet practical, medical, nursing, and psychosocial needs. Continuity of care is also very important. It was apparent that additional help at nights and weekends was often required. As these are particularly vulnerable times, 24-hr access to medical and nursing care is clearly essential. This intensive input is usually short term.

In most cases, the institutional care provided to terminally ill patients was judged by relatives as being good to excellent. Consistent with previous study results, satisfaction with care was highest among relatives of patients who died in a hospice.[7,8] Specifically, access to and appraisal of doctors was most favorably rated compared with other institutions. Caregivers of hospice patients felt more informed about the patient's condition and were more likely to have been told when death was imminent. These findings are likely to be at least in part attributable to the higher staffing ratios available in hospices.

Among relatives of patients who died in public hospitals, access to doctors was a problem for 20% of cases, and one in five of those who had access to doctors were dissatisfied with their care. A perception that there was insufficient information given about the patient's condition and progress, and the fact that some doctors were perceived as uncaring or insensitive contributed to this appraisal. A similar appraisal of private hospitals was also given with respect to care by doctors. Although all relatives rated nursing home care as good to excellent, access to doctors tended to be less than optimum. However, level of satisfaction with their care was quite favorable.

Most respondents considered that the place of death was the right place for the patient to have died, but caregivers reporting on cases where death occurred in a public hospital were less likely to express this view. Home deaths were characterized by the patient having expressed a wish to die at home, whereas institutional care was sought because it was perceived that there would be better control of problematic symptoms in the terminal phase of care, similar to the findings reported by Addington Hall and colleagues.[6] This theme of choice in favor of death at home is also consistent with the findings of a public opinion survey performed for the Select Committee, in which nearly 60% of a sample of South Australians indicated a wish to die at home if possible (Ashby and Wakefield, manuscript in preparation).

Experiences of caregivers were mainly positive, although public hospital care, medical access and communication, and provision of additional support services at home were especially identified as areas for improvement. The public seems to value the simple things: compassion, good relationships with staff, communication, and access to 24-hr medical and nursing care support, together with sound practical backup with equipment and services. The professions and services caring for dying people are judged as much on their degree of humanity and honesty, as on technical or clinical excellence. The days of the perception of a minimalist approach to the care of the dying are clearly over.

Acknowledgments

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Appendix 1: Select Committee of the House of Assembly on the Law and Practice Relating to Death and Dying

Terms of Reference

The Select Committee was established on December 13, 1991 with the following terms of reference:

To examine

(a) the extent to which both the health services and the present law provide adequate options for dying with dignity;

(b) whether there is sufficient public and professional awareness of pain relief and palliative care available to patients facing severe prolonged pain in a terminal illness; whether there is adequate provision of such services; whether there is sufficient public and professional awareness of the Natural Death Act and if not, what measures should be taken to overcome any deficiency; and

(c) to what extent, if any, community attitudes toward death and dying be changing and to what extent, if any, the law relating to dying needs to be clarified or amended.

Members

Hon. D.J. Hopgood, MP (Chairman) Minister of Health
Mr. M.J. Atkinson, MP
Hon. J.L. Cashmore, MP
Hon. B.C. Eastick, MP
Mr. M.J. Evans, MP
Mr. V.S. Heron, MP
Mrs. D.C. Kotz, MP

Secretaries

Anthony Murphy
Gordon Thompson

Appendix 2: Description of South Australian Domiciliary-Care Agencies

Royal District Nursing Society (RDNS)

Independent service that provides comprehensive community-based nursing services in South Australia to public and private patients. One specialist palliative care Clinical Nurse Consultant is available in each of the four metropolitan regions of Adelaide, and the field staff are instructed in palliative care.

Domiciliary Care

Multi-disciplinary community care agency in South Australia that provides comprehensive home-based care, with the principal object of preventing unnecessary or unwanted premature admission to hospital (or other institutions) of the disabled and aged. This agency provides rapid deployment of care equipment in the home after needs assessment.

Meals on Wheels

An independent voluntary organization that provides home delivery of food for those who are unable to cook and shop because of illness or disability.

APPENDIX 3

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General practitioners and palliative care

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Key words: education (medical, continuing), graduate medical education, hospitalization, pain, palliative treatment

A randomly selected sample of 158 South Australian general practitioners (GPs) were sent a questionnaire which assessed opinions and management practices in the palliative care of terminally ill patients. A total of 117 responses (74%) were received. Most GPs were at least moderately satisfied with the care they were able to give their terminally ill patients, although a substantial number reported difficulties in pain and other symptom control, dealing with relatives' emotional distress and attending to patients' psychosocial needs. There was considerable support for continuing education in these aspects of palliative care. More than half were at least somewhat concerned by opioid side effects and impairment of cognitive function, although opioid dependence was not a concern. Considerable dissatisfaction was expressed with public hospital care for the terminally ill and most felt excluded from decision-making once their patients were admitted. The findings suggest that continuing education is required for GPs and that palliative care should become an integral part of undergraduate education. There is also a need to enhance communication and co-ordination between hospital and community-based services for the terminally ill.

Mots-clés: formation (médicale, continue), formation médicale du troisième cycle, hospitalisation, douleur, traitement palliatif

Un échantillon choisi au hasard de 158 médecins généralistes (GPs) d'Australie-Méridionale ont reçu un questinnaire qui évaluait leurs opinions et pratiques dans le cadre des soins palliatifs pour les patients en fin de vie. Un total de 117 réponses (74%) a été retourné. La plupart des généralistes étaient au moins modérément satisfaits quant aux soins qu'ils étaient en mesure de fournir à leurs patients en fin de vie, quoiqu'un nombre substantiel faisaient état de difficultés dans le contrôle de la douleur et d'autres symptômes, de même que pour faire face à la détresse émotionnelle des proches et pour satisfaire les besoins psychologiques des patients. Il y avait un support considérable pour la formation continue dans ces aspects des soins palliatifs. Plus de la moitié s'inquiétaient au moins un peu des effets secondaires des opioïdes ainsi que de l'altefation de l'état de conscience alors que la dépendance aux opoïdes ne

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posaient pas de problèmes. Une insatisfaction considérable a été exprimée quant aux soins fournis par les hôpitaux publics aux malades en fin de vie et la plupart se sentaient exclus de la prise de décision une fois que leurs patients étaient admis. Ces résultats suggèrent que l'éducation continue est réclamée par les généralistes et que les soins palliatifs devraient faire partie de la formation du troisième cycle. Il ya a également un besoin d'amélioration de la communication et de la coordination entre hôpitaux et services sur le terrain pour les patients en fin de vie.

Introduction

Increasingly, society is insisting on improvements in the care of the dying,[1–3] and, as a consequence, palliative care services have expanded to become an integral element of patient care.[4] A select committee of the South Australian House of Assembly has been established to examine the law and practice relating to death and dying in this state. The committee considered that general practitioners (GPs) were an essential component in palliative care and commissioned a review of GPs' attitudes and management practices.

In the past, palliative care has been considered an important element in daily general practice, although recent reports suggest that there may be shortcomings in some areas of management. Difficulties have been reported in pain and other symptom control[5] and in managing patients' and relatives' emotional distress.[5,6] Bereavement counselling for relatives of patients dying at home has also been found to be imperfect.[7] Findings such as these have prompted calls for the development of postgraduate training programmes for GPs.[2,8] This study presents the results of a questionnaire survey of South Australian GPs, in which these and other issues related to the management of terminally ill patients were explored.

Methodology

A random sample of 110 metropolitan and 48 rural GPs was selected from a master list of South Australian GPs provided by the RACGP Research and Health Promotion Unit. The master list was collated from a number of sources including the RACGP membership list, the Medical Board of South Australia's Register of Medical Practitioners, and the Australian Health Insurance Commission's list of medical practitioners providing GP services. The list is updated periodically by telephoning the GPs to ensure correct address details. For the purposes of the present study, each randomly selected GP was mailed a questionnaire and reply-paid envelope; those who had not returned their questionnaire after two weeks were given a telephone reminder.

As part of the development of the survey instrument, two focus group discussions were convened for 14 GPs to discuss issues relating to the care of terminally ill patients in the context of general practice. A draft version of the survey questionnaire was pilot-tested on these GPs and, as a result of feedback, minor amendments were made. The final questionnaire explored the extent of GPs' experience in caring for terminally ill patients, satisfaction with the community care of terminally ill patients, use of and perceptions regarding institutional care, beliefs about pain control, and views concerning possible measures to assist improved care by GPs. The questionnaire also included questions about a range of legislative issues which are beyond the scope of the present paper. In addition, basic descriptive information was sought, including length of time in general practice, gender, location of main practice, membership of medical societies, additional qualifications and vocational registration.

Of the 158 questionnaires posted, a total of 117 (74%) were returned with complete information in the five-week period before data analysis was begun. Three GPs declined to complete the questionnaire. There was no difference in response rates between metropolitan and rural GPs.

Responses to each survey question were examined according to practice location, years of experience in general practice, and number of terminally ill patients treated in the preceding

year. Comparisons between subgroup proportions were analysed using conventional Chi-square tests of significance, or Fisher's Exact Test, when expected cell sizes were less than a value of five. Subgroup differences in mean opioid treatment preferences were analysed by a Friedman two-way analysis of variance. It should be noted that some questions were incompletely answered, accounting for the slight variation in the denominators in the tables.

Results

Sample characteristics

The 117 GPs from whom completed questionnaires were received were predominantly male (82%) and engaged in full-time general practice (88%). Respondents had been in general practice for a mean of 19 years (SD 10.5 years), ranging from two to 52 years. In all, 84 (72%) were members of the Australian Medical Association and 37 (32%) were members of the Royal Australian College of General Practitioners. Fifty-six (48%) held some additional qualification, such as FRACGP or Dip Obst RACOG; 29 (25%) had been or were currently Family Medicine Program (FMP) trainees; and 83 (71%) were vocationally registered.

There was a range of practice locations, with 21 (18%) describing their main practice location as central or eastern Adelaide, 20 (17%) as western Adelaide, 25 (21%) as southern Adelaide, 16 (14%) as northern Adelaide and 35 (30%) as country.

Experience of terminal care

Overall, 108 (92%) GPs reported that they had treated terminally ill patients. The remaining nine GPs who had never been involved in treating terminally ill patients were asked no further questions. Compared with other respondents, those who had never treated terminally ill patients differed only in the respect that they were more likely to be part-time ($\chi^2_1 = 19.3$, $p < 0.001$). Those who had treated such patients were asked to indicate the most common conditions from which patients were usually dying (Table 1).

The number of terminally ill patients treated by each GP in the past year ranged from none to 50, with a median of six patients per year. A minority of three respondents had treated 30 or more such patients in the past year. Compared with other GPs, respondents with more than six terminally ill patients each year were significantly more likely to have been in general practice for 20 years or more ($\chi^2_1 = 4.8$, p=0.03). However, neither practice location nor sex of practitioner were related to the likelihood of treating more terminally ill patients.

Each GP was asked to estimate the proportion of their terminally ill patients, in recent years, who expressed a wish to die at home, and the proportion who actually died at home. Overall, a median of 50% of patients had expressed a wish to die at home, with a median of 20% actually doing so. In recent years, a median of 25% of patients of each GP were referred to a hospice for inpatient care. However, this varied from no patients (23% of respondents) to 100% of patients (8% of respondents). There were no significant differences in the characteristics of the respondents comprising these two extremes.

Community care

Satisfaction with services

GPs were asked to indicate how satisfied they were in recent years with the care they had been able to give or arrange for terminally ill patients at home. Overall, 44 (42%) were very satisfied, 52 (50%) were moderately satisfied, six (6%) were slightly satisfied and three (3%) were not at all satisfied. Respondents who were moderately or very satisfied were significantly more likely to work in a rural area ($\chi^2_1 = 4.1$, p =0.04), to work in a metropolitan practice outside central or eastern Adelaide ($\chi^2_1 = 8.2$, $p = 0.004$), and to have had a greater number of terminally ill patients in the last year ($\chi^2_1 = 3.6$, $p = 0.05$).

Table 1 Most common causes of terminal illness as reported by responding GPs

	Most common condition *n* (%)	Second most common condition *n* (%)
Cancer	76 (70)	10 (9)
Cardiovascular disease	11 (10)	49 (45)
Neurological disease	2 (2)	8 (7)
Respiratory disease	1 (1)	20 (19)
Renal disease	–	2 (2)

The arrangements made by GPs for 24-hour medical back-up were explored, as was their level of satisfaction with this arrangement. Overall, 46 respondents (43%) undertook 24-hour care themselves and 53 (50%) made either themselves or a partner from their practice available. Thirty-nine GPs (37%) used a locum service, but only 13% of respondents in total used a locum service alone to provide 24-hour care. Rural practitioners were significantly more likely than metropolitan practitioners to make themselves or a partner available for 24-hour care ($\chi^2_1 = 9.9$, $p < 0.002$) and significantly less likely to use a locum ($\chi^2_1 = 29.0$, $p < 0.001$). More than half of the respondents (53%) were very satisfied with these arrangements for 24-hour care, 42% were moderately satisfied, and the remainder were slightly satisfied.

GPs were asked to indicate the extent to which they had experienced particular problems with aspects of service provision for terminally ill patients at home. Responses were coded on a four-point scale reflecting the frequency with which each problem was experienced: 'never', 'sometimes', 'often', or 'always'. Table 2 shows that problems with district nursing, private palliative nursing or domiciliary services were not frequently encountered. No significant differences between subgroups were observed.

Aspects of patient care

In terms of caring for terminally ill patients, more than half the GPs (59%) reported that they often or always had problems dealing with the emotional distress of relatives (Table 2). Rural GPs were significantly more likely to often or always encounter this problem (74%) than metropolitan practitioners (53%) ($\chi^2_1 = 4.2$, $p = 0.04$).

Just over one-third (37%) of all respondents identified that they often or always had problems dealing with the psychosocial needs of terminally ill patients. In contrast, only 10% indicated that they often or always had problems with their personal responses to death and dying. There were no subgroup differences in the frequency with which these problems were identified.

The concerns of GPs about particular aspects of pain control were also explored. Table 3 shows that approximately one in 10 GPs were very concerned about opioids impairing cognitive

Table 2 Frequency of problems encountered with services for terminally ill patients, as rated by GPs (results expressed as numbers, with percentages in brackets)

	Never	Sometimes	Often	Always	*n*
Service provision					
District nursing services	58 (55)	42 (40)	5 (5)	–	105
Private palliative care nurses	82 (74)	26 (24)	2 (2)	–	110
Other domiciliary services	40 (38)	58 (55)	7 (7)	1 (1)	106
Aspects of patient care					
Dealing with emotional distress of relatives	5 (5)	38 (36)	44 (42)	18 (17)	105
Dealing with psychosocial needs of patients	7 (7)	60 (57)	29 (27)	10 (9)	106
Your personal responses to death and dying	32 (31)	60 (59)	6 (6)	4 (4)	102
Controlling symptoms other than pain (e.g. hypoxia, insomnia, etc.)	7 (7)	65 (61)	32 (30)	2 (2)	106

Table 3 Extent to which GPs are concerned about particular aspects of treating pain in terminally ill patients with advanced cancer (results expressed as numbers, with percentages in brackets)

	Not at all	Somewhat	Very much	*n*
Opioid side effects impairing cognitive function	38 (36)	57 (54)	11 (10)	106
Other opioid side effects	27 (25)	67 (63)	12 (11)	106
Opioid tolerance	73 (69)	30 (28)	3 (3)	106
Opioid dependence	102 (96)	4 (4)	–	106

function (10%) or other opioid side effects (11%). Tolerance of patients to opioids was of significant concern to a minority of GPs (3%), whereas opioid dependence was not a concern.

Respondents were asked to rank the usefulness, in their experience, of five opioids for the management of cancer pain, from most useful (1) to least useful (5). There was a significant difference between mean rankings (Friedman's $\chi^2_4 = 148.8$, $p < 0.001$), with mean rankings being highest for morphine (1.2), followed by oxycodone (2.7), and the remaining three opioids being equally less favoured (pethidine 3.6, methadone 3.6, and codeine 3.7). There were no significant differences in opioid preferences between subgroups.

One-third of GPs (32%) reported that they often or always had problems controlling symptoms other than pain (such as hypoxia or insomnia). No subgroup differences were evident in the frequency with which these problems were identified.

Institutional care

Table 4 shows that there was a marked degree of dissatisfaction with public hospital outpatient clinics and inpatient facilities. Significantly higher levels of dissatisfaction with inpatient services were expressed by metropolitan, as opposed to rural, GPs ($\chi^2_1 = 6.3$, $p = 0.01$), and those based in central, eastern or southern Adelaide, as opposed to northern or western Adelaide ($\chi^2_1 = 9.2$, $p = 0.002$). Significantly higher levels of dissatisfaction with public hospital outpatient services were indicated by respondents based in central or eastern Adelaide, compared with other metropolitan general practitioners.

Table 5 indicates that difficulties in the admission of patients for respite care was encountered often or always by 18% of GPs, whereas 13% reported this frequency when admitting patients for emergency symptom control. Compared with rural practitioners, GPs based in the metropolitan area were significantly more likely to often or always have problems admitting patients for respite care ($\chi^2_1 = 10.0, p = 0.002$) and emergency symptom control ($\chi^2_1 = 4.1, p = 0.04$). However, frequent problems in admitting patients for terminal care were uncommon. In contrast, nearly one-third of respondents reported that they often or always had problems with communication and feedback from hospital specialists; indeed, only one in five GPs had never experienced this problem.

Respondents were asked to indicate to what extent they felt excluded from medical decision-making once a terminally ill patient had been

Table 4 Satisfaction with institutional care for terminally ill patients (results expressed as numbers, with percentages in brackets)

	Not satisfied	Somewhat satisfied	Very satisfied	*n*
Inpatient hospice facilities	1(1)	32(40)	48(59)	81
Private hospitals	4(5)	33(45)	37(50)	74
Nursing homes	10(10)	52(54)	34(35)	96
Public hospital outpatient clinics	41(51)	34(42)	6(7)	81
Inpatient public hospital facilities	30(31)	37(39)	28(30)	94

Table 5 Extent of specific problems encountered with institutional care for terminally ill patients, as rated by GPs (results expressed as numbers, with percentages in brackets)

	Never	Sometimes	Often	Always	*n*
Admission of patients for:					
– respite care	39(37)	48(45)	16(15)	3(3)	106
– emergency symptom control	35(33)	57(54)	14(13)	–	106
– terminal care	49(46)	49(46)	7(7)	1(1)	106
Communication and feedback from hospital specialists	22(21)	51(48)	28(26)	5(5)	106

admitted for inpatient care. Of the 108 GPs, 22 had not used a public hospital, eight had not used a private hospital, 14 had never used a hospice and four had not used a nursing home and were excluded from the denominator. Responses for each type of institution are presented in Table 6. The majority of respondents (56%) felt very excluded from medical decision-making once a patient had been admitted to a public hospital. By comparison, 23% felt very excluded when a patient was admitted to a hospice. GPs were less likely to feel excluded when a patient was admitted to a private hospital (although 14% felt this happened very often) or a nursing home (with only 2% feeling very excluded).

Forty-eight respondents (46%) agreed that elderly uninsured patients who require terminal care were disadvantaged in gaining access to quality terminal care in the current medical system. Metropolitan practitioners were significantly more likely (59%) to be of this opinion compared with rural GPs (16%) ($\chi^2_1 = 16.8$, $p < 0.001$). Of the 68 respondents who had access to private hospitals, 63% agreed that if government-subsidized beds were made available for the care of terminally ill patients who had no private medical insurance, this would influence them to become more involved in the terminal care of such patients. This response was significantly more common among metropolitan GPs (85%) compared with rural practitioners (30%).

Rating of measures to facilitate improved care by GPs

GPs were asked to consider whether they would benefit from additional training in a number of specific areas of terminal care and whether the ability to access advice from GPs with more experience in terminal care would be helpful. Table 7 shows that almost 80% of GPs thought they would gain at least some benefit from receiving more training in cancer pain management and the control of other symptoms encountered among terminally ill patients. Approximately 64% of respondents also indicated that training in communicating with dying patients and bereavement counselling would be of help. In addition, two-thirds of the GPs thought that

Table 6 Extent to which GPs feel excluded from medical decision-making once a terminally ill patient is admitted, according to type of institution (results expressed as numbers, with percentages in brackets)

	Not at all	Somewhat	Very much	*n*
A public hospital	22(26)	15(18)	47(56)	84
A private hospital	63(66)	20(21)	13(14)	96
A hospice	34(39)	34(39)	20(23)	88
A nursing home	79(77)	21(21)	2(2)	102

Table 7 Rating of measures to facilitate improved care by GPs (results expressed as numbers, with percentages in brackets)

	Would help little or not at all	Would help to some extent	Would help a lot	*n*
More training in:				
– cancer pain management	24(22)	57(53)	26(24)	107
– control of other symptoms	22(21)	58(54)	27(25)	107
– communicating with dying patients	37(35)	46(43)	24(22)	107
– bereavement counselling	41(38)	41(38)	25(23)	107
Access to advice from GPs with a lot of experience in terminal care	36(33)	49(45)	23(21)	108

access to the advice of colleagues experienced in terminal care would be helpful.

Compared with those who had been in general practice for 20 years or more, it was apparent that respondents who had been in general practice for less than 20 years were significantly more likely to consider that they would gain at least some benefit from training in communicating with dying patients ($\chi_1^2 = 8.1$, $p = 0.004$) and bereavement counselling ($\chi_1^2 = 6.2$, $p = 0.01$). Furthermore, those who had treated fewer terminally ill patients in the past year were also more likely to indicate that they would benefit from training in these areas ($\chi_1^2 = 4.9$, $p = 0.03$; $\chi_1^2 = 3.7$, $p = 0.05$) as well as in cancer pain management ($\chi_1^2 = 6.9$, $p < 0.01$) and to believe that they would benefit by being able to gain advice from other GPs with extensive experience in terminal care ($\chi_1^2 = 6.4$, $p = 0.01$).

Discussion

A comparison of the survey participants with the overall South Australian GP population[9] indicates that there were no significant differences with respect to sex, years in general practice, full-time/part-time work status, metropolitan/rural location or attainment of additional qualifications. However, our sample comprised a significantly smaller percentage of FMP trained GPs, so that there may be some under-representation of this group. However, with a response rate of approximately 75% we believe the survey has provided a reasonably accurate picture of the reported care of the dying patient in general practice.

The median estimation of six terminally ill patients treated yearly agrees with that found by Hunt *et al.*[6] Haines and Booroff[5] found in a questionnaire survey of London GPs that 151 of 196 (77%) treated less than six patients per year. Allbrook argues that although some dying patients may be suffering from rare conditions, the problems of end-stage cancer, such as chronic increasing pain, severe symptomatic constipation, nausea, confusional states and adjustment to bereavement, are likely to be regularly repeated.[8] As such, all GPs should be instructed in accepted palliative care techniques for these symptoms.

Epidemiological analysis of place of death in South Australia has revealed that between 1910 and 1970 there was a decrease from just over one-half to approximately one-quarter in the percentage of people dying at home in South Australia.[10] However, since 1970, this percentage has remained stable. In our survey, respondents estimated that although a median of 50% of patients had expressed a wish to die at home, a median of only 20% actually did so. Maddocks argues that there is likely to be an increasing number of patients choosing to die at home, due to earlier hospital discharges and greater family aspirations to provide care at home.[11] Indeed, a survey of community opinion on this issue found that almost 60% of South Australian adults indicated a preference for dying at home if they were to become terminally ill.[12] It is important that GPs foresee this social trend and update their palliative care skills.[3] General practitioners also have a major responsibility for the care of dying nursing home residents, where approximately 10% of cancer deaths, predominantly involving older patients, occur per annum.[13] The demand for these nursing home beds is likely to increase as the proportion of older people in the community increases.

Although 91% of GPs were either very or moderately satisfied with the care they were able to give the terminally ill, a significant number reported difficulties in patient management. More than half (59%) often or always had problems dealing with the emotional distress of relatives, a higher value than that found by Haines (45%)[5] and Hunt (23–24%).[6] A smaller, but significant, percentage of respondents (36%) experienced difficulties with the psychosocial needs of terminally ill patients and just under one-third had problems controlling symptoms such as hypoxia and insomnia. In these difficult situations, consultation with palliative care specialists and counsellors should be arranged.[3,14] This may already be occurring, given that Hunt *et al.* found, in a cohort of GPs in the southern suburbs in Adelaide, more than half of the GPs surveyed reported handing over care or sharing care with other professionals in all aspects of management.[6]

This multidisciplinary approach is an integral element of palliative care. The palliative phase of a fatal illness may last for many months or even years before the eventual terminal phase,

which is difficult to define.[15] For a GP managing a dying patient at home, the demands for care usually increase as time goes on. Frequent home visits become essential for the dying patient, and in this situation the involvement of other members of the multidisciplinary team, such as palliative care nurses, will help ease the burden.

Differences between rural and metropolitan GPs deserve some comment. Rural practitioners, compared with city respondents, were more likely to be satisfied with their care of the terminally ill, to provide after-hours care and to report satisfaction with public hospital facilities. These differences reflect different practising patterns. The surprising result is that almost three-quarters of the rural practitioners reported having substantial problems dealing with the emotional distress of relatives compared with approximately half the metropolitan practitioners. Herd, when examining the terminal care provided in a semirural community, found that the most common problem faced by the lay carer was emotional strain (74% suffered this difficulty) and in almost half the cases this was cited as a reason for the patients' hospital admission for terminal care.[16] Research is required to clarify the specific problems involved in the provision of terminal care by rural GPs. Several hypotheses require further investigation: a lack of support staff resulting in a heavier burden on rural GPs, professional isolation, being too close to the dying patient, lack of time off, and absence of debriefing opportunities for the practitioner, as well as other aspects of the rural milieu making the resolution of relatives' grief more difficult, such as physical distance from sources of formal or informal support.

Pain control is the cornerstone of good palliative care. It was pleasing to note that morphine was the most common opioid chosen by GPs – a drug that is widely accepted as the first choice.[17] There is a commonly held view among some groups that the medical profession, including GPs, is overly concerned about opioid dependence when treating the terminally ill and, as a consequence, adequate analgesia may not be administered to these patients.[18,19] The results obtained in the present study indicate that this is unlikely to be the case.

The survey raises a number of issues about institutional care for the terminally ill. It is disturbing that public hospitals, both outpatient and inpatient facilities, were rated so poorly. Approximately one-half and one-third respectively of the surveyed GPs were dissatisfied with each of these segments of public care. At a time when there is increasing pressure on the public hospital system, uninsured terminally ill patients may be particularly disadvantaged in gaining access to good palliative care. Strengthening community palliative care teams would allow more of these patients to die at home, easing the pressure on the public hospital system.[20,21] Other innovative approaches to this group are required and an option canvassed in the questionnaire was the use of government-subsidized beds in private hospitals for the uninsured, particularly the elderly. Overall, 63% of GPs with access to private hospitals would be happy to become more involved with terminal care if they had access to these beds.

Good palliative care also requires leadership and co-ordination.[1,14] Just over half (56%) the respondents felt excluded from decision-making once the terminally ill patient entered a public institution and almost a quarter (23%) felt excluded once they were admitted to a hospice. This breakdown in co-ordination and communication is further compounded by the reported lack of feedback from hospital specialists. Only one in five of the surveyed GPs had never experienced problems in this area. Models of management need to be introduced that will improve continuity of care (forward discharge-planning involving the GP and local community services and involvement of GPs in case conferences or ward-round discussions, for example, may assist in limiting disruptions to care). Continuity of care may also be enhanced, should Medicare payments be provided for GPs to visit their terminally ill patients in hospital.

The lack of training for palliative care is reflected by the fact that in all areas of palliative care – pain management, control of other symptoms, communication with dying patients and bereavement counselling – over 60% believed they would gain some benefit from further training. This proportion rose to almost 80% for pain management and control of other symptoms. There is evidence that new graduates feel deficient of skills in this area. A survey of preregistration house officers in the UK in 1989 indicated that 75% of those questioned

felt that they had not received adequate guidance on 'breaking bad news' and 64% considered they had never received adequate guidance on pain control.[22] Haines reported that approximately 80% of London GPs indicated the need for further training in all these areas.[5]

It is worth considering that most of those currently in general practice have had no formal training in palliative care. Pioneering undergraduate programmes are underway at three Australian universities: Austin Hospital – Repatriation General Hospital Clinical School, Melbourne,[1] Newcastle[4] and the University of Western Australia.[23] More FMP training programmes are needed and should include a requirement that the trainee be involved in the diagnosis, management, community care and consequent bereavement counselling of a dying patient. Relying totally on teaching hospital experience may not be appropriate, as demonstrated by Chan and Woodruff, who found that one-third of patients with terminal cancer who had been admitted to a general teaching hospital received inadequate pain relief and that allied services were under-used.[24] Practising GPs need to update their skills and although diploma[2] and masters[3] courses have been suggested or are already established, there is a need to reach a wider GP audience, perhaps by the use of a palliative care manual along the lines of the recently released GP chronic disease guidelines.[25,26]

This study has highlighted the importance of experience in general practice. Respondents who had been in general practice for more than 20 years were more likely to treat terminally ill patients. To a certain extent this reflects the logical ageing of a practice as the GP ages. These GPs were also more likely to perceive less need for training. It is debatable whether the low level of perceived need might reflect an underestimation of the value of further training or whether their greater experience may preclude the need for such training. MacAdam argues that experience in general practice offers the opportunity to develop skills that are particularly relevant to palliative medicine – an understanding of family dynamics and psychology, and care at home, for example.[2] This experience needs to be recognized as a valuable resource, and in the present study there was majority support for an arrangement whereby GPs experienced in terminal care could provide support and advice to less experienced colleagues.

This study was based on reported behaviour and further research is required to clarify whether actual behaviour is similar. Even with this caveat, these results have provided considerable insight into the strengths and weaknesses of palliative care in general practice. Skilled general practice palliative care can be demanding, but it is both rewarding and essential for the prevention of morbidity among patients and relatives.[2] Methods need to be developed to update GPs' skills and integrate them more fully into the care of the terminally ill. Furthermore, efforts to narrow the present gulf between hospital care and community general practice should be pursued. Good palliative and terminal care needs to be espoused as an integral and essential part of the philosophy of modern general practice.

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Original papers

Attitudes to some aspects of death and dying, living wills and substituted health care decision-making in South Australia: public opinion survey for a parliamentary select committee

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Key words: advance directives; death; hospices; living wills; palliative treatment; terminal care

This study aimed to provide evidence on community attitudes to certain death and dying issues in South Australia for a state parliamentary committee on the law and practice relating to death and dying. The following areas were studied: truth-telling, pain control, level of treatment, preferred place of death, rights of patients to refuse treatment, opinion about living wills and substituted health care decision making. A representative population survey of 625 households in metropolitan Adelaide and three major rural centres was made in August 1991, using personal interviews administered at home with one adult in each household aged over 18 years. A total of 462 (74%) adults completed the interviews. There was strong support for truth-telling by doctors about incurable cancer and impending death, although this was not universal. Fears of potential addiction, habituation, tolerance and impaired cognitive function as a result of analgesia for cancer pain were strongly expressed, particularly amongst those who reported least formal education. Those with experience of a death in the last eight years were most likely to consider the level of treatment offered to patients with incurable cancer to be inadequate, but 53% considered the level to be about right. Nearly 60% of respondents favoured death at home, but there was a trend for older people to favour death in hospital. Despite the existence of the Natural Death Act (1982), only 20% were aware that living wills were legal in South Australia. There was strong support for a medical power of attorney.

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Mots-clés: instructions préalables; décès; hospices; dernières volontés médicales; traitement palliatif; soins en fin de vie

Cette étude a pour objectif de fournir à une commission parlementaire traitant de la loi et de l'usage en ce qui concerne la mort et le décès, des informations sur les attitudes de la population à propos de certaines questions au sujet de la mort et le décès en Australie Méridionale. Les sujets suivants ont été abordés: l'annonce de la vérité, le contrôle de la douleur, le niveau de traitement, le lieu de décès préféré, le droit des patients de refuser un traitement, l'opinion au sujet des dernières volontés médicales et des prises de décision par procuration concernant les soins. Un échantillon de 625 ménages, représentatif de la population, a fait l'objet d'un sondage en août 1991 dans la ville d'Adélaïde ainsi que dans trois importants centres ruraux. Ce sondage a été conduit avec des interviews à domicile, là où il y avait au moins un adulte âgé de plus de dix-huit ans. Un total de 462 adultes (74%) a complété les interviews. Il y avait une opinion trés favorable pour que les médecins tiennent le langage de la vérité en ce qui concerne un cancer incurable et l'approche de la mort, encore que ceci ne soit pas universel. Des craintes d'intoxication médicamenteuse potentielle, d'accoutumance, de tolérance et d'une dégradation du fonctionnement du cerveau, celles-ci résultant de l'analgésie administrée contre la douleur d'origine cancéreuse, ont été exprimées clairement. Ces craintes ont été particulièrement fortes parmi ceux qui ont fait état du niveau d'instruction le plus faible. Ceux qui ont expérimenté une mort au cours des huit dernières années ont été les plus enclins à considérer comme mal adapté le niveau de traitement offert au patients atteints d'un cancer incurable, mais 53% ont jugé ce niveau à peu près adéquat. Près de 60% de ceux qui ont répondu ont émis une préférence pour décéder chez soi, bien qu'il y ait une tendance chez les gens plus âgés à choisir de décéder à l'hôpital. Malgré l'existence du *Natural Death Act (1982)*, 20% seulement savaient que les dernières volontés médicales étaient légales en Australie Méridionale. Il existe une opinion très favorable aux procurations médicales.

Introduction

Societies of the modern developed western countries such as South Australia are currently debating issues concerning death, dying and euthanasia. There are wider concerns about informed consent to medical treatment, respect for the autonomy of persons and substituted judgement when patients are incompetent. These observations result from three principal factors. Firstly, the greater availability of sophisticated life-sustaining treatment technologies, and consequent perceived legal and moral pressure to use them. Secondly, a move towards institutionalized death, despite recent trends back towards home and hospice.[1–3] Thirdly, a greater emphasis on bio-ethics and, in particular, individual rights and autonomy in health care decision-making. We appear to have moved from 'natural death' to 'medical decisions at the end of life',[4] and Weir talks of 'abatement of treatment with the critically ill – ethical and legal limits to the medical prolongation of life'.[5]

The modern hospice and palliative care movement has been an important vehicle for the improvement of the care and support given to dying people and their families. It has been a pioneering force in medicine and society, particularly in bringing about a more open attitude to issues about death and dying. Indeed in the UK it is now thought to be undergoing a process of integration into mainstream health

care which may alter its pioneering nature.[6] That the movement has grown so rapidly, and often with such strong community support, indicates that there is a fair degree of harmony with prevailing community attitudes. One cannot, however, diminish the support which is also given by the community to high-technology curative medicine, with consequently high expectations. The disillusionment when these expectations are not fulfilled can be very painful and death-denying world-views are dented or shattered. Thus, expectations of modern curative medicine may sometimes seem to contradict support for the hospice movement.[7]

This study was undertaken at the request of the Select Committee of the House of Assembly (Parliament of South Australia) on the law and practice relating to death and dying (see Appendix).[8–10] It had a dual focus in reviewing the care of the dying and in recommending changes to the law relating to death and dying, including revision or replacement of the Natural Death Act of South Australia (1982). The evidence submitted therefore ranged widely over medical, psychological, sociological, spiritual, religious and legal aspects of death and dying from the professions, churches, special-interests groups and health administrators. The present study aimed to assess the degree of harmony between public policy directions and professional perceptions on the one hand, and public opinion on the other. It focused on topics which might assist in planning future developments in palliative care and the formulation of advance directive and substitute health care decision-making legislation.

Methods

During August 1991 a representative population survey was undertaken in South Australia to assess the public's awareness of a number of issues relating to death and dying. The questionnaire sought to determine the respondents' beliefs about truth-telling, pain control, the extent of medical and surgical treatment for patients with a terminal illness, their understanding of the rights of patients to refuse life-prolonging treatment, awareness of living wills, views about substitute health care decision-making and preferences for place of death. Sociodemographic information pertaining to age, gender, country of birth, educational status and religious affiliation was also obtained.

A two-stage sampling procedure was employed, involving (1) the random selection of 125 households from the electoral roll to define a start point for a clustered area sample, and (2) the selection of five households per start point in a predetermined fashion, to yield 625 households in total. Five hundred households were located in metropolitan Adelaide and a further 125 in three major country centres. The survey was conducted by personal interview in the respondents' homes with the person in each household aged 18 years or more whose birthday was next. Each interview lasted between five and 15 minutes. Interviewers were established employees of a local market research agency with experience in the conduct of household interviews who had been provided with a one-hour briefing on the sample selection and questionnaire administration requirements of this survey. Following completion of fieldwork, 5% of the sample were re-contacted as a quality-control procedure, which confirmed that interviews had been appropriately conducted with the correct member of the household. Sample size was determined using the formula for a simple random sample and adding in a design effect to take account of the multistage sampling procedure. Given a target population size of 790 000, and assuming a population prevalence of 50%, a sample size of 384 would be required to provide a 95% confidence interval of ± 5%.[11] This figure was increased by 30% to account for the design effect,[12] and by a further 25% to account for the expected level of nonresponse in a survey of this type, yielding 624 households.

A total of 462 (74%) adults completed interviews. A further 15% were not able to be contacted at home after three call-back visits, and 11% declined to participate. No demographic information was available on nonrespondents. However, the age and sex distribution of the survey participants was similar to that applying to the population at large, although the sample was still weighted to reflect exactly the age and sex distribution of the adult population in the sampled areas of South Australia.

Results

Profile of respondents

Of the 462 respondents, 227 (49.2%) were male and the mean age was 43.8 years (SD = 17.8 years), ranging from 18 to 88 years. The majority (78.1%) were born in Australia or New Zealand, a further 10.1% in the UK, 7.8% in Europe and the remainder from Asia or other countries. In terms of educational attainment, 18.5% had left school early, 39.7% left school at 15 or 16 years of age, 26.4% had left school at 17 years, and the remaining 15.4% had obtained a university or other tertiary qualification. With respect to religious affiliation, 19.8% were Roman Catholic, 19.0% Anglican, 16.7% Uniting Church, 4.1% Lutheran, 15.8% affiliated with other religions and 24.6% had no religious affiliation.

Truth-telling

In order to assess opinion about truth-telling, the question was prefaced by the statement, 'Suppose a doctor found that an adult patient had incurable advanced cancer and was likely to have not long to live'. When respondents were then asked whether they thought the doctor should tell the patient the truth about his or her condition, 82.8% answered in the affirmative. A further 13.4% believed that the patient should be informed, but had some reservations relating to the age of the patient and their mental state. Only 3.8% expressed a clear preference that the patient should not be informed.

A preference for telling the truth without qualification was significantly more likely among younger respondents (aged 18–39) compared with older respondents ($\chi^2 = 8.9$, $df = 1$, $p = 0.003$), and those born in Australia or New Zealand, as compared with those born in the UK or elsewhere ($\chi^2 = 12.4$, $df = 1$, $p < 0.001$). Those with no religious affiliation ($\chi^2 = 5.2$, $df = 1$, $p = 0.02$) were also more likely to believe that terminally ill patients should be told the truth without reservation, with the exception of Anglicans and Uniting Church members, who were not significantly different in their views to those with no religious affiliation.

Pain control

When respondents were asked how often doctors could prevent patients with a terminal illness such as incurable advanced cancer suffering severe pain, more than four out of every five respondents (82.5%) had some perception. The majority (57.8%) believed that severe pain could be relieved in most or all cases, 18.7% indicated that they felt severe pain could be ameliorated in some instances, and only 6.0% expressed the view that there were few or no cases where this would occur.

Those who reportedly had a relative or close friend experience a terminal illness in the preceding eight years were more likely to offer a judgement about the frequency with which doctors could prevent patients suffering severe pain ($\chi^2 = 8.7$, $df = 1$, $p = 0.003$), as were those under 55 years of age ($\chi^2 = 8.5$, $df = 1$, $p = 0.004$). There was also a significant trend for an opinion to be offered with increasing levels of educational status (χ^2(trend) = 5.87, $df = 1$, $p = 0.02$). Among those who offered a view, respondents in middle age (40–54 years) were significantly more likely to believe that doctors could prevent severe pain in most or all cases, compared with younger or older respondents ($\chi^2 = 6.5$, $df = 1$, $p = 0.01$).

Table 1 shows the extent to which respondents believed each of the four statements about pain treatment to be true. Each of these statements was significantly more strongly believed by those with the least formal education. Males were more likely than females not to express a view to the second and fourth statements and to believe it was not at all true that patients get addicted to pain control drugs.

Level of treatment

When asked, 'Thinking about someone who has incurable cancer, do you think that patients do not receive enough medical and surgical treatment, receive about the right level of treatment, or receive too much medical and surgical treatment?', 78.5% offered a view on this issue, with just over half (53.2%) considering the level of treatment to be about right; 15.6% believed it was insufficient and the remaining 9.6% thought it was excessive. A significantly higher proportion of respondents who had known relatives or close friends with a terminal illness in the past eight years were more likely to consider the treatment received by these patients to be inadequate than was the case among other respondents ($\chi^2 = 5$, $df = 1$, $p = 0.02$). In contrast, males were more

likely than females to believe that the level of treatment was excessive ($\chi^2 = 6.1$, $df = 1$, $p = 0.01$).

Preferred place of death

When asked where they would prefer to die if they were terminally ill, the majority of respondents (59.3%) answered 'at home'. A further 20.9% of people expressed a preference to die in a hospital. 5.4% in a hospice, 2.5% in a nursing home, 6.2% at another place, and 7.8% did not know.

Although a preference for dying at home was most popular among all subgroups, there was a significant trend with increasing age for respondents to be less likely to want to die at home (χ^2(trend) = 19.8, $df = 1$, $p = <0.001$) and more likely to want to die in hospital (χ^2(trend) = 11.4, $df = 1$, $p = <0.001$).

Right of patients to refuse treatment

All survey respondents were asked, 'As far as you know, do patients dying from any illness have a legal right to refuse medical or surgical treatment that might enable them to live longer?' The vast majority (91.7%) replied in the affirmative, with only 3.8% believing patients did not have this right and 4.5% being unsure. No differences were observed between subgroups.

Opinion about living wills

After a brief explanation of a living will, when respondents were asked whether they were legal in South Australia, 20.4% answered correctly in agreeing that they were legal. Of the remainder, 24.7% believed that they were not legal, and 54.9% did not know. There were no statistically significant differences between subgroups.

When asked whether they would ever think about making a living will, 60.0% answered in the affirmative, 25.5% indicated that they would not make such a will, and 14.5% remained uncertain. Again, no significant differences between subgroups were found.

The 185 respondents who indicated that they would not make a living will or were unsure about the matter were further questioned as to the reasons that might prevent them from making one. These reasons are listed in descending order in Table 2.

Medical power of attorney

Respondents were further questioned about their attitude to the appointment of others to make medical treatment decisions, should the respondent be unable to. It was first explained to respondents: 'It has been suggested that, in case people develop a terminal illness and they are no longer able to make their own decisions (if they are in a coma, for example), there should be a law to enable these people to appoint, in advance, someone to make decisions about medical treatment on their behalf (maybe a relative or friend).' When they were asked for their opinion about this idea, most respondents (86.0%) indicated that they agreed with it. Of the remainder, 7.4% disagreed, while 6.5% had no opinion. No significant differences were observed between subgroups.

When respondents were asked whether they would ever consider nominating someone in advance to make such decisions on their behalf, 80.5% agreed that they would, 14.7% said they would not appoint anyone and 4.9% were

Table 1 Extent of agreement with four statements about pain control ($n = 462$)

Statement	Very true	Somewhat true	Not at all true	Don't know
Patients get addicted to drugs	40.9%	40.1%	9.1%	9.8%
Painkillers lose their effect if they are used too long	40.1%	38.8%	8.5%	12.6%
Painkillers make people confused	16.8%	50.4%	14.6%	18.1%
Too many painkillers shorten life	11.7%	25.0%	28.0%	35.3%

uncertain. There were significant differences in responses by religious affiliation, with Anglicans and Uniting Church members more likely to appoint someone than Roman Catholics (χ^2 = 6.9, df = 1, p = 0.009) or those with another religious affiliation (χ^2 = 24.8, df = 1, p = <0.001).

Of the 90 respondents who indicated that they would not elect to nominate someone, or were unsure about the matter, the most common reasons given for making this decision were the belief that it would put too much of a burden on the appointed person (28.8% of cases), and preference for things to take their course (20.5%).

Discussion

Honesty and truth-telling are strongly valued as essential components of autonomy and respect for persons,[13,14] and the present study confirms this tendency. However, this is not a universal view, with 13% of respondents wishing to modify the truth-telling according to factors such as age, frailty and mental state, and nearly 4% stating that patients should not be informed of the terminal nature of their condition. Younger respondents, those born in Australia and New Zealand and those expressing no religious affiliations were most in favour of complete candour, and this may represent evidence of the secular nature of large sections of the younger population in modern western societies such as Australia.

It is clear that there are significant variations in cultural and ethnic approaches to truth-telling.[15] In particular, difficulties are encountered in communicating the truth to some patients, where family concerns about issues of patient demoralization are strong. The importance of investing time and effort in this area is reinforced by the fact that approximately one-third of subjects in a study of surviving relatives interviewed one year after the death of a person identified at random from the Cancer Registry in South Australia expressed enduring anger at the way bad news was communicated to them and the deceased person.[16] Professionals may feel that they have ethical and legal obligations to tell the truth, particularly in order to comply with growing requirements for informed consent. Confrontation and imposition of perceived societal norms of behaviour may promote serious conflict and enduring psychological harm. Open questioning techniques need to be employed to ascertain patient and family attitudes to truth-telling and information giving.

It appears that the general public has major concerns about pain control. The majority of respondents expressed the belief that addiction, habituation and tolerance are real issues, although these beliefs may not preclude the use of analgesia in palliative care. It is still very common to hear anxieties expressed that opioid analgesics will be ineffective in the terminal stages of an illness if they are commenced 'too early'. Disturbance of higher cognitive function is perceived as a common problem, which is a correct observation.[17] The association between negative impressions of pain relief and lower educational attainment gives a clear message for those formulating policies for cancer pain control awareness.

In an effort to ascertain what the public thinks about how much active treatment patients with incurable cancer receive, a simple direct question was posed, and nearly 80% of respondents felt able to respond. Treatment may have been interpreted as potentially curative or palliative. The fact that those who had experienced a death in the last eight years were more likely to consider the level of treatment offered to be inadequate may reflect some dissatisfaction with the palliative care given. The question did not appear to reveal a significant impression that people with incurable cancer are overtreated. In future studies, it would

Table 2 Reasons offered by respondents for not wanting to make a living will (n = 185)

Reasons given for not making a living will	%
I would prefer things to take their course	21.2
I don't like to think about it (or have never)	20.4
I don't know enough about it	13.4
I might want to change my mind	8.2
It would depend on how ill I was	4.3
Might be a cure in the future	3.8
I would want as much treatment to live as long as possible	2.2
I wonder whether doctors would follow it	1.5
Other	25.0

be important to develop this topic with more clarity about treatment intent.

As in other studies in this state[2,3] and elsewhere,[18,19] the majority of respondents expressed a wish to die at home. The finding that older persons were more likely to indicate a preference for institutional death was noteworthy. This cohort group have lived through the rise of the hospital during the middle part of this century, with a consequent peak of institutionalization of serious illness and death.[1,3] This may therefore be more expressive of expectation rather than actual preference, with a consequent lack of knowledge of alternatives and a wish to spare family the burdens of care at home. This question warrants further study as it may also be that older people genuinely prefer to die in the relative safety and security of a hospital.

Living wills have emerged from the trend set by California with its Natural Death Act of 1976, which was followed by similar (but not identical) legislation in the majority of states in the USA.[20] They tend to concentrate on the right to refuse treatment in the event of a terminal illness, a term which has variable definitions in the different state jurisdictions. Living wills have been seen to be too restrictive and there is now a move to advance directives (which allow varying instructions to be laid down and operate in situations other than terminal illness), and various instruments which permit substitute health care decision-making when a person is no longer competent. These instruments include terms such as proxy, agent, medical or enduring power of attorney, and surrogate. In the majority of state's jurisdictions in the USA there is now provision for living wills, as well as wider advance directives with some form of substitute health care decision-making provision.[20] The Federal Patient Self-Determination Act (PSDA) 1990 requires all Medicare- or Medicaid-funded institutions in the USA to provide information about advance directives and rights to refuse life-sustaining treatment.[21]

In Australia the Medical Treatment Act of 1988, Enduring Power of Attorney (Medical Treatment) Act 1990 (EPA), together with the Medical Treatment (Agents) Act 1992 (MTAA) in the state of Victoria allow for an agent to refuse treatment on behalf of an incompetent donor, but there is no specific provision for an advance directive.[22] The Natural Death Act of South Australia (1982) established the right to refuse extraordinary measures in the event of a terminal illness by completion of a living will (notice pursuant to the act). Medical practitioners are obliged to follow these instructions, if made known to them in this prescribed format. There has been no case law generated as a result of this legislation. It might be argued that this act only codified the pre-existing common law requirement for consent to be obtained prior to any medical treatment (trespass against the person). As a result of a select committee recommendation, the Consent to Medical Treatment and Palliative Care Bill (1992) is before parliament; this includes a provision for substitute health care decision-making by an agent under a medical power of attorney, and clauses which deal with consent to medical treatment and the care of the dying.[10]

A medical power of attorney authorizes the agent, subject to the conditions (if any) stated in the power of attorney, to consent or to refuse to consent to medical treatment if the person who grants the power is incapable of making the decision on his or her own behalf. This is a form of substitute health care decision-making in which the donor of the power of attorney appoints the agent to act according to their known wishes and, where unknown, in their best interests. It uses the pre-existing power of attorney model, but is not the same legal instrument as that which exists for dealing with financial and other legal matters. It was felt that the power of attorney was well understood in the South Australian legal tradition, but that the medical and nonmedical instruments should be quite separate. As a general rule, a power of attorney has to be 'continuously willed', and lapses if the donor becomes incompetent, hence the use of the term 'enduring' power of attorney. In this legislation it is clearly stated that the agent may only act when the donor is incompetent, and hence the term 'enduring' was deemed to be unnecessary.

It is clear that a large majority of respondents (92%) knew that they had a fundamental legal right to decline treatment, even if the treatment might be thought to extend the length of life. Only 20% of respondents believed that they had the right to make a living will in South Australia, with 25% believing that this was not legal and 55% stating that they did not know, despite the fact

that the act had been in existence for nearly 10 years. This suggests that greater public education and awareness are required if these instruments are to be of any use.[23] The majority of respondents indicated that they would consider making a living will if they had known of their existence. However, enthusiasm should be tempered by the finding that 25% stated that they would not make one, and that the main reasons were that they did not wish to think of the eventuality or that they would rather 'let things take their course'.

Although a study from Massachusetts General Hospital indicated that there were difficulties in carrying out advance directive instructions,[24] this was not the case with 'Let Me Decide' in a Canadian nursing home environment,[25] and in the present study South Australians did not see this as a disincentive to make a living will. Despite British[26] and American concerns about people changing their minds, only 8% indicated that this was an issue and 4% wondered if new treatment might become available after the living will was made.

There was strong support for the concept of medical power of attorney, with, only 7.4% indicating that they would not wish to name another person to act in this capacity. The main reason for not wishing to do so was the concern of burdening another person with such a responsibility. It may also be that many people do not have another person available to them to assume this role. It would therefore appear to be important for it to be possible to make a living will or other advance directive without the obligation to involve a third party as an agent. The select committee also neard much evidence that the public found that these issues were not presented to them in a way in which they could either understand or relate to, and plain-language is required before any new approach can be tried. An educational programme such as 'Let Me Decide' from Canada may be helpful.[25]

The select committee's recommendations are set out in their final report,[10] and are summarized by Maddocks.[27] They are wide-ranging and address the improvement and coverage of palliative care service delivery and education in South Australia. As stated above, the select committee generated the Consent to Medical Treatment and Palliative Care Bill which is presently proceeding through the state parliament. Apart from allowing the appointment of a medical agent (medical power of attorney), there is also a clause which deals specifically with the care of the dying, and clearly indicates that relief of pain and distress are paramount in the legislators' minds. This appears to be the first piece of legislation in the world that includes palliative care in the title and specifically refers to the administration of medical treatment: 'with the intention of relieving pain or distress . . . in accordance with proper professional standards of palliative care'. The legal imperative is good palliative care, without the restraint of some putative (and usually ill-founded) notion of causing death by relieving suffering. However, (voluntary active) euthanasia as a means of abolishing suffering is clearly rejected.

The findings and recommendations of this South Australian parliamentary select committee would probably be reproducible throughout Australia, and indeed in most western countries. The Social Development Committee of the state government in Victoria made some similar observations and recommendations in 1987.[28] However, more research is required into the views of some ethnic groups (particularly migrant southern mediterranean communities such as the Greek and Italian communities), which appear to experience difficulties in the aspect of truth-telling and discussion of death and dying issues, an area which was not addressed in this study.

We commend the process described in this paper to any country or state which is seeking to clarify public policy in this area, and believe that the public welcome the opportunity to openly discuss death and dying issues.

Conclusions

Members of the general public are willing to discuss death and dying issues when given the opportunity, and both openness and honesty are clearly valued. Personal experiences of death have an influence on opinions expressed, and education may play an important part in dispelling common myths and fears, particularly with regard to opioid analgesia. Older people who have lived most of their lives during the era of the institutionalization of death in hospitals might welcome more information about the alternatives of home and hospice. There is strong support for

living wills and medical power of attorney, but poor public awareness must be addressed if such legislation is to be effective.

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Appendix: select committee of the House of Assembly on the law and practice relating to death and dying

Terms of reference

The select committee was established on 13 December 1991 with the following terms of reference. To examine:

1) the extent to which both the health services and the present law provide adequate options for dying with dignity.
2) Whether there is sufficient public and professional awareness of pain relief illness; whether there is adequate provision of such services; whether there is sufficient public and professional awareness of the Natural Death Act and, if not, what measures should be taken to overcome any deficiency.
3) To what extent, if any, community attitudes towards death and dying may be changing and to what extent, if any, the law relating to dying needs to be clarified or amended.

Members

Hon. DJ Hopgood MP (Chairman) Minister of Health
Mr MJ Atkinson MP
Hon. JL Cashmore MP
Hon. BC Eastick MP
Mr MJ Evans MP
Mr VS Heron MP
Mrs DC Kotz MP

Secretaries

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Australian Health Law Bulletin

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Law reform on death—over but not out

The Consent to Medical Treatment and Palliative Care Bill 1992 (SA) lapsed during recommittal proceedings in the Legislative Council when the SA State election was called in November 1993. There is however, widespread support for its re-introduction into the new parliament later this year. *Michael Asbby* discusses the reform process, issues raised and possible future directions.

The Bill was intended to replace the *Natural Death Act* 1983, and to encompass (in one Act) all of the law relating to consent to medical treatment and the practice of palliative care, together with the novel provision for a Medical Power of Attorney (MPA).

Introduction

The *Consent to Medical Treatment and Palliative Care Bill* (CMTPC) is one of a series of Australian legal initiatives or guidelines to address issues related to death and dying. It was tabled in the SA Parliament in November 1992 as part of the final report of the Select Committee on the Law and Practice relating to Death and Dying. It passed the House of Assembly on a conscience vote in February 1993 (37 in favour, three against, two paired, five absent), but after extensive amendment, lapsed in the Legislative Council when Parliament was dissolved for the State elections in November 1993. There is widespread support for its re-introduction into the new Parliament and informal consultations are already under way.

Contents of the proposed legislation

The Bill is intended to replace the *Natural Death Act* 1983 and the *Consent to Medical and Dental Procedures Act* 1985, with one comprehensive piece of legislation which deals with consent to medical treatment for adults, children, and emergency situations, together ➤

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➤ with the regulation of medical practice as it affects the care of the dying. It also allows for the appointment of an agent to make decisions on the person's behalf when that person is incompetent, under an MPA.

An objects section of the Bill was included after advice received from Professor Margaret Somerville of McGill University, Montreal (Somerville, unpublished submission, 1992). They are as follows:

(a) to make certain reforms to the law relating to consent to medical treatment to allow persons over the age of 16 years to decide freely for themselves on an informed basis whether or not to undergo medical treatment and to provide for the administration of emergency medical treatment, in certain circumstances, without consent;
(b) to provide for medical powers of attorney under which those who desire to do so may appoint agents to make decisions about their medical treatment when they are unable to make such decisions themselves; and
(c) to allow for the provision of palliative care, in accordance with proper standards, to the dying and to protect the dying from medical treatment which is intrusive, burdensome and futile (s 3).

Consent

Adults

Persons aged 16 years and over may consent to, or refuse to consent to medical treatment (s 6), and are entitled to adequate explanation by the medical practitioner of the nature, consequences and risks of the proposed treatment, the consequences of not pursuing the treatment, and any possible alternative treatments which might be used in the particular case (s 11). It thus appears that the Bill merely confirms in statute the common law right to refuse treatment, and the principles of informed decision-making along the lines argued in *Rogers v Whitaker* [1992] ATR 61, 612.

Children

If there is a conflict between a parent or guardian and a child, the child may consent to treatment alone provided that the attending medical practitioner can demonstrate that the child understands the nature and consequences of the proposed treatment, that it is in the child's best interests, and is supported by at least one other medical practitioner (s 9).

Emergency medical treatment

Emergency medical treatment may be undertaken without consent if the patient is incapable of making a decision whether to accept or refuse treatment, provided that there is no known prior refusal of that particular treatment: For such a decision it is necessary that there be an imminent risk to life or health, and a second medical opinion is obtained (s 10).

Medical power of attorney

A person over the age of 16 may appoint, by MPA, an agent 'with power to consent or to refuse to consent on his or her behalf to medical treatment' (s 7(1)). The agent must be aged over 18, and may not be involved in a professional capacity with the care of the person (s 7(3) or (4)). The agent may not reject the 'natural provision or natural administration of food and water, or the administration of drugs to relieve pain or distress' (s 7(6)(b)). The principal (or donor of the agency) may make directions which the agent must respect when exercising the agency (s 7(7)). This is the only reference to the possibility of an advance directive provision in the Bill.

Care of the dying

A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness incurs no civil or criminal responsibility for the administration of treatment for the purpose of relieving pain or distress. This provision extends to cover those who participate in the treatment or care of the patient under the supervision of the medical practitioner (s 13(1)). Protection from civil or criminal liability is dependent upon the treatment being administered with the consent of the patient or his or her attorney, and the treatment being administered in good faith, without negligence and in accordance with proper professional standards of palliative care (s 13(1)).

In essence, this is an indemnity clause for medical practitioners, and those working under their direction, such that palliative care measures for the terminally ill (for example, the administration of pain relieving drugs) are not deemed to be a cause of death.

The Bill further provides that, in the absence of an express direction to the contrary by the patient or his or her attorney, a medical practitioner (or those working under the practitioner's supervision) is under no duty to use or continue to use extraordinary measures in treating the patient if 'the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery' (s 13(2)). 'Extraordinary measures' in relation to a person suffering from a terminal illness, are defined in s 4 as:

> medical treatment that supplants or maintains the operation of ➤

➢ vital bodily functions that are temporarily or permanently incapable of independent operation but does not include medical treatment that forms part of the conventional treatment of an illness and is not significantly intrusive or burdensome.

As in the case of treatment for the relief of pain or distress, it is expressly stated that the non-application or discontinuance of extraordinary measures in the circumstances set out above, does not constitute a cause of death (s 13(3)(b)).

Discussion

The agency-medical power of attorney

This differs from the only other similar agency in Australia, the Enduring Power of Attorney in Victoria—*Enduring Power of Attorney (EPA) (Medical Treatment) Act* 1990, *Medical Treatment (Agents) Act* 1992. The Victorian EPA is focused on refusal of treatment by certificate, and the refusal may only be made if the treatment would cause 'unreasonable distress', or if there were reasonable grounds for believing that the patient would have considered the treatment 'unwarranted'. Furthermore, the refusal is only valid for a current condition. Both agencies exclude palliative care from the agent's powers.

The proposed South Australian MPA, on the other hand, is more in line with the tradition established in many American jurisdictions[1] and is intended to be based on the principle of substituted judgment. The principal is encouraged to make their wishes known, and this gives the opportunity for an advance directive to be made, although no prescribed format was set out in the original Bill, and only a very rudimentary one was eventually incorporated into the amended version in the Legislative Council (No 8A, Sched 1A), the first formal legislative reference to an advance directive in an Australian jurisdiction. It is already, of course, possible to make a living will in SA and the NT as a result of the Natural Death Acts [2] (NDAs), but these only allow for the cessation or non-initiation of extraordinary measures in the event of a terminal illness.

'There is a widespread belief that the care of dying persons, and in particular the use of opioid and sedative drugs to relieve suffering, involves a conflict as to the causation of death.'

It was felt to be a weakness of CMTPC by some observers that, as proposed with the repeal of the *Natural Death Act* 1983 (SA), an individual would no longer be able to make a living will, and would therefore be reliant on another person to be their agent. Most American jurisdictions now allow for an agency, located within an advance directive (Hill, Shirley 1992). This has the dual advantage of allowing a person to make their beliefs and views known without having to appoint an agent if they do not wish to, or have nobody to appoint, and if an agent is to be appointed, the directive provides evidence of what the principal wants. Discussion of the directive between agent and principal would provide the soundest basis for future substituted judgment by the agent, after which best interests would be the only guide for the agency if the principal's views on the situation faced are unknown. This will be fairly common as directives cannot possibly anticipate all potential future scenarios that may occur.

Opponents of the Bill, as it stood, had concerns about the absence of appeals procedures if an agent is thought to be acting against the principal's interests. Michael Atkinson MP proposed that there should be a channel of appeal to the Supreme Court, but this was vigorously opposed and defeated in the House of Assembly on the grounds that a judge or court should not be empowered to question or reverse the decision of an agent, which has the same weight as a decision made by the patient himself if he or she were competent. In the Legislative Council the (then) shadow Attorney-General, Trevor Griffin MLC, proposed that the Guardianship Board be empowered to act as the review body. An appeals procedure can be seen as a friendly amendment to the Bill, and substituted decision-making purists surely recognise that it is impossible to have advance knowledge of the precise circumstances under which the agency will need to be exercised, and consequently a process of explanation and consultation will need to take place with the agent, just as it would with the patient. This ➢

➢ process may well involve other significant persons in the patient's life (family and non-family), and particularly where medical decisions at the end of life are concerned, with members of the caring team. If the process breaks down, and there is disagreement about what the principal would have wished, or what now constitutes the principal's best interests, then it seems appropriate to have a clear review process in place.

Many views have been expressed about practicalities associated with the appointment of the agent and the making of an advance directive. Some people do not even know that they have a right to refuse treatment. Where living wills, advance directives and agencies exist, the bulk of the population either do not know about them, or do not use them, despite the fact that they may express strong approval of the ideas. In SA, for instance, only 20 per cent were aware of the existence of NDA, but 86 per cent approved of the idea of MPA. It is clear that public and professional education is essential if these instruments are to be widely used, and hence useful in clinical practice[3]. An upper house amendment provides for a register of MPA appointments, similar to the system which has been set up in Denmark, and wallet cards have also been considered. More research is required about the choice and process of appointment of an agent as there is evidence from community studies amongst the elderly that there is confusion between MPA and the well-established Power of Attorney provision for financial and legal matters, and also about alternative and shared agency. Many fear placing a burden on an elderly partner, or a busy child, and if there are children, which one do you appoint, and could they share the responsibility? As presently drafted this latter option is specifically excluded.[4] It might be clearer to name the agency quite distinctly as suggested by Somerville (1992).

Care of dying persons

It is important to refer to dying or terminally ill persons, not just the dying or terminally ill. When the term person is dropped there is a danger of initiating a process of depersonalisation, and hence unethical treatment of such 'non-persons' (Somerville, 1992).

There is a widespread belief that the care of dying persons, and in particular the use of opioid and sedative drugs to relieve suffering, involves a conflict as to the causation of death. Is it the disease or the drugs that ended the patient's life? The dose of an opioid drug often appears to be the reason for this conflict, and without any agreement as to what is meant by a 'high' dose in a given clinical situation, a high or escalating dose may be seen as causal. Legislators in Australia and Canada are keen to promote good palliative care, by stating that the provision and administration of drugs required to adverse pain and symptom relief to persons who are dying does not constitute a cause of death and therefore does not incur criminal liability. Queensland has specifically addressed this issue by proposing the following reform to the *Queensland Criminal Code*:

> 69. A person is not criminally responsible if he or she gives such palliative care as is reasonable in the circumstances, for the control or elimination of a person's pain and suffering even if such care shortens that person's life, unless the patient refuses such care.[5]

This provision was modelled on a similar recommendation by the Law Reform Commission of Canada in its 1987 revision of the Canadian Criminal Code, which was made with the following appended comment:

> Under present law, administration of palliative treatment likely to shorten life would in theory ... give rise to liability for murder. In practice, Canadian case law has no record of conviction of a doctor for shortening a terminal patient's life by administering pain-relieving drugs. Moreover, most people, including religious leaders, see nothing wrong in giving treatment for the purpose of relieving pain in certain circumstances even though one result of such relief may be to shorten life. Clause 6(6) clarifies the law, reconciles it with present practice and brings the Code into line with current moral thinking.[6]

It is clearly of great benefit to the care of patients if the law uses this non-culpability approach to indicate its approval of good standards of palliative care. An alternative would be to explore the concept of the timing of an otherwise inevitable death[7], rather than to focus on causation.

Ordinary and extraordinary distinction

As in the NDAs, this distinction is once again employed to differentiate between treatments which may legitimately be eschewed by dying persons. This distinction has been largely abandoned by North American legislators. The moral tradition from which it is derived essentially allows an individual to choose what is unduly burdensome in a particular situation. With the present definition of extraordinary measures as drafted in the Bill, there would be significant divergence of medical opinion about what constitutes 'conventional treatment of an illness'. It has been shown that it is the persons to whom the measures are to be applied, ➢

➢ rather than the measures themselves that are characterised as ordinary or extraordinary. This allows the introduction of subjective judgments masquerading as objective assessments, and thus combines the worst features of the subjective and objective approaches (Somerville, 1992).

It would now seem more appropriate to define modern medical treatment on the basis of the clinical nature of the intervention with due attention to concepts of futility and proportionality of harms and benefits[8] rather than tenuously through a moral tradition. For example, the defined 'life-sustaining medical treatment' means any medical treatment that supplants or maintains the operation of vital body functions that are temporarily or permanently incapable of independent operation, and includes assisted ventilation, artificial nutrition and hydration, and cardiopulmonary resuscitation.

Likewise, 'natural provision of food and water' means the provision of food and drink, to be taken voluntarily by mouth, to satisfy hunger or thirst, and may include physical assistance (if requested by the patient) from another person but does not include the administration of fluids or nourishment via nasogastric tubing or an intravenous line' (Ashby, unpublished)

Treatment cessation or non-initiation for non-dying persons

In *Airedale NHS Trust v Bland* [1993] 1 ALL ER 821, the Law Lords made a plea to the British parliament to legislate in the area of treatment withdrawal for those persons who are so severely brain damaged that they are left permanently unconscious or in the persistent vegetative state. These terms can be precisely defined, and 'vegetative' should only be used in this narrow sense to avoid confusion. Surely no legislature should ignore this request, as such decisions are being taken all the time in intensive care facilities, without adequate legislative back-up or consistent guidelines.

Cardiopulmonary resuscitation

A clear section on cardiopulmonary resuscitation should also be considered in legislative provisions like CMTPC. Unfortunately some form of clear 'opt out' policy has to be operated in acute care facilities, with all patients being assumed to be for active cardiopulmonary resuscitation unless the contrary is specifically stated in the form of a 'not for resuscitation' (NFR or DNR) order in the patient's hospital record. Consequently, the care of the dying in hospital seems to be predicated on the negative basis of the patient being 'not for resuscitation'. Maddocks has proposed the development of 'Good Palliative Care' orders, which might assist in a refocusing of care planning away from the irrelevance (for dying persons) of resuscitation.[9] It is to be hoped that hospices, nursing homes and chronic health care facilities would not operate a cardiac arrest team, where their effectiveness would be extremely dubious anyway.

Conclusion

CMTPC is an important step in the evolution of Australian law and guidelines to improve medical decision making at the end of life and care of dying persons. Many negative aspects of this area result in practice from misunderstandings about what the law and ethics have to say, and at the very least legislative reform will be a powerful tool for health care educators who seek to achieve more compassionate care for those close to the end of life. However there is now an opportunity to amend some of the unsatisfactory definitions in the original version, and boldly tackle some related issues which cry out for legislative clarification. ❖

Dr Michael A Ashby, Department of Palliative Care Medicine, Royal Adelaide Hospital, and Mary Potter Hospice, Calvary Hospital Adelaide Inc, Adelaide, South Australia

Footnotes

1. Hill TP & Shirley D, *A Good Death: taking more control at the end of the life* (Addison-Wesley Publishing Co, New York, 1992).
2. *Natural Death Act* 1993 (SA); *Natural Death Act* 1988 (NT).
3. Ashby M & Wakefield M, 'Attitudes to some aspects of death and dying, living wills and substituted health care decision-making in South Australia: a public opinion survey of a parliamentary select committee', Pall Med 1993: 7: 273-282
4. Brown M, 'The Medical Power of Attorney: a benefit or burden for the well elderly', Australian Bioethics Association 3rd National Conference, Adelaide, 1994.
5. Criminal Code Review Committee, Final Report on the Criminal Code Review Committee to the Attorney General, June 1992.
6. Report 31, Law Reform Commission of Canada CL 6(6), p 60.
7. Devlin P (ed), 'Easing the passing', *In: the trial of Dr John Bodkin Adams* (The Bodley Head 'Publishing Co, London, 1985).
8. Ashby M & Stoffell B, 'Therapeutic ration and defined phases: proposal of ethical framework for palliative care'. Br Med J 1991; 302: 1322-4.
9. Maddocks I, 'Good Palliative Care' (GPC) orders (156):(1992) 888.

➢ unwanted pregnancies. These cases have highlighted the difficult policy considerations involved in quantifying the parent's claim. The more traditional view, that a parent's love for his or her healthy child, even though unplanned or unwanted, should be set off against the difficulties, inconvenience and financial disadvantages which naturally accompany parenthood, is exemplified by the decision of Jupp J in the English case, *Udale v Bloomsbury Area Health Authority* [1983] 2 All ER 522. Later English cases have, in effect, suggested that 'the birth of a healthy child is not always a blessing' (see Pain J in *Thake v Maurice* [1984] 2 All ER 513 at 527). Other English cases where this issue has been discussed are: *Emeh v Kensington and Chelsea and Westminster Area Health Authority* [1985] 3 All ER 1044 and *Allan v Bloomsbury Health Authority* [1993] 1 All ER 651.

The Australian courts have considered this issue on only two occasions (see the judgment of Mohr J at first instance in *F v R* (1982) 29 SASR 437 (overturned on appeal) and Pratt J in *Dahl v Purnell* (unreported, Qld District Court, 24 September 1992)) but it has yet to be considered by a superior court. In the present case, Newman J made no remarks at all concerning quantum of damages presumably due to his conclusions on the liability issue.

Ultimately, liability was determined in the defendants' favour on the question of illegality. It was raised in the context of CES's wish to discontinue the pregnancy and although not specifically pleaded by the defendants, was raised as a defence. It was said that it could not be shown that CES, at the relevant time, could have obtained an abortion that would have come within the law. This was the illegality. Newman J accepted this proposition and said that on the basis of the High Court decision in *Gala v Preston* (1991) 172 CLR 243, he could not award damages for the loss of an opportunity to perform an illegal act.

The law in NSW regarding abortion is essentially that which was set down by Levine J in *R v Wald* (1971) 3 DCR (NSW) 25. Known as the 'Levine ruling', it has not been the subject of appellate scrutiny. It is there stated that for an abortion to be lawful, the doctor performing it must have an honest belief on reasonable grounds that the termination is necessary to preserve the woman from serious danger to her life, or physical or mental health. It is clear that economic or social grounds may be taken into account by the doctor when assessing the potential danger to a woman's physical or mental health, see *Wald* at 29.

In the present case, evidence was given by two doctors as to the state of CES's mental health during the early stage of her pregnancy. One had diagnosed the pregnancy. The other, the Director of Family Planning in NSW, had been asked to give her opinion as to the lawfulness of an abortion in the circumstances of CES, based on certain assumptions. Newman J found that the evidence did not satisfy the Levine ruling and, accordingly, that had the termination proceeded, it would have contravened the relevant provisions of the *Crimes Act* 1900 (NSW).

The Newman decision is now the subject of an appeal to the NSW Supreme Court, Court of Appeal and can expect to be heard in the first half of 1996. ❖

Catherine Henry,
McCourt Charlton, Solicitors,
Sydney.

Anyone interested in a copy of the decision or further information can contact the author on:
Ph: (02) 241 1466
Fax: (02) 241 5878

SA Law reform on death

Last month we published an article by Dr Michael Ashby, 'Law reform on death—over but not out' (1994) 2 HLG 81-85.

1. The article referred specifically to SA, but law guidelines in other States and Territories are summarised in Table 1 (p 102).

2. Page 83 correction: Trevor Griffin MLC tabled an amendment that the Supreme Court has 'supervisory jurisdiction' over the agency. It was the Hon Barbara Wiese (for the Minister for Health) who proposed a review function for the Guardianship Board.

3. Page 84 under the heading 'Discussion': the agency—Medical Power of Attorney (final paragraph) Professor Margaret Somerville suggested the term 'substitute health care decision maker' for the agency rather than Medical Power of Attorney (unpublished evidence to Select Committee on law and Practice Relating to Death and Dying in 1992).

SA Advance Directive

We also published an article by Dr Michael Ashby entitled 'A proposed advance directive format for South Australia' (1994) 2 HLB 89-91. This month we present SA's proposed advance directive and schedule of appointment of a substitute health care decision maker.

Note: The SA Advance Directive Study Group is now considering renaming the DIRECTIVE as a DECLARATION to reflect its evidential rather than directive role. A section will be included in which a person will be able to make any statement which they consider relevant.

All comments should be directed to: Dr Michael Ashby,
Calvary Hospital, PO Box 231,
North Adelaide, SA 5006.

continued overleaf ➢

South Australia Advance Directive

CONSULT THIS COLUMN FOR GUIDANCE

This declaration sets out your views about medical treatment for a future incurable illness.

It may be revoked or amended at any time, and regular review (annually with your general practitioner and family for example) is recommended.

This ADVANCE DIRECTIVE is specifically for use in SOUTH AUSTRALIA, but its contents provide evidence of your wishes which you request be respected in the jurisdictions of the other Australian states and territories.

Make sure you carry the plasticised wallet card with you, and that it and this advance directive can be found easily when required.

To my family, friends and medical carers

I, (here insert full name) _____

of (here insert address) _____

_____

make this DECLARATION at a time when I am of sound mind and after careful consideration. If the time comes when I can non longer take part in decisions concerning my medical care, let this DECLARATION stand as EVIDENCE of my VIEWS, WISHES and BELIEFS about my quality of life and eventual death.

In the event of a future illness or injury which leaves me in an INCURABLE and IRREVERSIBLE mental or physical condition, with no reasonable prospect of recovery, I REQUEST the medical practioner responsible for my care to initiate only those measures which are deemed necessary to maintain my comfort and dignity, with particular emphasis on the relief of pain and distress according to the prevailing standards of palliative care. I therefore also request that any treatment which might obstruct my natural dying process either not be initiated or discontinued. If I have severe irreversible brain damage and am in a coma or the persistent vegetative state, I give permission for life-sustaining medical treatment to be ceased.

This section explains the medical conditions for which this directive applies. It only comes into effect if you are UNABLE (INCOMPETENT) to express your wishes.

Initial by the alternative(s) to which you wish this directive to apply.

I wish these instructions to apply if the medical practitioner responsible for my care considers my condition to fall into one of the following categories: *(initial)*

(a) the terminal phase of an incurable life threatening illness. _____
(b) permanent unconsciousness (coma) _____
(c) persistent vegetative state# _____
(d) advanced dementia# _____

and it is thought to be very unlikely that I will regain the ability to make decisions or express my wishes.

You may specifically refuse any of these treatments

If I have the condition(s) here described above, I do not want the following forms of treatment: *(initial)*

(a) I do not want cardiopulmonary resuscitation (CPR) _____
(b) I do not want mechanical ventilation (on a respirator) _____
(c) I do not want artificial (tube or intravenous) feeding or hydration# _____

Unless required for my dignity and comfort as part of my palliative care:

(a) I do not want a surgical operation _____
(b) I do not want antibiotics _____
(c) I do not want to be admitted to hospital, provided that this does not place an unacceptable burden on my carers. _____

Appointment of a substitute health care decision maker

If you wish to name a SUBSTITUTE HEALTH CARE DECISION MAKER enter details here.

If you do not wish to appoint a SUBSTITUTE, you may leave this section blank.

I, (insert name and address of patient) _____

_____

_____

appoint: _____

Insert name, address, telephone number and occupation of SUBSTITUTE

To be my substitute health care decision maker,

_____

_____

and your alternative (second) SUBSTITUTE

and appoint: _____

_____

You should discuss this directive with your substitute. It will help the substitutes to know your wishes and beliefs when making decisions for you in the event of you being unable to do so yourself.

to be my alternative substitute health care decision maker.

1. I authorise my substitute or alternative substitute to make decisions about my medical treatment if I should become unable to do so for myself.
2. I require my substitute or alternative substitute to observe the conditions and directions contained in this advance directive in exercising, or in relation to the exercise of, the powers conferred by this appointment.
3. This appointment of a substitute health care decision maker is made under the consent to Medical Treatment and Palliative Care Bill 1994.

_____

(signature)

Acceptance of appointment as subtitute and alternative substitute health care decision maker

NOTE:
The substitute and alternative substitute CANNOT be exercised jointly.

** Delete if no alternative substitute.*

I, *(substitute)* _____

I, *(alternative substitute)* _____

accept appointment as substitute **and alternative health care decision makers respectively* and undertake to exercise the powers conferred honestly, in accordance with the principal's desires so far as they are known to me/us*, and, subject to that, in what I/we* genuinely believe to be the principal's best interests.

(signature of substitute) _____ *(Date)* _____

(signature of alternative substitute) _____ *(Date)* _____

Signature and witness certificate

Sign and date here in the presence of ONE witness, who should not be related to you and is over 18.

Signed _____ **(Date)** _____
(person making advance directive)

I, (name and address of witness) _____

_____

hereby witness the signature of _____
and therefore confirm the authenticity of this advance directive.

**Delete if no substitute has been appointed.*

**I certify that the grantor and grantee of this substitute appointment signed it freely and voluntarily in my presence; (signature)* _____

Details of your general practitioner or a specialist medical practitioner, who knows your medical history and views, whom you would be happy to have contacted if required. This is advisable but not mandatory.

Name: _____
Address: _____

_____

Telephone: _____
Fax: _____

Notes to assist in the completion of your Advance Directive form (definition of terms) - please see over page ➢

Definitions of terms used in the Advance Directive

Persistent vegetative state (PVS)
Is a state in which severe and irreversible damage has occurred to the higher cortical centres of the brain (eg after stroke or head injury), but the brain stem is intact and consequently the vital reflexive functions of the body (heart beat, respiration and digestion) continue. The patient may have periods of apparent wakefulness with eyes open, but does not appear to be able to communicate, talk, see or hear.

Dementia
Progressive impairment of brain function, with variable features and time course. Common features include loss of interest in life, personality change, and recent memory loss with antisocial and disinhibited behaviour and depression. Sleep disturbance and wandering, loss of bowel and bladder control also often occur. Increasing confusion and complete social disintegration lead to the person becoming bedridden, and eventually death occurs. The commonest cause of dementia over 60 years is Alzheimer's disease (cause unknown - average survival 5-7 years).

Cardiopulmonary resuscitation (CPR)
Emergency measures to maintain heart pumping (by massaging chest) and artificial ventilation (mouth to mouth or ventilator) when a person's breathing and heart beat have stopped. This is usually only effective if the underlying cause is correctable. Doctors, nurses and ambulance officers are usually required to undertake CPR unless they have a specific instruction from you to the contrary.

Artificial (tube or intravenous) feeding or hydration
The provision of food and fluid by artificial means when you are unable to eat or drink yourself. This may be done by passing a tube through the nose into the stomach (nasogastric tube) or by an intravenous line. It is only really useful if the underlying condition is being treated. If you do not have it, you may still be given fluids (eg; by infusion under the skin) and your mouth will be kept moist.

Australian legislation and guidelines on death and dying

Table 1

STATE	YEAR	TITLE	TYPE OF LEGAL INSTRUMENT	COMMENTS
SA	1983	Natural Death Act	living will	*Over 18, sound mind* *Future terminal illeness* *No extraordinay measures*
NT	1988	Natural Death Act	living will	*As above can specify extraordinary measures you do not want*
Victoria	1988	Medical Treatment Act (MTA)	Refusal of treatment certificate	*Refuse treatment of current condition*
Victoria	1990	Medical Treatment (Enduring Power of Attorney) Act (EPA)	Enduring power of attorney	*An agent can refuse medical treatment on your behalf if you are incompetent*
Tasmania	1990	Medical Treatment and Natural Death Bill (failed)	Refusal of treatment certificate	*Victorian model*
WA	1991	Report on Medical Treatment for the Dying	Refusal of treatment certificate (Victorian model) Law Reform Commission of WA Project No 84	*Recommends:* *1. Enduring power of arrorney* *2. Appointment of guardian* *3. Substituted judgments first, then best interests* *4. Palliative care and cause of death* *5. Definition of death* ***None implemented yet***
Victoria	1992	Medical Treatment (Agents) Act (MTAA)	Alternate agent	*Appointment of a substitute for first agent*
SA	1992	Consent to Medical Treatment and Palliative Care Bill (lapsed Nov 1993)	Medical power of attorney	*Appointment of Medical Agent consent or refusal (except natural provision of food and water, and palliative care)* *? Advance Directive*
Qeensland	1992	Final Report Criminal Code Review Committee	Criminal Code revision	*Palliative care not a cause of death* *Sched 3, s 69*
NSW	1993	Dying with Dignity (NSW Dept of Health)	Interim guidelines on management	*Guidelines for use in NSW hospitals re care of dying, advance directives, advocates and resuscitation*
ACT	1993	Voluntary & Natural Death Bill private members Bill	Legislation of physician -assisted suicide and medical aid in dying	*1. Withdrawal or refusal of treatment* *2. Power of attorney* *3. VAE (including by proxy)*
Victoria	1993	Medical Treatment (Assistance to the Dying) Bill	A proposal to legalise medical assistance for the terminally ill who wish to end their own lives	*Public Launch (Kubse and Syme) of private member's Bill — no member has yet adopted it*
ACT	1994	Medical Treatment Bill (Draft)	Refusal of treatment certificate and medical power of attorney	*Victorian model* *Promotion of pain control*

Australian Health Law Bulletin

A proposed advance directive format for South Australia

Dr Michael Asbby, with the assistance of a South Australian Advance Directive Study Group has drafted a palliative care directive. _Dr Asbby_ discusses the initiatives.

This is a prototype advance directive developed for pilot use and evaluation in SA, although it could easily be adapted for consideration in any Australian State or Territory. It is proposed that this might be the prescribed format if the *Consent to Medical Treatment and Palliative Care Bill 1992* (SA) is reintroduced, with a provision for an advance directive.

Advance directives have been endorsed by the NSW Department of Health in its Interim Guidelines on Death and Dying[1], and they are deemed to be legal in the UK by the House of Lords in *Airedale NHS Trust v Bland* [1993] 1 All ER 821. However in the absence of any legal provision for them, their implementation is questionable, although it would be a serious step for a practitioner to disregard authenticated written evidence of a person's wishes. This issue has not been brought before an Australian court, and only the living wills of SA and the NT, and the Refusal of Treatment Certificate in Victoria[2] are provided for in legislation. Further, Victoria is the only State that prescribes a penalty for disregard of the certificate, even if this only incurs the same number of penalty points as the false registration of a dog.[3]

An instructional advance directive is a document which allows a person to set out their wishes concerning medical treatment in the event of a future illness or injury which renders them incompetent.

'The directive may be considered to provide either evidence of a person's wishes, or to constitute an act of will by the person.'

The term 'living will' has come to be associated with a declaration or notice pursuant to a *Natural Death Act* (NDA). The NDAs vary as to the circumstances in which they are allowed to operate. Broadly, these instruments allow a person to state that they do not wish to have life-sustaining medical treatment (often termed 'extraordinary' means) in the event of a future terminal illness, and are activated by the person's incompetence. The first NDA was enacted in California in 1976, and this was followed by similar Acts in the majority of states of the US. The NDAs exist in SA (1983) and the NT (1988). NDA's have gradually been superseded by advance directives which are broader in scope, and may be applied to situations other than a (sometimes narrowly defined) terminal illness.

The directive may be considered to provide either evidence of the person's wishes, or to constitute an act of will by the person. This distinction will influence the degree of flexibility of interpretation which exists when the directive is invoked in a given clinical situation.[4] The proposed directive, for SA, has favoured the evidential model, in which the document is intended to provide evidence of what the person would have wanted. It will act as the principal determinant in the decision-making process which would normally occur if the person were competent. Discussion will still be possible between the substitute and medical pratitioner concerned, if the way to proceed in a given situation is unclear.

A proxy directive appoints a substitute health care decision-maker or agent by means of a legal instrument such as an ➤

➤ enduring power of attorney. The majority of States in the US now have combined instructional and proxy directives.[5,6] The proposed directive for SA follows the combined approach, but allows a person to make the directive without naming a substitute if they do not wish to, or have nobody they feel they can nominate.

Directives vary as to how specific they are in attempting to cover future medical treatment. For example, Molloy's 'Let Me Decide' uses carefully defined medical terminology, with substantial explanation of the technical language used and scenarios.[7] The intention is to provide a directive which will be easy (for doctors) to interpret when it needs to be implemented, and this is the style which has been favoured. By contrast others argue that the medical content should be downplayed, with an emphasis instead on values:

> the suggestion is ... that living wills also contain a 'values history' as a formal basis for dialogue in which objectives in terms of life-values are identified as opposed to the medical means by which those values might be recognised.[8]

The directive proposed for SA commences with a pre-drafted values section. Emphasis here is on the withdrawal or non-initiation of treatment in the event of a serious life-threatening irreversible condition, so that the natural dying process is not obstructed if it is inevitable. It also includes a request for appropriate palliative care. An opportunity to freely express personal values might be promoted in this section.

In the second section of the directive the person can choose to activate the directive in certain specific circumstances. The first alternative (terminal illness) is in line with the NDAs. The other three alternatives deal with severe brain damage, which was one of the main areas of concern expressed in the evidence submitted to the Select Committee on the Law and Practice relating to Death and Dying.[9,10,11] The issue of chronic, organic brain syndrome such as Alzheimer's disease and dementia process, cannot be ignored. This area requires a great deal more attention, with particular regard to criteria for assessment of competence, and strategies to deal with expressions of will by persons deemed to be incompetent which conflicts with previously expressed views in a directive, or the decision of a properly appointed substitute.[12] By specifically including the persistent vegetative state, the challenge of the Law Lords in the *Bland* judgment is taken up (see *Airedale*).

'Directives vary as to how specific they are in attempting to cover future medical treatment...'

In the third section of the directive a person can elect to specify any treatment which they particularly do not wish to undergo. Definitions of medical terminology are appended to the directive.

The appointment schedule for a substitute (and alternative) substitute health care decision-maker is included in the directive. This avoids the confusion of two separate documents, and also intends to emphasise that the contents of the directive should be discussed with the substitute(s). This should provide the soundest basis for substitute decision-making.

Proper education and assistance in the completion of an advance directive will largely determine how much they are used.[13] It is also highly desirable that the person's general practitioner be involved, and a section has been included to encourage people to name their doctor, and discuss the directive with him or her. This is, however, not made obligatory.

There is probably no such thing as an ideal advance directive. Extensive piloting and consultation are required, particularly in the community for which they are intended, if the poor knowledge and use of the NDAs is to be improved upon.[14] ◆

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The advance directive will appear in next month's issue.

All comments on this article are welcome and should be addressed to:

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Conferences

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Ecosystem health & Medicine

Integrating science, policy and management

Date: June 19-23 1994
Venue: Ottawa, Ontario, Canada

Overview

The Symposium will foster the development of an ecosystem health perspective for management of regional and global environments. The trans-disciplinary field of ecosystem health and medicine bridges the social, health, and natural sciences in encouraging integrated approaches to assessing, maintaining and improving the health of ecosystems under stress. The Symposium program will promote dialogue across disciplines to explore the conceptual and science base for this emerging field, the implications of changes in ecosystem health for human health, and practical applications to policies and programs. The goal is not only to develop the science of ecosystem health assessment, but also to promote healthy public policy and to inspire change so that integrative thinking on resources and the environment truly becomes the 'order of the day.'

Major themes

- Assessing ecosystem health
- The human health/ecosystem health interface
- Linking science, ethics and policy

Symposium events

Featured speakers from the medical, ethical, natural science and policy fields.
Trans-disciplinary panels addressing and debating key issues.
Interactive workshops for a detailed exploration of special topics and issues.
Contributed display area presentations for presentation of research results and programs.

General practitioners' knowledge and use of living wills

See p 236

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BMJ 1995;310:230

Making medical decisions for people who are mentally incompetent, particularly at or near the end of life, is of international interest. In the United Kingdom there are no legal provisions for advance directives or living wills,[1] but the High Court recently upheld that a patient's wishes expressed in an advanced directive are legally binding.[2]

Most of the work on the use of directives and making decisions about health care for others has focused on institutions. The promising role that living wills could have in longer term advance planning, particularly as a part of good family medical practice, has remained largely unexplored.

Living wills have been legal and binding in the state of South Australia for a decade in the format promulgated under the Natural Death Act 1983. We previously reported the results of a public opinion survey carried out for a parliamentary select committee in 1991 in which the concept of living wills and a medical power of attorney were widely supported, but there were significant concerns about lack of public awareness.[4] We report the results of a concurrent survey of general practitioners' attitudes to and knowledge of the Natural Death Act.

Subjects, methods, and results

A response rate of 74% (117/158) was obtained to a postal questionaire sent to a random sample of general practitioners. The design and survey methods have been described.[5] Only 74 of the respondents were aware of the provision for living wills, 23 of them reporting that they had the forms available in their surgeries. Forty one of the 74 doctors had discussed making a living will with patients, the subject having been raised by the patient in 26 cases and by the doctor in six. Twenty one doctors reported that the patient had completed a living will; the doctor considered it to have been helpful in decision making in 12 cases and to have not been useful in four and was undecided in five.

The general practitioners surveyed were concerned about the concept of living wills and their implementation, notably because of the difficulty in raising the issue with patients and families and the possibilities of having a negative effect on the doctor-patient relationship and generating differences of opinion between doctors and families (table).

To improve the practical application of the legislation, 37% (43/117) suggested introducing a bracelet indicating that a person had made a living will. Such wills, however, are unlikely to operate effectively in accident and emergency departments when patients are seen by staff who do not know them. Support for a more medically specific directive was low (14% (17/117)), and opinion was divided (51% (57/112)) on the proposed provision of an agent (enduring power of attorney) to make decisions on a person's behalf when he or she becomes incompetent.

Possible worries and degree of concern about discussing living wills with terminally ill patients who are mentally competent. Values are numbers (percentages) of general practitioners

	Not at all	Somewhat	Very much
It is a difficult concept to explain to patients (n=110)	71 (65)	33 (30)	6 (6)
It is a difficult concept to explain to relatives (n=112)	65 (58)	40 (36)	7 (6)
Patients might think the doctor-patient relationship too contractual (n=111)	67 (60)	35 (32)	9 (8)
It may make the patient lose hope (n=110)	57 (52)	48 (44)	5 (5)

Comment

Clearly, lack of knowledge of the Natural Death Act 1983 has been an obstacle to the effective use of living wills in South Australia, and this implies that a carefully executed awareness programme among the public and general practitioners must accompany any legislative change. Although conflict with families is viewed as a common problem, such conflict might arise less often if the person's views have been stated in an advance directive and been discussed within his or her family at the time of making the directive. Any form of living will, advance directive, or agency is intended to clarify what the patient wants and so should be an ally of good medical practice, not a troublesome intruder. General practitioners must be part of their development.

The data were gathered by Harrison Market Research. We thank Megan Ward and Lyn Earnshaw for typing the manuscript.

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A PATIENT WHO CHANGED MY PRACTICE

Biopsy before baptism

In 1989 I was in charge of a small, remote hospital on the Uganda and Zaire border. It belonged to the local Anglican church but apart from being a missionary I was also the government's district medical officer. We had running water, solar power electricity, and a basic laboratory—a typical rural African hospital. Histopathology services were available through the help of a London teaching hospital, where our biopsies were sent by airmail and examined.

The patient presented with postmenopausal bleeding. She had a large ulcerating tumour of the cervix, grown into the vagina; in fact the cervix seemed totally destroyed. I diagnosed her as having a stage three carcinoma of the cervix. It seemed a purely academic exercise and a waste of time for my learned friends in London but I did take a biopsy. Meanwhile I told the family the bad news, as I did not see any point in waiting for six weeks for the result. There was no hope; this disease could not be removed by an operation. It was my duty to refer her to the hospital chaplain and while I was defeated his sympathetic approach was successful. Soon the woman expressed the wish to be baptised before she died and her wish was granted.

The histology came back as amoebiasis. I invited the woman back and put her on metronidazole, vaginally as well as orally. Within 10 days she was cured and her cervix looked entirely normal. Her baptism had saved her. To my surprise the story did not damage my reputation; she never dreamt of blaming me for my rash and wrong diagnosis. On the contrary, God had done a miracle through my hands and had blessed my drugs, albeit after some delay.

Of course, I wholeheartedly agree with her view, but I also learnt my lesson. I have never again told a patient any bad news before the biopsy result was available.—CHRISTINA M DE WIND *is medical coordinator for Médecins sans Frontières in Somaliland*

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Medicine and the Community

For debate

The euthanasia controversy

Decision-making in extreme cases

Paul A Komesaroff, J Norelle Lickiss, Malcolm Parker, Michael A Ashby

A HARD CASE TO ANSWER

A 34-year-old woman was diagnosed with cancer of the breast. The primary tumour was removed and an axillary dissection was performed, revealing lymph node involvement. Further local and systemic therapy was recommended, but the patient declined further treatment and decided instead to leave the city and move to a commune in southern Queensland where "alternative" medical practices were promoted.

The patient was married with a daughter, aged four. She had been working as a high school teacher and had been to that time a keen sportswoman. Although her husband was in favour of pursuing conventional approaches to treatment, he accepted her decision and accompanied her, with their daughter, to the commune. There, she lived according to a Buddhist philosophy and engaged in regular meditation and other practices designed for cleansing and healing. After two years, she remained well and considered herself cured. The family returned to the city to resume their lives. The patient went back to teaching and gave public talks about how she had conquered breast cancer without drugs.

Unhappily, about six months after their return she suffered an acute spinal cord compression at the T9–10 level, leaving her paralysed and without bladder and other functions. Medical help was eventually sought, and although emergency radiotherapy was attempted it was without effect. She was advised that significant recovery was most unlikely and was subsequently admitted to a hospice for long term care. There were no other medical issues at this time and she was in no (physical) pain.

Naturally, she was distressed about this outcome, but maintained a warm relationship with her husband and child. She became determined that she would return home and announced that if this were not possible she would prefer to die. After a few weeks in the hospice, elaborate arrangements were made for her to go home on a weekend visit. She left in high spirits on the Saturday morning, only to return about six hours later, it having emerged that her husband was unable to perform the complex tasks involved in caring for her (which included pressure care, and attending to bowel and bladder function).

When seen on the following Monday morning, she announced that after careful thought she had realised that she would never be able to live the kind of life that satisfied the minimum conditions she demanded. Accordingly, she had decided that she wanted to die. She asked the treating doctors and nurses for assistance in dying. Her husband was distressed about this decision but said that he understood it and that it was consistent with what they both believed and had discussed many times in the past.

Should doctors, in some circumstances, assist their patients to die? This question, which has been debated since antiquity, has recently attracted great interest. The reasons for this are uncertain, but probably include the enhanced capacity of medicine to keep people with serious illnesses alive, an increased emphasis on patient autonomy and free choice, and a possible shift in the practice of medicine from a concern with caring and listening to a preoccupation with technical results.

Most of the debate concerns so-called "voluntary active euthanasia", in which a patient makes a request for assistance in dying. The main arguments in favour are that individuals should be able to make free choices about the circumstances of their own deaths, and that in the case of intractable illness an assisted death may prevent considerable pain and suffering. Against this is the argument that involvement by doctors in killing their patients not only represents a travesty of the goals of medicine, but also imposes unconscionable pressures on chronically ill, disabled and elderly patients to submit to these practices; instead, so it is argued, increased emphasis should be placed on providing palliative care services.

Lately the debate has focused on whether the law should be changed to permit doctors to practise euthanasia. Renewed interest was sparked by a proposal from the Northern Territory Chief Minister to introduce such reforms and by an open letter to the Victorian State Government by seven doctors who claim to have contributed on various occasions to the deaths of patients, in contravention of existing law. The doctors' letter, in particular, has aroused strong feelings, with expressions of support or condemnation coming from all sections of the community.

While it is both simplistic and paternalistic to say that all calls for euthanasia are really disguised calls for effective palliative care, it is none the less true that the excessive emphasis on legislative reform and the resolution of dramatic "dilemmas" has led to a relative lack of discussion about

For editorial comment, see page 566

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questions of communication and pain relief and other issues of patient care. Most, although not all, cases in which euthanasia becomes an issue have been preceded by long processes of clinical decision-making; in each of these, the illness has been shaped over time in accordance with the values and preferences of the patient and his or her caregivers as much as by the technical apparatus. Individual decisions are often negotiated over the course of an illness and usually represent responses to the outcomes of previous decisions. In many cases, an intractable dilemma reflects a series of lapses in communication which have upset the delicate equilibrium of the clinical process.

This is not to deny that difficult decisions sometimes need to be made; rather, it is to emphasise the complexity and subtlety of clinical practice in the hope of refining the debate about euthanasia and encouraging the development of new resources. The questions at issue here are important and need to be discussed publicly within the medical community. To contribute to this debate, I asked three practitioners with experience in palliative care to discuss their approaches to the particularly difficult clinical circumstances detailed above.

Paul A Komesaroff

Listening and talking

Norelle Lickiss

The consternation that Monday morning is palpable, with the staff inevitably distressed, and the patient, having declared a decision, possibly calm. As an external consultant, presumably well known to at least one of the "treating doctors", my first step would be simply to be there, in all that tension and sadness, soaking up some of it like blotting paper, pain and all: this is the exercise of compassion, the first duty of a consultant given permission to enter such an arena. The complexity of the situation, its depth and ramifications, simply must be perceived, felt by the consultant as a human being. Few words may be passed.

Once calm begins to emerge with respect to each person present, there is room for beginning an assessment process. I need to learn from the patient the way she thinks, feels, relates, moves through life, hopes and reaches decisions, and how she has experienced her disease. What led to the diagnosis? How did she experience the telling? How did she experience the time away in the commune? Most persons would be shattered by the turn of events leading to her loss of power in her legs. What are her real priorities now?

Before commenting, I would wish to sit alone with her, and hear her story from the beginning. On the first encounter she may not wish to talk, nor even want "yet another doctor" present, but she is in such desperate need that she may at least accept my presence for a little while — and this small sharing of presence is one little step to reducing her existential isolation.

If she can tell her story — as have most of the patients I have been privileged to encounter[1] — she will have begun the process of resolving her present existential crisis. She will discover the possibility of restructuring her hope. The most probable outcome is a steady personal development towards finding her real self again, albeit on a new key.

There is of course also a need to "assess" — that is, to understand — several other persons: her husband, her child, the treating doctors and nurses and other staff, and other relatives and friends. Where are they?

If she can tell her story... she will have begun the process of resolving her present existential crisis. She will discover the possibility of restructuring her hope.

The "biography" of the tumour also needs to be clarified. The consultant must be alert to odd features which may even herald an incorrect diagnosis. The possibility of anticancer measures improving the patient's quality of life should always be kept in mind, for she may herself decide to have such measures reviewed, despite her previous stance. She may agree at least to tamoxifen, and may respond for years. Future problems caused by the tumour if untreated need to be anticipated. There are abundant measures available to reduce disabilities due to cancer-related symptoms,[2-5] although it is true that there are limits to what is possible with respect to palliation.

Later, this woman may still or again insist that what she wants to do is die now, but also may request that her death be deliberately accelerated, or ask for the means to suicide. These wishes need to be clearly distinguished, and there may well be a circumstance in which no measures should be taken to prolong her life, and death should be given a chance.

It is my conviction that a doctor must be the boundary bearing the pressure of society and individuals in the matter of euthanasia. Autonomy of the individual cannot be the ultimate guide to action. I would contend that the interests of the individual are best served by refraining from euthanasia.

The focus in this case is surely to explore with the patient the possibilities for resolving her existential isolation and despair, and the opportunities for growth into her human possibilities. We must also recognise that suffering is in the end not wholly a medical issue. Yet there is an opportunity to assist this woman to move into a new dimension of hope in herself, her husband, her child, her friends, her treating doctors and nurses — and a new hope in life itself, however she prefers to conceive it.

The patient's choice

Malcolm Parker

While philosophers are sometimes criticised for testing their theories against hard cases, clinicians must respond to them in their daily practice. Clinical management requires therapeutic competence, but also implies moral positions which are more assumed than articulated in everyday clinical activity. In treating the dying, hard cases demand justified articulations of the integration of clinical and ethical components.

This is a hard case because it pits a competent request for assistance to die against the medical commitment to save and prolong life and relieve suffering. Complying with the request would contravene traditional medical ethics as well

as be a criminal offence in all Australian jurisdictions. But a refusal to assist the patient would, *prima facie*, impose on her an unacceptable quality of life. It would amount to requiring her to continue living according to my views, or the wider views of a profession or society, rather than her own. This would be inconsistent with considerable change within medical practice of late which has recognised the importance of patient autonomy as a cornerstone of modern health care. It would also be inequitable as it would fail to vouchsafe to this patient the outcome available to those who die as a result of directing the removal of life-sustaining medical treatment.

Absolute refusal to consider complying would be a failure to respect the wishes of a competent adult.

In helping this patient I need to find a justifiable path between two sorts of failure. Immediately agreeing to the request for assistance would be to fail to explore all the elements which have led to it. Absolute refusal to consider complying would be a failure to respect the wishes of a competent adult. Both types of failure offend against my idea of reasonable clinical care.

I need to offer sympathetic understanding of her present tragic circumstances. Acknowledging the gravity of things would reassure her that I take her seriously as an individual; that her interests, beliefs and wishes count in my deliberations. None the less, I must regard her request for assistance to die after the first weekend trial of home nursing as, at the least, premature, as she has not had an opportunity to adjust to conditions which she decided, while in good health, would be unacceptable. We should explore all possible avenues of home care and support. Considerable community resources can be summoned to this end. This is clearly a clinical duty, but intertwines with the need to distinguish just what desires are corrigible (perhaps she will be willing to try again with a better domiciliary support) from those which are not (her desire to remain at home may be immovable).

I need to inform her fully about my ability to treat pain, a symptom she may well develop later, and my willingness to consult with the palliative care service with which I have developed a working relationship through treating other patients. I have interviewed many patients who are anxious about how painful dying will be because they have not been reassured about pain relief by their own doctor.

I am also cautious about the precipitate nature of her decision in terms of her family situation. Despite their previously agreed views, only now is she in the circumstance they envisaged. Given that she has a warm relationship with her husband and child, she needs to consider the implications for her family of rapid compliance with her request. There may well be matters concerning her child's welfare and future which need to be addressed. I don't believe that it is an affront to people's self-determination to seek to guide them, advise them, or even influence them. If it were, social life as we know it would not exist.[6] However, I need to be careful not to coerce her in her decision.

All this may persuade the patient to rescind her request. I consider that most such requests for assistance in dying would, in fact, be rescinded. But it may not be, or it may be repeated at a later stage. Then, with all avenues explored and rejected, and with an understanding that the decision is mindful of the implications for the patient's family, I would see a clear moral duty to comply, reflecting respect for the patient which is integral to the doctor–patient relationship.[7]

Physician-assisted suicide has not been prevented by its prohibition within the law and medical codes.[8,9] There are cases where the distinction can be made between decisions of convenience and actions of genuine mercy, in the face of acknowledged limits to medical capability.[10]

I would then have offered management consistent with medicine's presumption to treat, offered all available options for treatment, provided the space for reflection on the implications of acceding to the request for assistance to die, but finally agreed that compassionate care in some cases will involve such assistance, and have assisted.[11]

State interests versus individual wishes

Michael A Ashby

My approach to management would be based on open acknowledgement and discussion of this woman's request for medical assistance in bringing about her death, and my inability to meet this request for legal and ethical reasons. I must establish that the request is consistent and persistent, and whether it results from suboptimal symptom control or depression. I must not regard the request as irrational or the result of either a psychiatric or personality disorder unless there is clinical evidence of this.

For many people who are dying it is not just a question of comfort and the absence of physical suffering (framed in the negative), but a loss of function, independence and role which are the hardest to bear. It is not the role of any health care team, including a palliative care service, to suggest that its ministrations can give meaning, purpose and dignity to a dying person's remaining life if the person feels that these are irretrievably lost, although sometimes this perception will change, either as a result of palliative care or for other reasons.

In this case, the immediate reason for wishing to die is not pain and suffering, or absence of significant others, but rather the patient's inability to be at home with her family. The failure of her discharge after only six hours indicates inadequate discharge planning and home palliative care support or lack of resources. Professional nursing assistance should be provided for all the tasks which her husband found difficult. This would entail several domiciliary nurse visits per day as well as evening and night service. Community palliative care volunteers could also assist in taking the pressure off the family and help in the physical care.

I would reassure her that nothing would be done to prolong her life, and that if a time came when she did not wish to be aware this could be achieved by pharmacological means. It is sometimes argued that intentional shortening of life may be justified if requested by a terminally ill patient and that so-called "pharmacological oblivion" (using sedation to make a person drowsy or unconscious while they are dying) is merely a rationalisation of what the medical practitioner is really doing.[12] However, intentional ending of life is not part of palliative care practice and it is different in kind

from all other clinical interventions. I believe that intention determines the moral character of acts, although in practice moral intuition is usually more relevant than abstract philosophical debate.

I hope that a trusting relationship can develop between the palliative care team and both patient and family, with a closeness and involvement that is real and emotionally engaged, but still professionally defined — what is sometimes called the "accompanying" of the dying person. It is important for the team to work through the issues that arise from the care of this woman and support any individual team member who is feeling guilty or inadequate for failing to acquiesce to her request. There is no ideal death or dying process, and often for all our efforts the best we can achieve is a "good enough" death or, more importantly, death with integrity, consistent with the life that the person has led.

Palliative care is a model of care, not a moral crusade, and should not be used as a strategic weapon in social debates.

In their criminal codes, most societies deem themselves to have an interest in preserving the lives of their citizens which overrides any individual's wishes for medical assistance in dying. This is unacceptable to many people who give the highest priority to personal autonomy and control over their life decisions. There is a potential for alienating these people from mainstream medical services if their views are ignored or rejected in a paternalistic way. Those caring for people making such requests should continue to offer and deliver care without allowing personal religious beliefs to intrude into the clinical encounter. They should also try to remain neutral, in their professional roles, with respect to the political debate about voluntary active euthanasia. Palliative care is a model of care, not a moral crusade, and should not be used as a strategic weapon in social debates.

It is clear that an unknown but significant number of Australian doctors are agreeing to act on requests (such as the one presented in this case) in secret, and are prepared to run the risk of prosecution. Nevertheless, many would agree that genuine and consistent euthanasia requests are few. It remains to be seen whether Australian jurisdictions will follow the path of the Netherlands with a non-prosecution stance on voluntary active euthanasia, subject to guidelines. However this may be, the need for palliative care will continue to increase regardless. The euthanasia debate has acted as a significant distraction for those of us who are trying to improve access to, and the quality of, palliative care, but whatever our views on changes to the law we can all walk a long way together to improve this aspect of our health care system.

What is the answer?

These three points of view do not exhaust all the possible approaches to managing this tragic case, but they draw attention to important features that are likely to be widely shared: they agree that there is a need to provide a high level of skill in diagnosis and treatment as well as special attention to communication and negotiation; they recognise that there is generally not just one point at which an "ethical" decision is to be made that determines the course of an illness, but that such decisions are made on a continuous basis over time; and they emphasise that effective management often requires the involvement of various health professionals, each of whom may have a specific, important contribution to make.

We need research into the "microethical" content of medical decision-making in cases such as this to enhance our understanding of the processes of communication involved and so to improve patient care. We need to ensure that medical students and graduates develop skills to deal with such problems. Doctors should be encouraged to anticipate the possibility that end-of-life issues may arise in a particular illness and to adopt an open and frank approach to talking about them; in these cases, the concept of "planning the course of the illness" should be considered to ensure that management is directed towards appropriate endpoints. Such communication should occur at all levels and not be regarded as the domain of only one group of specialists. The significant improvement in clinical communication that could result from these measures might well bring far greater benefits and save more in pain and suffering than a mere change in the law to permit doctors to practise active euthanasia.

However, from time to time, despite the most sensitive and well-considered care, a patient faced with intractable suffering will request assistance in dying; these cases will always be hard. Eventually it may be considered that it is better and safer from the point of view of society to develop procedures to allow decisions to be subjected to some public scrutiny than it is to force them to be taken in secrecy and guilt.

There will be no last word on euthanasia. The complexity of clinical medicine — and the human condition — is such that it is likely that none of the protagonists is right — or, rather, that all are right in their own manner. There are many clinical and ethical ways. We look forward to further contributions to the debate.

Paul A Komesaroff

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Artificial hydration and alimentation at the end of life: a reply to Craig

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Abstract

Dr Gillian Craig (1) has argued that palliative medicine services have tended to adopt a policy of sedation without hydration, which under certain circumstances may be medically inappropriate, causative of death and distressing to family and friends. We welcome this opportunity to defend, with an important modification, the approach we proposed without substantive background argument in our original article (2). We maintain that slowing and eventual cessation of oral intake is a normal part of a natural dying process, that artificial hydration and alimentation (AHA) are not justified unless thirst or hunger are present and cannot be relieved by other means, but food and fluids for (natural) oral consumption should never be 'withdrawn'. The intention of this practice is not to alter the timing of an inevitable death, and sedation is not used, as has been alleged, to mask the effects of dehydration or starvation. The artificial provision of hydration and alimentation is now widely accepted as medical treatment. We believe that arguments that it is not have led to confusion as to whether or not non-provision or withdrawal of AHA constitutes a cause of death in law. Arguments that it is such a cause appear to be tenuously based on an extraordinary/ordinary categorisation of treatments by Kelly (3) which has subsequently been interpreted as prescriptive in a way quite inconsistent with the Catholic moral theological tradition from which the distinction is derived. The focus of ethical discourse on decisions at the end of life should be shifted to an analysis of care, needs, proportionality of medical interventions, and processes of communication.

Introduction

Dr Gillian Craig (1) has raised what she sees as serious concerns about the ethical and legal aspects of the practice of palliative medicine, with particular regard to the non-provision of artificial hydration and alimentation (AHA). We will argue that the ethical reasoning which we have developed to describe our practice of palliative care can accommodate Dr Craig's concerns (2). The sensitivities and consultative process of negotiation which she articulates are well heard, and we believe are already embodied in contemporary palliative care practice.

There is a broad consensus on aims and ethics of palliative care, and an internationally agreed WHO definition (4), although some diversity of clinical practice and ethical argument has emerged, particularly with regard to the relationship between palliative care and euthanasia (5,6). This article is written from the perspective of an inpatient hospice unit which functions as the acute/crisis intervention facility for a comprehensive palliative-care network (hospital, hospice, home). There are no set policies about who may be admitted, and there is no arbitrary requirement for any therapeutic intervention to be stopped prior to admission. Many patients, particularly those who are young, or have haematological malignancies or AIDS, are in real need of hospice care for symptom control, respite or terminal care. However, they are not yet ready to stop having chemotherapy, blood transfusions, antibiotics or other so-called 'active' treatments with palliative intent, and AHA would certainly come under this category in our institution. A gradual process of negotiation will allow the cessation or non-initiation of treatment as the person's condition deteriorates. We agree that abrupt revision of treatment goals, particularly without adequate consultation of patient, family and staff will lead to anger and disharmony which may have lasting adverse consequences. Consequently communication with these persons is required, but it does not mean that the patient is treated in order to comfort the relatives. The issues raised by Dr Craig are discussed under two main headings: clinical, and ethical/legal.

Key words

Nutrition; hydration; death; dying; palliative care.

Clinical

Dr Craig acknowledges the high public esteem for hospice and palliative care but goes on to state that 'some doctors have reservations'. The grounds for these are that there is a danger of patients being labelled as 'terminal' by the therapeutically inactive

(palliative care) doctor. They may then be denied life-saving medical treatment which would be administered in the same situation by a treatment-orientated physician, perhaps for a wholly or partially reversible condition which has been misdiagnosed. Wilkes acknowledges that this is a real but rare eventuality, which does not occur more than a few times in a professional lifetime of palliative care practice (7), and probably no more so than in any other domain of medical practice. Dr Craig cites two case histories where patients were assessed as dying, but were rehydrated and survived. These constitute poor evidence for mistaken or possibly neglectful assessment in palliative care, even if the patients had been seen by a palliative care service (which is not stated). Careful clinical assessment is a *sine qua non* for any medical endeavour, and certainly before entry into any therapeutic model or protocol, although it is, of course, not infallible. When used to judge the robustness of the ethics of palliative care, these cases might at best fall into the category of hard cases which can be mobilised to undermine any approach. It is not suggested that cholecystectomy be banned because occasionally it is performed inappropriately. Many policies and probably most procedures or interventions in the medical context are dangerous if employed 'without due care and thought'. In our service patients from the main teaching hospital which we serve are accompanied by their notes and we insist on fuller clinical information than some referring doctors think is really necessary for palliative care.

Three phases

Dr Craig quotes from an article in which we described an approach based on three phases of a life-threatening incurable illness: curative, palliative and terminal, with different aims and levels of treatment-related morbidity being acceptable in each phase (2). A similar approach has been described for patients with cancer, for the purpose of making not for resuscitation orders (8). We stated that in the terminal phase 'no form of artificial hydration or alimentation is undertaken, all measures not required for comfort are withdrawn, and no treatment-related toxicity is acceptable' (8).

The framework we proposed was not intended to be a rigid and arbitrary 'policy', and we would not make a virtue of death without artificial hydration (in particular), as in some situations it might even be necessary for comfort right up until the time of death. We agreed that our model is ambiguous as presently worded, and should be amended by the addition of the following: '... unless the effects of this are less than the benefits achieved by the treatment. For example, artificial hydration may be required in the terminal phase to satisfy thirst or other symptoms attributable to lack of fluid intake.'

Thus we give 'comfort measures' priority, including or excluding AHA as may be the case. It is further stated by Dr Craig that in the last few days of life the lack of food and drink will not contribute to death and artificial hydration would not be appropriate, which is our point entirely.

Important review

It is also not usual 'policy' in hospices to sedate patients in order to mask any proposed unpleasant effects of dehydration. Rather sedation is administered when it is needed to alleviate suffering caused by acute organic brain syndromes (particularly where the underlying cause cannot be identified or reversed) and emotional distress for which other non-medical interventions have failed. It is possibly true that sedation may hasten the actual time at which relatively imminent death will occur. But it is not deemed necessary to hydrate sedated patients during the dying process when they are unable to maintain oral intake, as it makes no sense to attempt to treat a transiently reversible component of their overall dying process. Fainsinger and Bruera (9) have undertaken an important review of the clinical arguments for and against rehydration, and it is clear that there is more to learn about the physiology and clinical practice in this area of care. Dehydration can be a contributory cause of an organic brain syndrome, but these are usually multifactorial and in our experience rehydration alone rarely improves cognitive function in dying patients. It is also stated that staff in hospices would be more familiar with drips if they used them more often, and that it is this lack of practice which prejudices them against their use. In our hospice all staff are acute-care trained, and are therefore able to deliver whatever level of medical technology is required in the circumstances to maintain comfort (for example, spinal analgesia, venting gastrostomy, central venous lines, etc). They are always eager to learn new techniques which might benefit their patients. Subcutaneous fluid infusion (hypodermoclysis) has gained considerable acceptance as a means of providing fluids in palliative care (10). This hopefully obviates any need for the practice, described by Wilkes, of infusing tap water into the rectum, especially if this practice is instituted to appease relatives (7).

In our view Dr Craig's real concerns are ethical and legal rather than clinical, and are based on a belief that medicine has a duty always to prevent death. This preoccupation with 'buying time' suggests a belief that doctors are responsible for death unless they do all possible to sustain life in all circumstances, a situation that Callahan calls 'technological brinkmanship': 'doctors still do not, as a rule, talk comfortably and directly with patients about death. ... A worry about malpractice, a zest for technology, a deep-seated moral belief in the need to

prolong life, and the pressure of families and others still often lead to overtreatment and an excessive reliance on technology' (11).

Such an approach may have unfortunate consequences for medical practice, and is in part responsible for the difficulties which many doctors experience with appropriate treatment abatement for dying people. If the care of dying people is to improve in all its settings, we need to try and address the issue of non-provision of AHA as a cause of death, which was raised by Dr Craig as there appears to be considerable confusion both within the medical and nursing professions, and also for many members of the public.

Ethical and legal

There is now a broad consensus that AHA should be regarded as medical treatment (12), and Beauchamp and Childress refer unequivocally to medically administered nutrition and hydration (MN&H) (13). The decision whether or not to use AHA should be based on the balance of benefit and harm to the patient (therapeutic ratio). If AHA can be shown to have no medical benefit for the person, and potentially to cause harm and discomfort, there is a moral duty not to initiate or continue it.

On the other hand the 'natural' provision of food and water for oral intake is both a basic human need and a right, and no civilised person or health care institution could possibly argue for its non-provision or so-called withdrawal. It has been defined as follows: 'the provision of food and drink, to be taken voluntarily by mouth, to satisfy hunger or thirst ... [This] may include physical assistance (if requested by the patient) from another person, but does not include the administration of fluids or nourishment via nasogastric tubing or an intravenous line' (14).

The distinction between natural and artificial provision is made on the basis of what means are required to deliver the fluids and nutrients. All artificial techniques requiring intrusion on the person and medical and nursing skill for insertion and maintenance are medical treatments. In palliative care units food and drink, and assistance with eating and drinking are always available to satisfy a patient's thirst and hunger. But AHA is not routinely used when oral intake ceases, which is a normal part of the natural dying process. All treatments which are not required for comfort are stopped when a person is dying, and AHA, for example subcutaneous fluid infusion, is only used for symptomatic thirst or hunger which cannot be adequately treated by other means. Families and health care professionals are often uncomfortable with this practice. Although all therapeutic interventions should be for the benefit of the patient, the emotional needs and ethical views of the patient's family and care-givers must be acknowledged and considered. There must be recognition and fulfilment of the primary ethical duty to the patient, but the needs of those close to her or him must also be considered. The patient's decisions should determine how his or her medical treatment is to be conducted, but communication with family and friends, within the limits of respect for the patient's right to confidentiality, is almost always required. The way in which it is undertaken is a matter of skill, judgement and consultation. It should also be kept in mind that the degree of family involvement in individual patient decision-making can vary substantially between cultures.

There are two main polar approaches to decision-making at the end of life. Either the treatments or the persons to whom the treatments are applied are focused on. The two approaches are either one that would allow abatement of only certain treatments in all patients, or the other that would allow abatement of all treatments in certain patients. Somerville (15) argues against the ordinary/extraordinary distinction for deciding which treatments may morally be abated, on the grounds that it is not the treatments which tend to be so characterised but the patients to whom they are applied, and that this distinction allows subjective standards to be applied under the masquerade of objectivity. We would add the objection that it is not the duty of any moral, legal or medical commentator to decide *a priori* which treatments may or may not be chosen by a person or his/her substitute health care decision-maker or agent.

Objective standards

With respect to distinguishing patients, we would concur with Ramsey (16), Dyck (17), Grisez and Boyle (18) that a distinction is possible between those persons who are dying and those who are not (although we would hold some different views about treatment abatement for non-dying persons). A hard and fast objective clinical distinction as to when the dying process commences is not always possible, but *the recognition of the existence of a natural dying process is central to the ethics and practice of palliative care* (5). The objective standards consist of clinical evidence (disease progression, vital organ failure) and overt or covert psychological evidence (from both the person who is dying and family members: anticipatory grief, emotional withdrawal, future planning which acknowledges the impending death – for example, funeral planning in the context of terminal illness). Caution should be exercised in appearing to label people as 'dying', because of the attendant dangers of depersonalisation. There is no suggestion that people who are dying have diminished rights, or that their dying days are of less value than their non-dying ones: it may be said that most people want to live until they die. Rather, their dying process should be acknowledged by all; their vulnerability increases our obligation to give care and respect, but does

not lead us to give, and in fact, requires that we do not give, treatment which confers no benefit upon them.

Hydration and alimentation, including by artificial means, have become located in the category of so-called ordinary measures. Kelly (3) was the first to use the extraordinary/ordinary distinction to characterise specific treatments as either one or the other. In the orthodox interpretation of the Catholic moral tradition from which the concept is derived, as reviewed by Cronin (19) and described by McCormack (20), it is understood that it is up to individuals to decide, on the basis of proportionality, what constitutes ordinary and extraordinary treatment in their particular situation (Hepburn personal communication). A competent person determines what is ordinary or extraordinary for him/herself in the particular situation when he or she gives informed consent or informed refusal, respectively, of the medical treatment in question. If that person is no longer able to take oral nutrition and fluid, and does not wish to have these provided artificially then there the matter rests, regardless of what others have to say about the 'ordinariness' of the treatment. For an incompetent person the situation is more problematical, and there are those who would argue, as Craig appears to, that AHA cannot be abated morally or legally by anyone on behalf of an incompetent patient, particularly if the incompetence is the result of medically induced sedation. In other words she appears to propose that the provision of alimentation and hydration is a truly ordinary measure, with the means of delivery being irrelevant to the moral duty to provide them, even when a person is dying. For those who conceptualise the issues in this way, there is a clear moral and legal 'bottom-line' for the treatment that may be withheld, namely only that of which provision is medically impossible or which would cause undue distress, in other words, only in the most extreme circumstances may treatment be withheld.

'Assisted feeding'

Weir (21) cites one of the most prolific and visible proponents of this position in the United States, Robert Barry OP. Barry relies on the *amicus curiae* brief of the New Jersey Catholic Conference in the Nancy Jobes case (22) and policy statements of the Committee for Pro-Life Activities of the National Conference of Bishops as evidence for his position as the correct interpretation of the tradition. Food and fluids, including AHA, should be given to all patients unless it is medically impossible to provide them. The term 'assisted feeding' is adopted to describe all provision of nutrition and hydration, and this is characterised as different from other medical treatments on the grounds that death inevitably results from non-provision; less skilled expertise is required to carry it out (tubes become passive conduits); and it is 'natural'. Assisted feeding is deemed to be always morally required, and moreover it is argued that this provides an acceptable objective moral standard which can stand firm against other more subjective morally unacceptable standards and tests that might be used in treatment abatement. In short, this stance is seen as a necessary safeguard against the so-called slippery slope to morally unacceptable withholding of treatment, with the wider attendant societal effects which might ensue from AHA abatement.

A litany of suffering is listed as a consequence of starvation and dehydration, with no mention of the effects of the underlying condition. The palliative care experience has simply not been like this, and there is no basis for believing that patients receiving palliative care are dying whilst suffering from symptoms of starvation and dehydration (13), which would be lessened or abolished by the routine provision of AHA. We agree that continual review of symptom-control profiles of patients in palliative care services is necessary – with changes in treatment where necessary, including the provision of AHA (10).

For a potentially reversible condition, and for people with incurable conditions who are not yet dying, artificial hydration and alimentation (AHA) is a medical treatment which must be offered. For incompetent persons with irreversible brain damage, the decision to cease AHA should depend on any available evidence of prior wishes of the person, and where such evidence is not available or is unclear, on their best interests, and not on a preconceived position on the obligatoriness of AHA. Nearly all the legal deliberations on the provision or withholding of AHA have been for people in this category. As Dr Craig states, the issue of AHA abatement for dying persons has not been specifically tested in the courts of the United Kingdom, and the most relevant recent legal deliberations are those in Airedale NHS Trust v Bland (12). Tony Bland was not dying, but was irrefutably in a persistent vegetative state (PVS) from which no prospect of recovery was deemed possible, by all but one dissenting piece of medical evidence (23). The judgment of the House of Lords permitted the discontinuation of AHA, which was acknowledged to be his life support, on the grounds that since it was not in his best interests (because he no longer had an interest in being alive owing to an absence of higher cognitive function) there was no duty to continue this treatment. Bland cannot be directly extrapolated to the case of dying people, as they may well be sensate until the moment of death, and often will have both an interest in being alive and the means to express that interest. Nonetheless, the deliberative process in the Bland case has been helpful to all who study decision-making at the end of life, although the court's emphasis on the act-omission distinction, with respect, may have been excessive (24); and if the patient's best interests are identified as the main concern, the problem still

remains of who determines them – it can be argued that there was an over-reliance on doctors by the court in the Bland case.

The crucial question is whether the dying person's interests are served by the provision of AHA, and this must surely be a decision based on what these measures can contribute to the person's comfort and quality of life. There are three groups of considerations to take into account in determining this. First, if these measures are requested, or are identified as necessary for comfort by attending staff or family members and may be effective in achieving the stated aims, then they should not be refused. It seems that there is no case law on the issue of AHA abatement for dying persons because no court has been asked specifically to consider it. This seems to indicate that in practice it has not been seen to be an issue which requires legal judgment. There is no established or accepted duty that in all cases hydration and alimentation must be maintained by whatever medical means available until death. Moreover, if AHA was not required for Bland who, unlike the dying person was not actually and actively dying of a progressive fatal condition at the time of the judgment, there is even less basis for saying that it is required for all dying persons.

Unpleasant side-effects

Second, all forms of AHA carry associated unpleasant side-effects and possibly may induce premature death. The introduction of a nasogastric tube is unpleasant and its continued presence is usually a source of discomfort and irritation, and regurgitation and inhalational (overspill) pneumonia are common when patients are weak and debilitated. Venous lines can cause infective complications, and neck lines are uncomfortable and potentially hazardous to insert. Tubes and lines also become blocked or dislodged, and their replacement can be unpleasant and distressing, particularly for conscious patients with cognitive impairment. For incompetent patients in whom there is a prospect of recovery all of these problems will usually be regarded as acceptable, but the same trade-offs could not possibly apply to people who are dying.

Third, the shortening or lengthening of life can be an issue associated with the provision or non-provision of AHA. Whilst such provision or non-provision of AHA may influence the timing of an anticipated death, it is not usually possible to predict in which way, ie, whether death would occur sooner or later than it would have done otherwise. We argue, that just as in the consideration of the issue of pain control for dying persons, the influence on timing of death should be a secondary consideration to the comfort and dignity of the dying person.

A number of legal reports and judgments have addressed treatment abatement and palliative care, and analysed the issues this raises of duties to provide care and treatment, and regarding causation of death. The non-initiation or continuation of AHA will not constitute a cause of death in the eyes of the law, if there is no duty to provide it. In such cases causation is an irrelevant consideration, because if there is no duty there can be no breach of duty which might be a cause of death of the person. From a legal point of view, in such cases the cause of death is the underlying condition which has led to the absence of oral intake, and the use of sedation for the palliation of another symptom, as an essential component of care in an otherwise natural dying process, does not alter this. There is no place for emotive language about killing patients in this context.

With respect to determining when a medical practitioner has a duty to provide care, in 1982 the Canadian Law Reform Commission recommended that: 'the law should recognise that the prolonging of life is not an absolute value in itself and that therefore a physician does not act illegally when he fails to take measures to achieve this end, if these measures are useless or contrary to the patient's wishes or interests'; and: 'the law should recognise that the incapacity of a person to express his wishes is not a sufficient reason to oblige a physician to administer useless treatment for the purpose of prolonging life' and 'the law should recognise that in the case of an unconscious or incompetent patient, a physician incurs no criminal responsibility by terminating treatment which has become useless' (25).

In other words, in each of the three sets of circumstances represented by these statements of the commission, there is no legal duty on the physician to initiate or to continue to provide useless treatment, or that which is refused by a competent person.

A court in New Zealand authorised withdrawal of ventilation from a man rendered incompetent and completely paralysed by an extreme form of the Guillain-Barré syndrome. In this case, Justice Thomas throws light on what might be termed 'useless' with regard to medical care: 'Medical science and technology has advanced for a fundamental purpose: the purpose of benefiting the life and health of those who turn to medicine to be healed. It surely was never intended that it be used to prolong biological life in patients bereft of the prospect of returning to an even limited exercise of human life. Nothing in the inherent purpose of these scientific advances can require doctors to treat the dying as if they were curable. Natural death has not lost its meaning or significance. It may be deferred, but it need not be postponed indefinitely' (26).

Gillon suggests that, where the negotiation and communication process has broken down, a mediation process should exist for situations involving differences of opinion about whether a person with a terminal illness should receive AHA (27). This may be useful in very difficult situations,

where referral to an institutional ethics committee or bioethical consultant may also help. It is to be hoped that this need can usually be avoided by the sensitive and appropriate raising of the issues addressed in this paper. Due regard is, however, required for the cultural and ethnic dimensions involved. Families who feel that they are neglecting their role and duty in the provision of nourishment will not appreciate having a discussion about the ethical or legal issues raised in relation to treatment abatement. They are, however, much more likely to agree to a care plan which is gently worked out with them, where all parties agree on their common values concerning the comfort, value and integrity of the person who is dying, and the absence of anyone's responsibility for that dying.

In conclusion, we believe that the approach which we have described here is the dominant one in modern palliative care practice, and is accepted in the mainstream of contemporary ethical discourse. We agree with Beauchamp and Childress who see: '... no reason to believe that medically administered nutrition and hydration is always an essential part of palliative care or that it necessarily constitutes, on balance, a beneficial medical treatment' (13).

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Hard Cases, Causation and Care of the Dying

The Rights of the Terminally Ill Act 1995 (NT) is the first statute in the world to allow for medical assistance in dying at the request of terminally ill persons whose suffering cannot be adequately relieved by other means. As legislation which is therefore intended for application in "hard cases", it may make "bad law". Its (necessarily) intrusive and procedural provisions will probably ensure that it is rarely used. This article examines the factors which appear to have motivated the passing of the Act, focusing particularly on an analysis of causation as a means of explaining the distinction between modern palliative care practice and euthanasia.

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Introduction

It is safe to state that nearly all members of the Australian and international palliative care communities oppose the *Rights of the Terminally Ill Act* 1995 (NT). Most practitioners believe that it is morally wrong, largely irrelevant to the needs and wishes of the majority of persons who face a terminal illness, and would agree with Somerville that it will have adverse consequences for societies.[1] Palliative care practitioners believe that intentional ending of life is not a part of currently accepted palliative care practice. They are not persuaded by what well people say in opinion polls, nor by arguments which appear to intellectually undermine the doctrine of double effect, or the sanctity of life. For many doctors, and particularly those who care for dying people, there is a profound moral intuitive objection to intentionally and actively causing the death of a patient.

My initial reaction is to ask: if this Act is the answer, what was the question? I actually found myself having an imaginary dialogue with the principal proponent of the Act, the former Chief Minister of the Northern Territory, Marshall Perron, about the personal, ethical, legal and political issues which motivated the introduction of the legislation. It is clear that the issues raised need more than a blanket dismissal by affronted palliative care workers, and maybe we need to hear what the community is really trying to tell us. Virtually nobody opposes palliative care, but is it really inclusive, and does it connect with real concerns in our societies which find articulation in a piece of legislation such as this? Perhaps the passage of the Act does pose a constructive challenge to accepted ethical boundaries to modern palliative care practice. But given that the legislation has been passed, the following questions must be asked about its practical implications. For whom is it intended? Will it meet the needs of the people for whom it appears to be constructed? As drafted, is it actually sound and workable, and what is its potential impact on the care of dying people? Are there other ways to achieve the same aims?

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[1] M A Somerville, "Death Talk in Canada: The Rodriguez Case" (1994) 39 McGill LJ 602.

Palliative care in the Northern Territory

It is noteworthy that the Act was substantially driven by the personal experiences of Marshall Perron, and in particular the deaths of a parliamentary colleague and recently of his own mother.[2] It is perhaps reassuring that people in political life should bring these very human experiences into their parliamentary roles. It would be interesting to note how many pieces of social legislation have been initiated as a result of this type of formative, lived experience. It has been said that these experiences simply highlight the deficiencies of palliative care in the Northern Territory. It is not possible to comment on these particular cases although it is quite possible that access to palliative care was sub-optimal. However, one should be cautious about dismissing all such care in the Northern Territory as being deficient. Service distribution is uneven, but educational and outreach services have been available, and a domicillary palliative care service has operated in Darwin since 1989. A number of specialists and general practitioners have an interest in the field, and further training is being sought. Many specialist services have to be imported into the Territory because of the low population and its distribution across such a vast area. Palliative care expertise has been no exception. One of the best spin-offs of the whole process of the Select Committee on Euthanasia and the passage of the Act has been to put the spotlight on palliative care, with firm commitment to significant improvement in both access and quality of palliative care services.[3] It is surely important that any advice from outside the Territory have due regard for existing services, expertise and interests, and that resources be concentrated on support for, and expansion of, existing services.

The right of the individual or the common good?[4]

The title of the Act specifically talks of *rights* in the plural, but only one *right* is legislated for, namely that of a terminally ill individual to request and receive medical assistance in suicide or active medical assistance in dying. As such, this is the first time that the so-called *right to die* has been enacted in statute law, although the Oregon (USA) *Death with Dignity Act* 1995 (presently blocked on appeal) would allow doctors to assist in the suicide of a patient, but not administer the drug, and the non-prosecution stance in The Netherlands is well known. A *right to die* is not specifically articulated in any recognised national or international code of human rights. Perron may well have been more swayed by Cory J's approach in *Rodriguez*,[5] where she argues for a right to die by the *inclusion* of dying in the process of living:

> "The life of an individual must include dying. Dying is the final act in the drama of life. If, as I believe, dying is an integral part of living, then as a part of life it is entitled to the constitutional protection provided by s 7. It follows that the right to die with dignity should be as well protected as is any other aspect of the right to life. State prohibitions that would force a dreadful, painful death on a rational, but incapacitated terminally ill patient are an affront to human dignity."

[2] *The Australian*, 1 Feb 1995.

[3] Legislative Assembly of the Northern Territory, *The Right of the Individual or the Common Good?*, Report of the Inquiry by the Select Committee on Euthanasia (Government Printer, Darwin, 1995), Vol 1.

[4] Title of Report of the Inquiry by the Select Committee on Euthanasia, ibid.

[5] *Rodriguez v Attorney-General (British Columbia)* [1993] 3 SCR 519 at 630.

The *right to life* is, of course, already protected as the most basic of fundamental human rights, and in Canada specifically by the Canadian Charter of Rights and Freedoms.

Despite being a member of the inherently conservative Country-Liberal Party, Perron would no doubt have found attractive the arguments about personal autonomy and death presented by Max Charlesworth in his book *Bioethics in a Liberal Society*:[6]

> "We are on a slippery slope only when we move away from seeing the decision to end one's life as a moral decision belonging to the individual patient . . . In a liberal society then any legislation giving expression to a 'right to die' must relate essentially to the patient's autonomous right to control the ending of her or his life. Extraneous considerations, for example whether the continuation of a patient's life is a burden on parents, family or society in general, should not be taken into account."

When considering the issue of the so-called principle or doctrine of *the sanctity of life*, Perron would also be influenced by Dworkin's approach in *Life's Dominion*, in which he argues that we all agree about the sacredness of life, but how we express that sacredness varies according to personal beliefs and world view:

> "If people retain the self-consciousness and self-respect that is the greatest achievement of our species, they will let neither science nor nature simply take its course, but will struggle to express, in the laws they make as citizens and the choices they make as people, the best understanding they can reach of why human life is sacred, and the proper place of freedom in its dominion."[7]

So for Dworkin, an individual who chooses assistance in suicide or active voluntary euthanasia may be seen to be making an ultimate expression of autonomy, integrity and dignity, which is consistent with the way the person has led his or her life—rather than to be opting for a necessarily negative, desperate or hopeless last act:

> "Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying—the emphasis we put on dying with 'dignity'—shows how important it is that life ends appropriately, that death keeps faith with the way we want to have lived."[8]

As with Charlesworth, the pivotal issue is the autonomous expression of personhood. As an astute politician, Perron has surely read the prevailing majority community view on this matter, namely, if the state's interests in preserving the lives of its citizens are weighed against individual autonomous choice in dying, the majority favour autonomous choice. Any person or group seeking to thwart this primacy of autonomy will be in for a very rough ride in most Western societies. Opinion poll trends indicate that there is a generational cohort shift in action which very strongly favours what is often termed "choice in dying", which presumably means choice in the manner and possibly timing of death, rather than whether death occurs. However, there must be some serious question-marks over the level of control which modern generations appear to think they have over all aspects of their lives, including death and dying. Michael Ignatieff sheds light

[6] M Charlesworth, *Bioethics in a Liberal Society* (Cambridge University Press, 1993), p 53.

[7] R Dworkin, *Life's Dominion. An Argument about Abortion and Euthanasia* (Harper Collins, London, 1993), p 241.

[8] Ibid, p 199.

on this when reflecting on the slow death of his own mother from Alzheimer's disease:

> "The real problem, of course, is what we are to think of death. People like us who live by the values of self-mastery are not especially good at dying, at submitting to biological destiny. The modern problem is not death without religious consolation, without an afterlife. The problem is that death makes the modern secular religion of self-development and self-improvement appear senseless. We are addicted to a vision of life as narrative, which we compose as we go along. In fact we didn't have anything to do with the beginning of the story; we are merely allowed to dabble with the middle; and the end is mostly not up to us at all, but to genetics, biological fate and chance."[9]

In rightly focusing public policy in health care firmly on individual choice, it is nonetheless essential to reflect on the individual's social context. The modern palliative care practice model is firmly based on acknowledgment of the *centrality of the patient's autonomy* in all decision-making, but with due recognition and support for those family members and friends who are identified as being close and supportive of the patient. Autonomy is never absolute, and health care, particularly palliative care, cannot be conducted in an autonomous vacuum.

Target population

Perron and his supporters would probably argue that they are proposing not a *right to die* per se and regardless of context or circumstances, but a *right to comfort and dignity during the dying process, inclusive of active ending of life if a terminally ill person can obtain relief by no other means*. The originally drafted Bill, and the extensive amendments to it which were introduced during the final night sitting of the Legislative Assembly of the Northern Territory,[10] are testimony to the rigorously restrictive intended application of the legislation, namely only to those terminally ill persons who have exhausted all other options for palliative care and psychosocial support.

The potential target population is probably therefore a very small one. Hunt and colleagues at Daw House, an in-patient hospice and palliative care unit in Adelaide, found that only 6 per cent of their patients actually expressed a wish for assistance to die at the time of being asked the question.[11] Data on requests to die because of poor pain and symptom control are not available. Palliative care specialist experience has consistently attested that it is an unusual problem, and that the majority of patients can and do obtain acceptable levels of symptom control.[12] However, the idea that modern palliative care can relieve *all* suffering associated with death and dying is a flawed approach. This impression has often been conveyed, particularly in the early pioneering days of the hospice and palliative care movement, in an attempt to improve glaring deficiencies in the care of dying people. Just as palliative care has exhorted the rest of medicine to recognise its limitations, so too it must acknowledge its own. Propaganda (however well intentioned) masquerading as objective medical information will be judged (harshly in my opinion) by the

[9] M Ignatieff, *Scar Tissue* (Penguin, 1994).

[10] See S Trollope, "Legislating a Right to Die: The Rights of the Terminally Ill Act 1995 (NT)" (1995) 3(1) JLM 19.

[11] R Hunt et al, "The Incidence of Requests for a Quicker Terminal Course" (1995) 9 *Palliative Medicine* 167.

[12] See, eg, evidence of Association for Palliative Medicine to the Select Committee on Medical Ethics of the House of Lords, Vol 2—Oral Evidence (HL Paper 21-11) (HMSO, London, 1994), pp 183-21.

community if it is revealed by community experience that inflated claims are made by palliative care practitioners as a weapon in the debate about legalisation of active voluntary euthanasia. Latimer sounds a realistic note in evidence to a Canadian Senate inquiry, in which she points to future areas of palliative care research:

> "We use opioid analgesics . . . very well in palliative care but we have reached our saturation point with what we can do with these drugs. There are two or three pain syndromes that are particularly difficult for us to treat, nerve pain, bone pain, and pain that is largely comprised of suffering in the psychological sphere."[13]

Heavy sedation may be used to induce a state of impaired consciousness to control so-called terminal restlessness, or when symptoms and suffering cannot be controlled by other palliative treatments. This practice has been termed "pharmacological oblivion";[14] the Canadian Senate calls it "total sedation" or "the practice of rendering a person totally unconscious through the administration of drugs without potentially shortening life".[15] Such treatment is argued to be within accepted palliative care practice, as the death is not intended, and the doctrine of double effect applies, although it is surely impossible to state that such treatment does not have the potential to shorten life. Hunt also disputes this, believing that there are occasions on which it is appropriate to intentionally hasten death, and that this is often the case with so-called pharmacological oblivion. The interpretation is that sometimes practitioners are hiding behind a false application of the doctrine of double effect, as the unstated intention and the outcome are to hasten the patient's death, and this should be openly acknowledged.[16] Perron would, no doubt, argue that it is exactly this situation which he sought to regularise in his Act, to obviate the need for uneasy compromises such as pharmacological oblivion, where both intention and outcome seem somewhat blurred.

If we can all acknowledge that there are "hard cases", where dying persons cannot obtain acceptable relief of suffering, regardless of our views on active voluntary euthanasia, this would be a first constructive step in obtaining community consensus about how to proceed.

Privacy and practicality

It is my contention that the *Rights of the Terminally Ill Act* 1995 (NT) is a classic instance of legislation drafted for "hard cases" and will therefore make bad law. In its final form, the Act as it stands appears to be almost totally unworkable, and it seems unlikely that many people will be able to avail themselves of its provisions, even if they wish to. The hastily drafted final amendments have added to an already unwieldy process which is intrusive for the patient and family and detracts from the intimacy of the doctor-patient relationship. They provide graphic evidence of the ethical and practical fragility of the Act's basic premises. In a rushed attempt to get the legislation through, the results of trying to cover every potential abuse or loophole—in other words, to cover the "hard cases"—are plain to see. It would surely have been better to attempt to deal with some of the process issues under regulations proclaimed at a later date by the

[13] *Of Life and Death*, Report of the Special Senate Committee on Euthanasia and Assisted Suicide, Senate of Canada, Ottawa (May 1995), p 19.

[14] M Ashby, unpublished.

[15] Op cit, n 13.

[16] R Hunt, "Palliative Care—The Rhetoric-Reality Gap" in H Kuhse (ed), *Willing to Listen, Wanting to Die* (Penguin, Melbourne, 1994).

Minister. It would also have been worthwhile to locate procedures for "hard cases" within the framework of general guidelines on all aspects of dealing with death and dying, and medical decision-making at the end of life, such as those promulgated by the New South Wales government.[17]

Cause of death and care of dying people

In the writer's opinion, misinterpretation by many doctors and nurses of what the law has to say, and the consequent fear of being found to be the "but-for" cause of death, is the biggest single obstacle, together with lack of knowledge, to the proper and appropriate care of dying people in our community.

The Australian courts, recognising the multi-factorial nature of causation, no longer use the "but-for" test as the sole legal standard for ascertaining or apportioning legal responsibility.[18] Nevertheless, clinical behaviour is often predicated on an almost instinctive belief that the law will inevitably attribute the cause of the death on a "but-for" basis.

It is actually extremely difficult to determine the precise cause of death, the cause of death in fact or the "but-for" cause of death in patients dying of a chronic malignant or non-malignant condition. Many factors come into play, and the use of drugs to maintain patient comfort occurs against a background of multi-system organ failure. It is usually not possible to determine whether a particular drug has made a causal contribution to death. We have no way of knowing what the timing of the death would have been in the absence of the drug, unless it has been administered in a particularly large dose which puts intention into question. This is also not a suitable area for clinical trials.

It is a common belief, and the basis of a considerable body of legal and legislative opinion, that morphine dose is the main determinant of whether the drug causes or hastens death. In fact, there is no such determinative or threshold dose, and this approach is flawed. What matters is the present dose in relation to the previous dose. Gradual dose escalation by a factor in the region of 50 to 100 per cent of the previous dose is usual practice, although substantially higher increases can usually be well tolerated by patients who are not new to the drug (that is, they are no longer "opioid-naive"). It is therefore the size of the initial dose and the rate of subsequent increases which are important. Cancer pain management with morphine is unusual compared to most other forms of drug treatment in that there are no predetermined dose ranges to achieve satisfactory pain control for adults or children. Most adults will achieve initial pain control with a daily dose in the region of 100mg-200mg (per 24 hours, orally), but the range of doses is very wide.[19] The accepted practice (of which there is nearly 20 years of safe experience) is to adjust the regular dose upwards according to the "top-up" requirements to keep the pain under control, balanced against the incidence of side effects. Despite an extensive and sustained international campaign (by the World Health Organisation),[20] many doctors still believe that they are causing or hastening the death of patients by this process, despite the absence of any evidence to support this view. In the much-quoted

[17] New South Wales Department of Health, "Dying with Dignity: Interim Guidelines on Management" (1993).

[18] *March v E & M H Stramare* (1991) 171 CLR 506 at 522 per Deane J.

[19] M Ashby, B Fleming, M Wood and A Somogyi, "Plasma Morphine and Glucuronide (M3G and M6G) Concentrations in Hospice Patients with Cancer Pain and Relationships to Adverse Effects", in preparation.

[20] J Stjernsward and N Teoh, "The Cancer Pain Relief Programme of the World Health Organisation" (1989) 4 *Palliative Medicine* 1.

Remmelink Report from The Netherlands, 17.5 per cent of so-called MDELs (medical decisions at the end of life) were attributed to opioid dose escalation by the treating doctor.[21] As there are no clinical data provided by which to judge the actions of the doctors who participated in this study, the report is reliant on their beliefs and interpretations of the consequences of their treatment, which may well have been mistaken with respect to causation.

One of the important functions of the *Consent to Medical Treatment and Palliative Care Act* 1995 (SA)[22] is to send a powerful message to health care professionals about the priority which the legislators wish to be given to pain and symptom control for dying persons. This Act clearly establishes, for the first time in statute, the principle that if there is thought to be a conflict between hastening the timing of an inevitable death and proper symptom control, then the latter should have priority. The doctrine of double effect is used to deal with the issue of causation in palliative care practice. If an incidental effect of accepted palliative care practice measures is to hasten the (inevitable and anticipated) death of a person, then this is not deemed to constitute a cause of death in law, because such practice does not constitute a new intervening act in a pre-existing chain of causation. This provision helps to correct the widely held, false perception that the heavy hand of the law is waiting to land on the shoulders of practitioners who administer morphine to terminally ill patients (especially "the last dose"), but this indemnity from civil or criminal prosecution only applies if the treatment has been "in accordance with the proper standards of palliative care."[23] It does not apply to circumstances in which the practitioner's use of drugs is transparent with regard to his or her intention to bring about the death of the person, even as a means of relieving the suffering of a person for whom other measures have failed. Perron would argue that this next step is essential, and would agree with Hunt that there is a "rhetoric-reality gap" in palliative care practice, and the *Rights of the Terminally Ill Act* closes it by allowing active assistance in dying.[24]

Over-reliance on the underlying disease or injury as the cause of death has been argued. Keyserlingk[25] opposes decriminalisation of assisted suicide in his analysis of *Rodriguez*, by arguing that it is necessary to move away from standard and "but-for" causality of death approaches in legal analysis, and adopt what he terms a *normative causality approach*:

> "[This] position emphasises not simply scientific causality, the cause-in-fact of a death, but normative or legal causality as well. This more nuanced and comprehensive analysis holds that empirical, scientific or 'but-for' causality cannot alone account for what distinguishes assisted suicide from voluntary euthanasia, or what distinguishes both from withdrawal of life support or appropriate pain control resulting in death."[26]

This normative approach allows the "but-for" cause of death to be overridden as a cause of death if a society decides that public policy on a certain issue requires that it not be viewed as a cause of death in law. Examples of this in action would be the several judgments and legal reports which have dealt with the issue of pain control in a terminal illness.[27]

[21] P J Van der Maas et al, "Euthanasia and Other Medical Decisions Concerning the End of Life" (1991) 338 *The Lancet* 669.

[22] See objects of *Medical Treatment Act* 1988 (Vic) and *Consent to Medical Treatment and Palliative Care Act* 1995 (SA).

[23] *Consent to Medical Treatment and Palliative Care Act* 1995 (SA), Pt 3, Div 2, The Care of People Who are Dying.

[24] Hunt, op cit n 16.

[25] E W Keyserlingk, "Assisted Suicide, Causality and the Supreme Court of Canada" (1994) 39 McGill LJ 708.

[26] Ibid.

[27] Thomas J in *Auckland Area Health Authority v Attorney-General* [1993] 1 NZLR 235; Devlin LJ in *R v Adams* [1957] Crim LR 365 at 375; Law Reform Commission of Canada, *Euthanasia, Aiding Suicide and Cessation of Treatment*, Report 20 (Ottawa, 1982), p 35. See also G Gillett, "Ethical Aspects of the Northern Territory Euthanasia Legislation" (1995) 3(2) JLM 145 (above).

Specific drafting problems

There are some specific problems in the drafting of the legislation which should be pointed out.

Psychiatric qualifications: Section 7(1)(c)

The term "diploma of psychological medicine" refers to a now-defunct psychiatric qualification. If it was intended that a psychiatric opinion be sought in all cases, then the appropriate professional body should have been consulted. It seems excessively specific to make this stipulation, and it should be a matter of professional discretion for the general practitioner to seek such other specialist medical assistance as he or she deems appropriate in the circumstances. It should not be a matter for statute. There also appears to be some conflation of palliative care, psychiatric and psychological skills.

Extraordinary measures: Part 1, Section 3—interpretation

The extraordinary/ordinary distinction has now been largely abandoned in modern bioethical discourse. Characterising treatments into those that may and those that may not be stopped (or not initiated) is an unhelpful way to proceed. The goal posts can be moved at whim, and surely all that matters is what the patient wants, and what is appropriate and proportionate in the circumstances. Somerville[28] has argued that this distinction also allows subjective judgments to masquerade as objective ones. It is, however, important to try and determine when a person is in the process of actually dying, while recognising the dangers of labelling people as "dying".[29]

Health care provider definition: Part 1, Section 3—interpretation

In the definitions section, "institutions" and "individuals" may be "health care providers". This may be a difficult term to apply, as surely individual clinical and institutional liabilities and responsibilities would have to be distinguished from one another, and could not be dealt with synonymously.

Conclusion

It would be unfortunate if these specific drafting problems (and no doubt others will be identified by other commentators) are allowed to obscure the bigger issues involved in the passage of the *Rights of the Terminally Ill Act* which do require, and merit, parliamentary attention. We should not lose sight of the fact that societies make laws and courts interpret them, that the law is not immutably set. Neither is the law set up above ethical considerations. None of us should shirk the responsibility to ensure that the law serves its solemn purpose to protect dying people, who are particularly vulnerable, from

[28] Op cit n 1.

[29] M Ashby and B Stoffell, "Artificial Hydration and Alimentation at the End of Life: A Reply to Craig" (1995) 21 *Journal of Medical Ethics* 135.

incompetence or worse. Medicine and the law need to have a far better intellectual and practical dialogue in order to prevent false perceptions from arising on both sides to the detriment of all. The *Rights of the Terminally Ill Act* 1995 (NT) raises more problems than it solves—but the issues it raises will not go away. It is arguable that for the improvement of pain and symptom control in dying people, it would have been better to adopt the sort of legislation which has been enacted in South Australia.[30]

It is essential that it is understood by all that there is a clear distinction between widely accepted standards of modern palliative practice, inclusive of pain and symptom control, on the one hand and euthanasia on the other. This distinction can be sustained on empirical and moral grounds. Motive and intention are decisive and can usually be discerned by the choice of drug matched to indication, initial dose and dose escalation. Treatment abatement for non-dying persons is not the same as for dying persons for whom absolute or relative futility is the indication rather than any intention to end the person's life. Consequentialist moral equivalence arguments about acts and omissions cannot ignore clinical proportionality and most treatment abatement decisions which are taken in palliative care practice are made on the basis of inefficacy.

There is much that needs to be done to improve the care of dying people about which the vast majority of all communities will agree. Most importantly palliative care access and quality must be improved for all, together with an acknowledgment of its limitations and the fact that dying cannot be an ideally comfortable and controlled process. Further exploration of the use of living wills, advance directives and substitute health care decision-making as a part of mainstream general medical practice would be helpful. Guidelines for management and decision-making at the end of life should also be evolved in all health care systems. Lastly, we must all acknowledge that there are "hard cases" where not even the best palliative care gives adequate relief and reasonable people will differ about how to proceed depending on their personal religious and ethical world-views. The prevailing emphasis on personal autonomy is clearly tipping the balance of community opinion in favour of non-prosecution or legislation to allow for active voluntary euthanasia in these exceptional situations. But it seems strange for a community to start by legislating for its "hard cases" and to predicate public policy on the perceived needs and wishes of the minority, which is what appears to have occurred in the Northern Territory with the *Rights of the Terminally Ill Act* 1995.

[30] *Consent to Medical Treatment and Palliative Care Act* 1995 (SA).

Of Life and Death:* The Canadian and Australian Senates on Palliative Care and Euthanasia

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This article considers the recent Senate inquiries on euthanasia which have taken place in Canada and Australia. Both reports opposed the legalisation of euthanasia, in the face of substantial public opinion support for it. They endorsed palliative care, which is differentiated ethically and legally from euthanasia on the basis of intention and double effect. The assumptions and arguments made about the ethics of palliative care practice in the course of these deliberations are discussed. The author concludes that the issue of causation in respect of palliative interventions and treatment abatement for dying persons requires further clarification. In particular, as the deliberations of both Senate committees show, the "morphine-causation fallacy" and over-reliance on empirical ("but-for") causality permeate public discourse on palliative care internationally. Medicine, law and ethics should correct these false predicates about palliative care and the cause of death and assist societies in the necessary task of moving on from narrow perceptions of causation to improvement of standards of care and decision-making processes for people at the end of life.

Introduction

Over recent years in the United Kingdom (1994),[1] Canada (1995)[2] and Australia (1997),[3] there have been parliamentary upper house inquiries into death and dying, with particular regard to whether euthanasia should be legalised. This article will primarily examine the report of the Canadian Special Senate Committee on Euthanasia and Assisted Suicide entitled *Of Life and Death*,[4] and compare it to the deliberations of the Australian Senate Legal and Constitutional Legislation Committee on the Euthanasia Laws Bill 1996.[5]

* Senate of Canada, *Of Life and Death. Report of the Special Senate Committee on Euthanasia and Assisted Suicide* (Ottawa, June 1995).

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[1] House of Lords, *Report of Select Committee on Medical Ethics*, Vol I – Report (HL Paper 21-I); Vol II – Oral Evidence (HL Paper 21-II); Vol III – Written Evidence (HL Paper 21-III) (HMSO, London, 1994).

[2] Senate of Canada, *Of Life and Death. Report of the Special Senate Committee on Euthanasia and Assisted Suicide* (Ottawa, June 1995).

[3] Parliament of the Commonwealth of Australia, Senate Legal and Constitutional Legislation Committee. *Consideration of Legislation Referred to the Committee. Euthanasia Laws Bill 1996* (Canberra, March 1997).

[4] Op cit n 2.

[5] Op cit n 3. This Bill became known as the Andrews Bill, see below at 44.

Where relevant, reference will also be made to the House of Lords Select Committee on Medical Ethics.

There are compelling reasons for comparing the way in which Canada and Australia deal with public policy issues. Both are vast federal countries with common British colonial histories, and hence constitutions based on the Westminster system of government and English common law.[6] There are, however, some important constitutional and legal differences. In particular, Canada has one national Criminal Code and a Charter of Rights and Freedoms, whereas in Australia each State and Territory has its own Criminal Code, and there is no charter of rights. The proximity of the United States exerts a major influence on Canadian affairs, and while all countries experience substantial American influence, this is a particularly strong and controversial issue for Canadians. However, Canada shares with Australia a common commitment to the availability of publicly funded health care, a fact which is regarded by many Canadians as a core-defining national value, particularly in contrast to the United States.[7] Both countries have prominent First Nations[8] concerns as major issues in national life. Aboriginal issues were accorded a separate chapter in the Australian report because Aboriginal people constitute a significant proportion of the Northern Territory population, whereas Canada's First Nations were not considered separately in the Special Senate Committee Report. Quebec separatism influences every aspect of Canadian national life, but this did not appear to be a significant issue in the euthanasia debate. Despite the strong historical influence of the Roman Catholic church in Quebec, one witness pointed out that poll results in favour of euthanasia were even higher there than elsewhere in Canada.[9] The content of the euthanasia debate itself is international.

It is particularly noteworthy that, as in many present and former British Commonwealth countries, the hospice and palliative care movement, which originated in Britain, took early root in Canada and Australia and has penetrated extensively into both health care systems.[10] The structure of the medical profession, social values and a thread of British pragmatism may all be responsible for this. Palliative care is a practical response to care at the end of life and has never approached death primarily as a legal or ethical problem to be solved. Palliative care evolved out of strong Christian charity roots, and its workers and organisations are mostly opposed to euthanasia.[11]

[6] For comparative studies on a wide range of topics see *Australian-Canadian Studies*, which is the official journal of the Association for Canadian Studies of Australia and New Zealand (ACSANZ). See also G Donaghy, *Parallel Paths: Canadian-Australian Relations since the 1890s* (Historical Section, Corporate Communications Division, Department of Foreign Affairs and International Trade, Government of Canada, Ottawa, 1995). This monograph is a brief analysis of relations between Australia and Canada. It shows that despite obvious similarities, the two countries have also experienced competition and substantial disagreements during the course of this century.

[7] For opposing views of the realities of the Canadian health care system and its meaning for Canadians, see M Rachlis and C Kushner, *Strong Medicine – How to Save Canada's Health Care System* (Harper Collins, Toronto, 1994); and C Ramsay, M Walker and W McArthur, *Healthy Incentives: Canadian Health Reform in an International Context* (Fraser Institute, Vancouver, 1996).

[8] This writer finds the Canadian term particularly dignified and appropriate to the reconciliation processes which are so important for both countries.

[9] Op cit 2, p 83.

[10] The hospice and palliative care movement originated in Britain and its beginning is usually considered to have been the opening of St Christopher's Hospice in Sydenham, south east London, by Dame Cicely Saunders and colleagues in 1967. Noted pioneers such as Robert Twycross (Oxford) and Derek Doyle (Edinburgh) and many others saw the rapid growth of services for dying people, particularly free-standing hospices and specialist home care programs in the United Kingdom during the ensuing decade. The movement then spread firstly to present and past Commonwealth countries: Canada, Australia, New Zealand, South Africa, Eire. Balfour Mount, a surgeon from the Royal Victoria Hospital in Montreal, visited Dame Cicely Saunders and subsequently set up the first unit in North America in 1975 (the opening of St Boniface's Hospital unit in Winnipeg also occurred at this time). Spread to the rest of Europe and some Asian countries has largely occurred from the 1990s onwards. For reflections on the history of the hospice/palliative care movements see the foreword of D Doyle, G Hanks and N Macdonald (eds), *Oxford Textbook of Palliative Medicine* (Oxford University Press, Oxford, 1993), p vi, and Cicely Saunders, "Some Challenges That Face Us" (1993) 7 (suppl 1) *Palliative Medicine* 77. See also N James and D Field, "The Routinization of Hospice: Charisma and Bureaucratization" (1992) 34 *Social Science and Medicine* 1363. They present a Weberian social movement analysis of the development of palliative care and its integration into mainstream health systems. In addition, see I Higginson, "Palliative Care: A Review of Past Changes and Future Trends" (1993) 15 *Journal of Public Health Medicine* 3.

[11] The Canadian Palliative Care Association Board Position on Euthanasia (19 Sept 1993) and the Australian Association for

The evidence and opinions of palliative care experts have been very influential with both Senate inquiries. Nonetheless, both countries are experiencing ongoing debates about whether the law should be changed to permit euthanasia,[12] with consistent majority public opinion poll support for it. Euthanasia is now completely dominating contemporary consideration of death and the process of dying in most Western societies.

The matter at stake is whether it is ethical to change the criminal law to allow doctors (or others) to assist persons to commit suicide or to administer to them a drug with the intention of ending life. In other words, in the discourse of public policy debate, "euthanasia" is used not in its literal sense of a gentle or easy death (about which there is little dissension), but to make a specific point about causation, namely that the death in question is caused by intervening human agency. For those who oppose euthanasia, there exists a nuanced notion of natural death,[13] in which death is seen as an inevitable part of life and neither an enemy to be defeated, nor to be tamed or controlled by human agency if it cannot be ultimately averted.[14] Those who campaign for euthanasia have emphasised that it should be voluntary (the person's request, consistently and lucidly expressed, is pivotal), active (a drug or agent can be supplied or administered by a medical practitioner) and (usually) the person concerned should be terminally ill.[15] This has been summarised as voluntary active euthanasia (VAE) and is the agreed position of the vast majority of individuals and organisations who advocate euthanasia. Access to VAE has been argued to be a basic human right by those who support it.[16] The denial of access to such assistance has given rise to (at times emotionally charged)

Hospice and Palliative Care Position Statement on Voluntary Active Euthanasia (27 Oct 1995) both explicitly oppose the legalisation of euthanasia. They also adopt similar definitions of euthanasia, and seek to differentiate proper standards of palliative care practice (particularly pain and symptom relief and treatment abatement) from any kind of euthanasia. See two editorials from *Palliative Medicine* which show the firm view against euthanasia taken by palliative care practitioners: C Saunders, "Voluntary Euthanasia" (1991) 6 *Palliative Medicine* 1; I Finlay, "Palliative Medicine Overtakes Euthanasia" (1994) 8 *Palliative Medicine* 271.

[12] The word "euthanasia" will be used in its "narrow" sense throughout this article, as defined by the Australian Association for Hospice and Palliative Care in its position statement of October 1995: "the deliberate action to terminate life by someone other than, and at the request of, the patient concerned."

[13] The use of the term "natural death" is ubiquitous but its meanings are diverse and ill-defined. A number of *Natural Death Acts* were passed in the United States (mid-1970s) and also in South Australia and the Northern Territory of Australia (mid-1980s) to allow persons to make binding "living wills" to prevent them being subjected to life-sustaining medical treatment when incompetent, if the underlying condition is terminal and/or irreversible. Incidentally, it has sometimes been argued (wrongly in this writer's view) that these legislative instruments allowed for so-called "passive euthanasia". (N Cica and G Williams, in "A Clumsy Attack on Territories", *The Australian*, 22 Oct 1996, write: "Legislation has operated for some time in the Northern Territory and the ACT – as well as in Victoria and South Australia – explicitly allowing this kind of 'euthanasia'. One effect of the passage of the Andrews Bill could be that the Territories lose the power to amend or replace their existing 'passive voluntary euthanasia' legislation.") There is an underlying theme of the need to bolster patients' rights to refuse treatment, redressing a past power imbalance, seen as being in favour of "paternalistic" doctors. The ethical and theoretical derivation of "natural death" in this context is difficult to identify and may not have been worked through in this or any modern context. See, for instance, the quote from the British Columbia Crown Counsel Policy Guidelines: "withholding or withdrawing treatment means ... discontinuing or not intervening with medical procedures to prolong life *beyond its natural length*" (emphasis added), op cit 2, p 40. For a discussion of natural causes of death in a respirator withdrawal case, see B Sneiderman, "A Winnipeg Inquest: A Case of Natural Death or Physician-assisted Suicide?" (1996) 24 Manitoba LJ 365. See also B Stoffell and M Ashby, "On Natural Death" (in preparation): " 'Natural death' cannot be used without careful explication ... it can be understood as a composite of two moral elements: patient self determination and avoidance of harm; that is, the priority of patient choice in determining what they personally find acceptable treatments in the terminal phase of an illness, plus the avoidance of certain obstructions to the process of dying. The first element is of course the one that the law is interested in protecting, whereas the latter will demand close scrutiny of treatment decisions."

[14] M A Somerville, " 'Death Talk' in Canada: The Rodriguez Case" (1994) 39 McGill LJ 602.

[15] For an examination of how euthanasia in The Netherlands has occured in persons who are not terminally ill, see B Sneiderman and M Verhoef, "Patient Autonomy and the Defence of Medical Necessity: Five Dutch Euthanasia Cases" (1996) 34 Alberta LR 374.

[16] One of the main campaign groups in Canada is the Right to Die Society; the international umbrella organisation is the World Federation of Right to Die Societies. The Act to permit euthanasia in the Northern Territory of Australia was entitled "*The Rights of the Terminally Ill Act*" (underlining added for emphasis).

accusations of cruelty against individuals by governments and society.[17]

The parliaments (with the one notable exception of the Northern Territory of Australia), courts and health professions in both countries have been more cautious than their respective publics, who are expressing progressively increasing majority support for euthanasia.[18] Although the law of both countries has upheld the legality of palliative care, albeit on a false predicate about opioids and causation, there has been extensive questioning of treatment abatement and palliative interventions by those who campaign for euthanasia, who frequently argue that it is already being practised by those (in palliative care particularly) who argue back, based on intention and the doctrine of double effect, that they are not.[19] Resolution of the issue of whether third party assistance (medical or otherwise) is permissible will not come easily and disagreement about it reveals a deep political, ethical and spiritual fault line in post-modern societies.

Events preceding Senate inquiries

Canada

It was the case of the late Sue Rodriguez, a young woman from British Columbia with motor neurone disease, which has probably done more than any other single event to bring the issue of euthanasia to the attention of Canadians.[20] Her quest to have medical assistance to end her life led to a court case which resulted in the narrow rejection (five-to four) of her appeal to the Supreme Court of Canada.[21] It was a very public dying process, with extensive media coverage,[22] an authorised biography,[23] and political and academic analysis during her life and afterwards.[24] She was 44 years old when she finally died at her home in February 1994, allegedly with the assistance of an (unnamed) medical practitioner, in the presence of her prominent friend and supporter, Svend Robinson MP. The case was constructed around a claim that Sue Rodriguez' Charter rights were infringed by the *Criminal Code* prohibition on assistance to commit suicide. The majorities in the three courts which considered her case argued that a blanket prohibition was appropriate and proportionate to prevent the harms that would be caused (to other members of society) if it were removed. They supported the doctrine of double effect as the major ethical underpinning of the distinction between palliative care and euthanasia. Claims of discrimination on the basis of her inability to kill herself without assistance did not prevail. Both Chief Justices involved, MacEachern CJ and Lamer CJ, dissented in her favour and laid down a series of safeguarding conditions which should be met before her request could be granted.[25]

Australia

In July 1996 the *Rights of the Terminally Ill Act* (the RTI Act) of the Northern Territory came into force, being the first such statute successfully enacted in the world (although the Oregon State law mandated as Measure 16 is now stated to be operative but subject to a United States Supreme Court hearing).[26] The RTI Act had been passed by the Legislative Assembly by a margin of 15 to 10 after a legislative passage of only four months. This included consideration by a Select Committee and

[17] Cory J argues that since dying is a part of life and life is protected by the Charter of Rights and Freedoms, so too should the right to die: *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519 at 630. See also R Dworkin, *Life's Dominion. An Argument about Abortion and Euthanasia* (Harper Collins, London, 1993). For a riposte to the argument that compassion mandates the legalisation of euthanasia, see R Gaita, "The Victorian Doctors and the Demand of Compassion" (1995) (May) *Quadrant* 23.

[18] See op cit n 2, p 83, for Canadian figures which range from 70 to 80% in opinion polls, and op cit n 3, p 81, where an entire chapter (Ch 7) is devoted to survey results in Australia which indicate similar levels of support for euthanasia. See also op cit n 1, HL - II, p 271.

[19] M Ashby, "Fallacies of Death Causation" (1997) 166 *Medical Journal of Australia* 176.

[20] M Ashby, "The Rodriguez Case and Care of the Dying" in *Canada – Australia, Towards a Second Century Partnership* (in press).

[21] *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519.

[22] See Canadian Broadcasting Corporation documentary, "Witness – Sue Rodriguez".

[23] L Hobbs Birnie and S Rodriguez, *Uncommon Will* (Macmillan Canada, Toronto, 1994).

[24] See B Dickens, "When Terminally Ill Patients Request Death: Assisted Suicide Before Canadian Courts" (1994) 10 *Journal of Palliative Care* 52. See also various authors in (1994) 39 McGill LJ 602.

[25] [1993] 3 SCR 519 at 539 and 579.

[26] Op cit n 3, p 180, per Senators Collins and Tambling.

49 amendments during the committee stage. In September 1996, the Liberal member for the federal seat of Menzies in Victoria, Kevin Andrews MHR, introduced a private member's bill (the Euthanasia Laws Bill 1996) into the House of Representatives to override this Act. It was passed by the House but was referred by the Senate Selection of Bills Committee to one of its standing committees: the Senate Legal and Constitutional Legislation Committee. This parliamentary inquiry received 12,577 submissions, a record, the majority (93.3 per cent) of which were interpreted as being against euthanasia,[27] a startling result from a country which expresses 70 to 80 per cent support for euthanasia in opinion polls. The committee made no recommendation to the Senate because the matters were the subject of a private member's Bill and hence, of a "conscience vote". However, a majority of senators supported the Bill and advised that the Commonwealth Parliament had the requisite legal powers to override the RTI Act. Minority reports against the Bill were filed by several senators, including the only medical practitioner on the committee, Dr Bob Brown, Australian Greens Senator for Tasmania. He argued that palliative care and euthanasia lie on a moral or clinical "choice" spectrum, and hence euthanasia is not different in kind in a moral or clinical sense, a position rejected by nearly all palliative care practitioners.[28] The Senate passed the Bill and it was given Royal Assent on 27 March 1997.

Canadian Senate report

The Canadian Senate report made recommendations under six chapter headings: palliative care, pain control and sedation practices, withholding and withdrawal of life-sustaining treatment, advance directives, assisted suicide, and finally euthanasia.

Palliative care

The committee received considerable amounts of evidence concerning the present state of palliative care in Canada, with strong endorsement of what is being done already, but also with concerns about lack of coverage of services. It recommended that Provinces make palliative care "a top priority in the restructuring of the health care system".[29]

It also specifically endorsed better training and research and the promulgation of guidelines and standards. However, the report expressed initial surprise that palliative care emerged as such an important practical issue at all:

> "The Committee began its hearings with the expectation that the large majority of its time would be spent on the ethical, social, legal and medical issues that have come to be associated with assisted suicide and euthanasia. However, at the outset of the hearings, it became apparent that a major and unanticipated issue was the question of alternatives to assisted suicide and euthanasia."[30]

These words are highly significant, as they suggest that for this group of senators, which included a prominent medical practitioner, the departure point in public policy concerning death and dying was the necessity for euthanasia, absent any reference to palliative care. It was not that palliative care was failing, rather that its role was either unknown or underestimated. The final report included a whole appendix on palliative care services which had not originally been scheduled.

Similarly, in the Australian report palliative care was listed merely as one of a series of arguments against euthanasia.[31] However, in the report's summary it was stated that "[b]oth sides of this debate recognise the fundamental importance of effective and available palliative care". The continued federal funding for palliative care was the subject of questions in both Houses and a motion in the Senate during the passage of the *Euthanasia Laws Act* 1997 (Cth).

The two inquiries were very important for the status and future of palliative care, as the practical response to suffering during the dying process was not as widely understood as many who work in the area might have hoped, including among public policy makers and parliamentarians.

[27] 38% of submissions were interpreted as opposing euthanasia on primarily moral grounds: op cit n 3, p 190.
[28] See Senator Bob Brown, ibid, p 173.
[29] Op cit n 2, p ix.
[30] Ibid, p 17.
[31] Op cit n 3, p 65.

Pain control and sedation practices

The Minister of Justice and Attorney-General of Canada, the Hon Allan Rock, stated that palliative care practice was legal and that the distinction between palliative care and euthanasia is "relatively clear" in law:

> "The *Criminal Code* does not require futile treatment, nor does it require capable patients to accept treatment which they do not want. Similarly, necessary palliative care which is carried out in accordance with generally accepted medical practice is not prohibited by the Code whether or not this treatment results in the death of the patient."[32]

However, he succumbed to the "morphine causation fallacy",[33] but with regard to professional and public perception rather than the law itself:

> "When is it permissible to keep prescribing morphine when you know within the next six hours it will cause death? The underlying disease will not kill the person, however the treatment for the pain will. At present, that is shrouded in obscurity." [34]

Witnesses seemed united in their agreement on the need for proper pain and symptom management, and the unevenness of this, due to lack of knowledge and fears of causing death or inducing addiction. One of the most influential palliative care physicians in Canada, Dr Neil Macdonald, addressed the assumption that morphine can cause the death of patients with cancer pain, by pointing out that tolerance occurs to the respiratory depressant effects of the drug.[35] The committee decided to operate on the assumption that palliative interventions may shorten life, and to recommend legislation to clarify the practice "of providing treatment for the purpose of alleviating suffering that may shorten life".

The majorities in both appellate courts in *Rodriguez* and the Senate inquiry therefore maintained that a moral and legal distinction between palliative care and euthanasia could be upheld on the basis of double effect and intention. However, this position was in turn based on a predicate which is of concern to palliative care practitioners: namely, that pain and symptom relief measures hasten or cause death, as expressed by Sopinka J, writing for the majority in *Rodriguez*:

> "The administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes active contribution to death by any standard."[36]

This is allowed by Sopinka J as follows:

> "However, the distinction drawn here is based upon intention – in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause death... In my view distinctions based upon intent are important, and in fact, form the basis of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear." [37]

The Australian Attorney-General's Department gave legal advice to the Senate inquiry about the meaning of the term "intentional killing" in the Euthanasia Laws Bill, and whether the passage of the Bill would generate legal "uncertainty" about end-of-life decisions. This passage of the evidence is revealing of the fragility of the legal understanding of palliative care:

> "The Attorney-General's Department noted that English cases refer to a rule that a doctor caring for a dying patient may lawfully administer pain-killing drugs despite the fact that he or she knows that an incidental effect of doing so will be to shorten the patient's life. The Department said 'it is uncertain whether the rule *as stated* is part of the law in all common law jurisdictions in Australia... [and a] degree of further uncertainty exists as to Code jurisdictions...' The Department said if the rule were to be adopted [in Australia], 'which seems probable as to general principle, if uncertain as to reasoning and detail', many uncertainties remain on matters of significant detail."[38]

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[32] Op cit n 2, p 26.

[33] For a discussion of morphine and causation in palliative care practice, see M A Ashby, "Hard Cases, Causation and Care of the Dying" (1995) 3 JLM 152 at 157.

[34] Op cit n 2, p 27.

[35] Ibid, p 28.

[36] [1993] 3 SCR 519 at 607.

[37] Ibid.

[38] Op cit n 3, p 29.

Significant obstacles to the good care of dying people arise from deeply entrenched myths that morphine causes addiction and death, and these false impressions are perpetuated in medicine, ethics and law. In particular, the notion that there is agreement about a "high" dose of an opioid drug such as morphine beyond which timing and possibly causation might be in question, has permeated every legal deliberation on this issue since the 1957 judgment by (later) Lord Devlin in *R v Adams (Bodkin)*:[39]

> "If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life. This is not because there is a special defence for medical men but because no act is murder which does not cause death. We are not dealing here with the philosophical or technical cause, but with the commonsense cause. The cause of death is the illness or injury, and the proper medical treatment that is administered and that has an incidental effect on determining the exact moment of death is not the cause of death in any sensible use of the term. But ... no doctor, nor any man, no more in the case of the dying than of the healthy, has the right deliberately to cut the thread of life."[40]

This approach, and in particular the assumption about opioids causing death, has been cited in a number of end-of-life decision-making cases before courts in various countries over recent years.[41] It was also endorsed by the Law Reform Commission of Canada in 1982.[42]

There is no empirical evidence that morphine causes death in pain management. Causation is not called into question by pain relief practices where the intention to relieve symptoms and the accepted principles of modern palliative care practice are followed. There are limitations to the use of empirical studies in this area. We cannot know when a particular patient would have died in the absence of palliative interventions or treatment abatement, particularly during the final dying process, and it would be unethical to design randomised controlled trials to find out. Like any class of drugs, the opioids are dangerous if used inappropriately. There is now a substantial body of clinical experience in palliative care about safe standards of practice, with particular regard to initial doses for "opioid-naive" patients and subsequent dose titration according to the person's pain or symptom reporting.[43] The Ontario coroner

[39] [1957] Crim LR 365.

[40] See also P Devlin (ed), "Easing the Passing" in *The Trial of Dr John Bodkin Adams* (Bodley Head, London, 1985).

[41] It has been common for courts considering treatment-abatement cases to refer to pain and symptom relief as being allowed, even if death is believed to be hastened or caused, provided the intention is not to bring about death. See Lord Goff in *Airedale NHS Trust v Bland* [1993] 2 WLR 316 at 370: "a doctor may, when caring for a patient who is, for example, dying of cancer, lawfully administer painkilling drugs despite the fact that he knows that an incidental effect of that application will be to abbreviate the patient's life. Such a decision may properly be made as part of the care of the living patient, in his best interests; and, on this basis, the treatment will be lawful. Moreover, where the doctor's treatment of his patient is lawful, the patient's death will be regarded in law as exclusively caused by the injury or disease to which his condition is attributable." For discussion of the dangerous consequences of the assumption that accepted palliative care practice already incorporates intentional ending of life (the "morphine-causation fallacy" in particular) being mobilised (by courts) to allow euthanasia, see G Annas, "The Promised End – Constitutional Aspects of Physician-assisted Suicide" (1996) 335 *New England Journal of Medicine* 683.

[42] Law Reform Commission of Canada, *Euthanasia, Aiding Suicide and Cessation of Treatment*, Working Paper 28 (Ministry of Supply and Services Canada, Ottawa, 1982).

[43] It is a common belief, and the basis of a considerable body of legal and legislative opinion, that morphine (or other opioid) dose, per se, is the main determinant of whether the drug causes or hastens death. In fact, there is no such determinative or threshold dose, and this approach is flawed. What matters is the present dose in relation to the previous dose. Gradual dose escalation by a factor in the region of 50 to 100% of the previous dose is usual practice, although substantially higher increases can usually be well tolerated by patients who are not new to the drug (that is, they are no longer termed "opioid-naive"). *It is therefore the size of the initial dose and the rate of subsequent increases which are important. Cancer pain management with morphine is unusual compared to most other forms of drug treatment in that there are no predetermined dose ranges to achieve satisfactory pain control for adults or children.* Most adults will achieve initial pain control with a daily dose in the range of 30 mg to 200 mg (per 24 hours, orally), but the range of doses is very wide. *The accepted practice (of which there is nearly 20 years of safe experience) is to adjust the regular dose upwards according to the requirements to keep the pain under control, balanced against incidence of side effects.* Despite an extensive and sustained international campaign by the World Health Organisation, *many*

has laid down four conditions which apply for palliative care interventions to be legal:

> "(1) the care must be intended solely to relieve suffering; (2) it must be administered in response to suffering or signs of suffering; (3) it must be commensurate with that suffering; and (4) it cannot be a deliberate infliction of death. Documentation is required, and the doses must increase progressively."[44]

This approach is clear, helpful and sits very comfortably with modern palliative care practice.

Most people without a legal background, and hence most health care practitioners, will have a narrow medical view of causation, which approximates to the but-for test of causation. In fact, the law (particularly in Australia) looks at causation from the stand-point of determining liability and the possibility of the existence of multiple sufficient causes and by recognising the multifactorial nature of causation, no longer uses the "but-for" test as the sole legal standard for ascertaining or apportioning legal responsibility:

> "In law ... problems of causation arise in the context of ascertaining or apportioning legal responsibility for a given occurrence... Thus, at law a person may be responsible for damage when his or her wrongful conduct is one of a number of conditions sufficient to produce that damage."[45]

Keyserlingk, in an argument against decriminalisation of assisted suicide based on an analysis of *Rodriguez*, proposes a move away from standard and but-for causality of death approaches in legal analysis, and the adoption of what he terms a normative causality approach:

> "[This] position emphasises not simple scientific causality, the cause-in-fact of a death, but normative or legal causality as well. This more nuanced and comprehensive analysis holds that empirical, scientific or 'but-for' causality cannot alone account for what distinguishes assisted suicide from voluntary euthanasia, or what distinguishes both from withdrawal of life support or appropriate pain control resulting in death."[46]

This normative approach allows the but-for cause of death to be overridden as a cause of death if a society decides that the intervention or non-intervention in question not be viewed as a cause of death in law. As stated above, Australian courts already recognise that the but-for test is too limited. There is no tradition (in Australia or elsewhere) of regarding the relief of pain and suffering in the setting of a terminal illness, subject to proper standards of palliative care practice, as causative of death.

While a doctor's intention may not always be easy to validate, evaluation of intention and motive are fundamental to legal analysis, and many would argue that intention is also determinative of the moral character of medical interventions. At present the law and prevailing codes of medical ethics draw a sharp distinction between these two acts. It is preferable that this continues to be the case for the sake of social solidarity and the practice of palliative care. Both Senate inquiries referred to this issue but did not propose a particular remedy.

A novel approach to these issues, in law, comes from South Australia. Double effect was put into statute law for the first time, with regard to the care of dying persons, with the *Consent to Medical Treatment and Palliative Care Act* 1995 (SA). In Div 2 of this Act, entitled "The Care of People Who Are Dying", there is a non-culpability clause which specifically states that medical treatment for the

doctors still believe that they are causing or hastening the death of patients by this process, despite a lack of any evidence to support this view. See R Twycross, *Pain Relief in Advanced Cancer* (Churchill Livingstone, London, 1994); D Zech et al, "Validation of World Health Organisation Guidelines for Cancer Pain Relief: A 10-year Prospective Study" (1995) 63 *Pain* 65; J Stjernsward and N Teoh, "The Cancer Pain Relief Programme of the World Health Organisation" (1989) 4 *Palliative Medicine* 1; Expert Working Group of the European Association for Palliative Care, "Morphine in Cancer Pain: Modes of Administration" (1996) 312 BMJ 823.

[44] Op cit n 2, p 26.

[45] *March v E & MH Stramare* (1991) 65 ALJR 334 at 335, quoted in D Mendelson, "Medico-legal Aspects of the 'Right to Die' Legislation in Australia" (1993) 19 MULR 112.

[46] E Keyserlingk, "Assisted Suicide, Causality and the Supreme Court of Canada" (1994) 39 *McGill Law Journal* 708. Causality is divided into three categories. *Standard causality* entails the characterisation of treatments (eg, ordinary versus extraordinary) in order to allow abatement. Cause of death is usually ascribed to the underlying disease rather than the decision or intervention in question. *But-for or empirical causality* relies on the scientific cause. *Normative causality* allows a more comprehensive analysis including normative considerations *and* empirical data.

relief of pain or distress, and the non-application or discontinuance of life-sustaining measures (for people who are dying) does not constitute *an intervening cause of death* (novus actus interveniens, that is, a cause that breaks a pre-existing chain of causation).[47] The parliamentary select committee from which this piece of legislation emerged heard wide-ranging evidence, including assertions by palliative care physicians that death was not necessarily caused by palliative interventions and treatment abatement. Nonetheless, they heard sufficient professional and community concern about this issue to take the same view as the Canadian Senate, namely that it was important to be specific in law, in order to prevent false perceptions of what the law had to say in this area from obstructing appropriate care of dying people.[48] The House of Lords also endorsed double effect but did not recommend any legislation.

[47] Consent to Medical Treatment and Palliative Care Bill 1994:
"DIVISION 2 – THE CARE OF PEOPLE WHO ARE DYING
The care of people who are dying
17. (1) A medical practitioner responsible for the treatment and care in the terminal phase of a terminal illness, or a person participating in the treatment and care of the patient under the medical practitioner's supervision, incurs no civil or criminal liability by administering medical treatment with the intention of relieving pain or distress –
(a) with the consent of the patient or of patient's representative; and
(b) in good faith and without negligence; and
(c) in accordance with proper professional standards of palliative care,
even though an incidental effect of the treatment is to hasten the death of the patient.
(2) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, is, in the absence of an express direction by the patient or the patient's representative to the contrary, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state.
(3) For the purposes of the law of the State –
(a) the administration of medical treatment for the relief of pain or distress in accordance with subsection (1) does not constitute cause of death; and
(b) the non-application or discontinuance of life sustaining measures in accordance with subsection (2) does not constitute a cause of death."

[48] Parliament of South Australia, Select Committee on the Law and Practice Relating to Death and Dying, *Second Interim Report* (PP No 185) (Adelaide, 1992), p 8.

The objects sections of the four Australian State and Territory Acts of parliament [49] which have been passed over the last decade on matters related to death and dying all have significant comment to make about the issue of proper pain and symptom control, but only the South Australian Act specifically articulates and codifies the principle of double effect in this context.[50] This is not to suggest that there have been prosecutions of doctors for treatment-abatement decisions or palliative interventions, which there have not, nor to propose legal remedies for clinical problems. Rather, if the law specifically articulates, in statute, the priorities and parameters it sets for the care of dying people and differentiates palliative care from euthanasia, this sends a powerful message to practitioners and their teachers which may fundamentally influence such care for the better. This holds even if the predicate about opioids and causation is inflated and unsubstantiated.

Total sedation

This term was defined by the Canadian committee as

> "the practice of rendering a person totally unconscious through the administration of drugs without potentially shortening that person's life".[51]

The witnesses quoted in the report offered a consensus that the practice was widespread, and an accepted part of palliative care. There were some concerns expressed about the possibility of a fine line existing between total sedation practices and voluntary active euthanasia, presumably based on causation.[52] However, the definition expresses a certainty which cannot be defended clinically: namely, that such practices at least have the *potential* to influence the timing of death. In clinical terms it is important to specify the circumstances in which such sedation is deployed. It is one thing to use sedatives during the last few days or hours of a

[49] *Natural Death Act* 1983 (SA); *Natural Death Act* 1988 (NT); *Medical Treatment Act* 1988 (Vic); and *Medical Treatment Act* 1994 (ACT).
[50] Op cit n 47.
[51] Op cit n 2, p 33.
[52] Ibid, p 34.

person's life for the comfort and dignity of a person who has terminal restlessness.[53] It is another to sedate a person, who is not dying, possibly to the point of coma, as a means of relieving symptoms which have not responded to the specific measures which are normally effective for the condition in question. It would be hard to suggest that this is distinguishable from euthanasia, unless it is temporary treatment, such as the parallel with heavy sedation occasionally used for severe fitting, or when a person is being ventilated on an intensive care unit.

As with most facets of its deliberations, the committee noted an absence of empirical data and guidelines and called for these to be produced.

Withholding and withdrawal of life-sustaining treatment

The committee recognised uncertainty in law concerning treatment abatement, which had previously been identified by the Law Reform Commission of Canada in 1982, but no legislative action ensued.[54] The landmark *Nancy B* case in the Quebec Superior Court clearly asserted the right of a person to reject medical treatment, even if this would result in her death.[55] The committee received some evidence from proponents of an absolute sanctity of life position that no life-support measure, including artificial hydration and alimentation, could be abated, but these views did not prevail. The committee accepted the views that there was no moral distinction between withholding or withdrawing treatment and that artificial hydration and alimentation constituted medical treatment like any other. They took a narrow definition of futility as needing to be absolute (completely ineffective), but this did not include treatment that may be effective but whose results are deemed undesirable. If futility can be shown, treatment abatement may prevail even for a competent person against his or her wishes. The importance of competence assessment was underlined, substitute decision-making was endorsed and those Provinces which had not passed advance directive legislation were urged to do so.[56]

Assisted suicide and euthanasia

These were considered in separate sections of the report. A majority of the committee favoured the status quo of both remaining illegal. However, they did not preclude allowing assistance in suicide in future if more information were available to show that it was needed. With regard to euthanasia, they recommended that while it should remain a criminal offence, if elements of compassion and mercy could be demonstrated, for either voluntary or non-voluntary euthanasia, then a less severe penalty than the mandatory life sentence required by the *Criminal Code* for murder in Canada should apply.

Minority recommendations were made by three (of the seven) senators on the committee to allow assistance in suicide and by two of those to allow euthanasia in certain highly regulated circumstances. Mullens has pointed out that the senator who changed from minority support for assisted suicide to majority opposition to euthanasia was Senator Wilbert Keon, a cardiothoracic surgeon from Ottawa, eminent in the medical profession of the country. He was apparently swayed by the poignant testimony of witnesses seeking this avenue for their relatives.[57]

Mercy killing, leniency and civil disobedience

It is of note that there is a strong thread of civil disobedience with regard to euthanasia in Canada and Australia.[58] Seven doctors in Melbourne,

[53] A L Burke, "Palliative Care: An Update on 'Terminal Restlessness'" (1997) 166 *Medical Journal of Australia* 39 at 39.

[54] Op cit n 2, p 40; Law Reform Commission of Canada, op cit n 42.

[55] B Schneiderman, "The Case of Nancy B: A Criminal Law and Social Policy Perspective" (1993) 1 *Health Law Journal* 25.

[56] Most provincial legislatures in Canada have considered advance directive legislation, but so far only Quebec, Ontario, Manitoba and Nova Scotia have proclaimed legislation that codifies advance directives into law.

[57] A Mullens, *Timely Death: Considering Our Last Rights* (Knopf Canada, Toronto, 1996), p 201.

[58] B Schneiderman, "The Rodriguez Case: Where Do We Go From Here – A Multi-Dimensional (6-layered) Approach" (1994) 2 *Health Law Journal* 1 at 10 (the Picard Lecture in Health Law, 1993). The author argues that "de facto legalisation [of euthanasia] has long been the name of the game [in Canada]. Whether it be lethal injection or assisting suicide, the law's policy has been grounded in the spirit of benign neglect."

Victoria, have publicly challenged the State to prosecute them after admitting in a newspaper article that they had practised euthanasia and would continue to do so. No specific cases were presented and no prosecutions ensued.[59] Recent surveys of Australian doctors show increasing approval of euthanasia, and a willingness by doctors in confidential surveys to indicate that they have practised VAE.[60] Two prominent palliative care physicians, one in Canada (Dr Marcel Boisvert)[61] and one in Australia (Dr Roger Hunt)[62] have also supported medical assistance in dying. It is clear that there is an international trend for a non-prosecution stance, reduced charges or light sentences for people who commit acts of mercy killing. Mullens has chronicled a number of Canadian cases to support her argument that VAE should be allowed, because it is already happening and the law imposes hardship despite its lenient sentencing.[63] Non-prosecution, on the basis of the force majeure of a person's suffering, is, of course, the basis of the legality of euthanasia in The Netherlands.

The *Latimer* case has proved to be an exception to leniency in so-called "mercy-killing" cases, because of incompetence. In November 1994, Robert Latimer, a farmer from Wilkie, Saskatchewan, asphyxiated his daughter Tracy by placing her in the cab of his truck and piping exhaust into it so that she died of carbon monoxide poisoning. She had severe cerebral palsy and was severely physically and developmentally disabled. Her father's main defence was her severe pain due to musculoskeletal deformities which had not responded well to attempts at surgical relief, although she did not receive adequate pain and palliative care.[64] Robert Latimer was found guilty of second degree murder and given the mandatory minimum life sentence with no possibility of parole for 10 years.[65] The case has subsequently gone to the Supreme Court which has ordered a retrial due to alleged jury interference. It has caused strong public feeling, with particularly strong reactions from many disabled groups about the dangers of discriminating against incompetent persons with disabilities.

In Melbourne a jury recently found a man not guilty of the murder of his wife whose wrist he slashed, resulting in a fatal haemorrhage, after repeated requests to die as a result of pain and disability from a severe stroke and arthritis.[66] Dr Philip Nitschke, a doctor practising in the Northern Territory of Australia, has openly stated that he will continue to help people to die despite the overriding of the RTI Act. In Canada, a prominent member of the House of Commons, Svend Robinson MP, was publicly involved with the Sue Rodriguez' quest for assistance to die and stated that he was present at her death, which was assisted by an unnamed medical practitioner.[67]

The Canadian Senate was willing to advise codification of leniency for "mercy killing". In contrast, the House of Lords Select Committee recommended against this step. They received advice from the Home Office that prosecution for murder in such cases was very rare.[68] The issue was not resolved one way or the other by the Australian Senate as this issue fell substantially outside its terms of reference. It is clear, however, that cases are emerging consistently in all three countries and leniency or non-prosecution appears to prevail.

[59] *The Age*, 25 March 1995.

[60] For surveys of Australian doctors and attitudes to euthanasia, see P Baume and E O'Malley, "Euthanasia: Attitudes and Practices of Medical Practitioners" (1994) 161 *Medical Journal of Australia* 137; C Stevens and R Hassan, "Management of Death, Dying and Euthanasia: Attitudes and Practices of Medical Practitioners in South Australia" (1994) 20 *Journal of Medical Ethics* 41.

[61] Op cit 57, pp 220 and 260.

[62] R Hunt, "Palliative Care – The Rhetoric-Reality Gap" in H Kuhse (ed), *Willing to Listen, Wanting to Die* (Penguin, Melbourne, 1994).

[63] Op cit n 57.

[64] Ibid, p 288.

[65] Op cit n 2, p A-31.

[66] "Aged Mercy Killer Acquitted", *The Age*, 10 May 1997 and soon afterwards, on 15 May, another case, "Daughter Assisted in Death: Coroner".

[67] Svend Robinson is a member of the New Democratic Party, and holds the seat of Burnaby-Kingsway (British Columbia) in the House of Commons. He has introduced two private members' Bills into the House of Commons to allow assistance in suicide, both of which have lapsed (C-215 and C-385).

[68] Op cit n 1, HL-II, p 18.

Conclusions

So, as a result of different triggers – a prominent court case in Canada and the passage of a statute in Australia – the federal upper houses of both countries have been charged with the task of reviewing the issues surrounding death and dying, including the relationship between palliative care and euthanasia. Both reports have endorsed palliative care and rejected euthanasia, as did the House of Lords. In Canada and the United Kingdom, courts had urged parliament to ascertain public opinion and consider legislative change where appropriate.[69] In Australia the initial step was a piece of Territory legislation, which was subject to constitutional challenge in federal institutions: the Federal Court and Commonwealth Parliament. In all three countries, the resulting reports constituted, on balance, a defence of the status quo, but all rejected a narrow interpretation of the principle of the sanctity of life. The Canadian report appeared to entertain the possibility of allowing assisted suicide or euthanasia at some point in the future if data were provided to support such a move. The majority of senators on the Australian committee took a more conservative and categorical stance against any present or future allowing of euthanasia.

There are limits to the capacity of empiricism to determine moral and ethical issues. It is noteworthy that the Canadian report responded to most of the topics addressed by calling for guidelines and more information. While this is hard to disagree with per se, it is arguable whether the rightness or wrongness of an issue such as euthanasia, can be (exclusively or predominantly) determined by empirical data.[70] Similarly, in law, exclusive reliance on empirical analysis of causality is limiting. A balance needs to be struck between empirical and normative considerations.[71]

Professional, academic and religious evidence against euthanasia was influential. For both committees, palliative care evidence was particularly important, and was acknowledged to have changed the point of departure for the Canadian committee's deliberations. Palliative care was therefore endorsed and distinguished from euthanasia, albeit on a predicate that death may be hastened or caused by palliative interventions and treatment abatement. This is a right outcome in the sense of promoting better palliative care, but it still sends the community and the professions a mixed message with regard to causation and responsibility for death in the care of people who are dying.

Both public opinion in favour of euthanasia, and increasingly frequent acts of civil disobedience will combine to exert continuing pressure on legislatures. New approaches are required, which ensure that shared values about how care is delivered and decisions are made move the debate away from narrow empiricism to an acknowledgment that death is not medical defeat but an inevitable consequence of living. Stopping or not initiating treatment aimed at cure for people who are dying should not bring into question the issue of responsibility for death, nor is it necessary to bring about the death of a person in order to achieve symptom control. Medico-legal and ethical dialogue should focus public policy more on practical care, and the clear differentiation of palliative care and euthanasia is an ongoing imperative.

[69] D Brahams, "Persistent Vegetative State" (1993) 341 *Lancet* 428.

[70] E Pellegrino, "The Limitation of Empirical Research in Ethics" (1995) 6 *Journal of Clinical Ethics* 161 at 161.

[71] J Ralston Saul, *The Unconscious Civilisation* (Penguin, Toronto, 1995). In his 1995 Massey lectures, and in *Voltaire's Bastards* (Penguin, Toronto, 1992), Saul argues against corporatism and an excessive reliance on reason to the exclusion of other human attributes such as common sense, ethics, intuition and creativity.

APPENDIX 12

REVIEW

Palliative care, death causation, public policy and the law

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Introduction

The hospice and palliative care 'movement' has developed over the last three decades as a practical response to the history of neglect of care needs at the end of life which occurred during the middle part of the twentieth century. It has brought about significant and continuing improvement in the way health care systems deal with the process of dying. Over the same time period, however, euthanasia has become one of the main optics through which societies view death in the post-modern world. The central question at stake is therefore whether it is permissible for a terminally ill person to have third party assistance to die. Although euthanasia is an old issue and campaigning groups have existed for over a century, the debate has been developing considerable momentum in the nineties and public opinion in favour of it has risen steadily in most OECD countries. As a result, end of life issues have received unprecedented attention from courts, parliaments, professions and the media.

The purpose of this review is to examine recent public policy deliberations on these issues in Australia, New Zealand, Canada, the United Kingdom and the United States, by reference to the major legal cases and parliamentary enquiries which have taken place in these countries since 1992. It will be shown that the balance of contemporary international legal and political opinion has concluded that palliative care interventions and treatment abatement decisions may indeed constitute a cause of death, at least in an empirical sense. However, such practice is allowed in law, in the context of a terminal illness, because of almost universal agreement that public policy should support the imperative to relieve suffering and avoid prolongation of the process of dying. So, whilst in general, this legal endorsement of accepted standards of palliative care practice is a good outcome for the care of those at the end of life, the causal predicate concerning palliative interventions and treatment abatement decisions should be subjected to scrutiny.

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Background

In both the Bland (1) and Rodriguez (2) cases, the courts of England and Canada were consulted in advance of a proposed treatment abatement decision and a request for assistance to die respectively. As a result, the highest appellate courts in the two countries undertook some of the most significant intellectual analyses of law, ethics and public policy on care and decision-making at the end of life. These two landmark cases, by revealing the absence of specifically applicable legislation, gave rise to parliamentary upper house enquiries into death and dying in the United Kingdom (1994) (3) and Canada (1995) (4). In Australia (1997), a senate special committee resulted from the passage of territory legislation to allow euthanasia (5). In all three enquiries euthanasia was the main issue under consideration, but palliative care was also looked at in depth (6).

In judgments on two cases in 1997 (7,8), the Supreme Court of the United States has ruled against physician-assisted suicide. In the process the court has endorsed palliative care, but some of the evidence presented, and predicates of the lower courts (9, 10), make for disturbing reading (11,12). In particular, Annas has pointed out that the Second Circuit Court relied heavily on Justice Antonin Scalia's concurring opinion in Cruzan that refusals of treatment that result in death are all suicides, and that any notion that the patient dies a "natural" death from the underlying disease is nonsense. He also shows that the Ninth Circuit Court "recognised" that:

> "as part of the tradition of administering comfort care, doctors have been supplying the causal agent of patients' deaths for decades.....double effect - reduce the patient's pain and hasten (his or her) death."(13)

Palliative care differentiates the basis of its practice from euthanasia, and dissociates itself from it. In fact, in the first book solely devoted to palliative care ethics, the subject is dismissed altogether, on the basis of scope, ie, euthanasia is not a part of palliative care therefore it is not discussed (14). Those outside the palliative care world do not see things quite like this. For instance, one of the major consequentialist lines of argument run by many of those who support euthanasia, is that it is already being widely practised because palliative interventions or treatment abatement commonly result in death anyway (15-17). Palliative care is challenged, whether it likes it or not, to publicly argue how it can be distinguished from euthanasia (18,19). It is not sufficient for the field to have its own internal understanding of causality, agency and intention, if society sees things differently, including in very high level intellectual analyses of superior courts and parliamentary enquiries.

United Kingdom

Bland

The case of Anthony Bland brought end of life issues into the public eye in Britain in 1993 when the House of Lords (sitting in its role as the highest appeal court in England and Wales) decided that artificial hydration and alimentation might lawfully be ceased. Bland was a victim of the Hillsborough football ground disaster in 1989, and as a result of crush injuries received, was in a persistent vegetative state (PVS). Despite acknowledging that death would ensue, the Law Lords reasoned that there was a distinction between acts and omissions, that the cause of death was the underlying condition, that his best interests were not served by continuing his nasogastric tube sustenance (which was considered to be medical treatment like any other, and not different in kind), and that there was no duty to continue it in this particular case. There was agreement with the decision by the family, the hospital, the inferior courts who considered the case, and a large proportion of the British public, although public 'right to life' protests were made, up to and at the time of his death. Throughout the case, the judges involved showed great humanity towards the family, and humility in their role, both in terms of not wishing to intrude into clinical practice, and requesting parliament to consider the whole area of end of life decision-making. Ultimately many saw this as a right outcome, but disputed the reasoning, in particular the notion that such treatment abatement decisions are distinguishable from euthanasia. The Law Lords were adamant that their holding did not create a precedent for euthanasia. The judgment is long, complex and scholarly, and most of the assumptions have subsequently been examined and challenged, by writers such as Michael Freeman ("Death's Dominion", unpublished, in which the best interests test is supported, but the active-passive distinction is not), and others (20-24). The case revealed the intellectual fragility of such decisions, with particular regard to agency and causation. Although the case did not specifically address palliative care, it did comment extensively on it, and some aspects of the judgments are relevant to it (eg see Lord Goff below).

Cox

In 1992, Dr Nigel Cox, a rheumatologist at the Royal Hampshire County Hospital in Winchester, UK, administered a lethal dose of potassium chloride to a woman (for whom he had been caring for 13 years) who was dying of advanced rheumatoid arthritis and multiple complications. He was convicted of attempted murder, but given a suspended sentence and was required by the General Medical Council to undergo palliative care training (3,25). The case received widespread publicity, and once again there was substantial public support for the doctor and his action.

House of Lords

Parliament did indeed take up the challenge of the courts, with the appointment of the House of Lords Select Committee on Medical Ethics in March 1993 (3). It recognised as a major predicate, that the nature of medical practice had changed substantially, as a result of technical progress, demographics, and changes in public expectations, notably around autonomy. The Committee recommended that there be no change to the law to permit euthanasia or 'mercy killing'. They strongly endorsed patients' rights to refuse treatment, and supported advance directives and a new judicial forum with the power to make medical decisions for incompetent persons, both of these last two issues being taken up by the present British government in a new report by the Lord Chancellor's Department (26,27). Palliative care was also strongly supported, and the doctrine of double effect was accepted as a sound ethical basis for pain and symptom relief:

> "Double effect is not in our view a reason for withholding treatment that would give relief, as long as the doctor acts in accordance with responsible medical practice with the object of relieving pain or distress, and without intention to kill."

The wording is interesting in that double effect is surely being argued here to be *the* reason why palliative treatment is ethical (see below for further discussion of double effect as it is usually applied to palliative care).

Canada

It was the case of the late Sue Rodriguez, a young woman from British Columbia with motor neurone disease, which has probably done more than any other single event to bring the issue of euthanasia, and thereby palliative care to the attention of Canadians (4,28-31). Her quest to have medical assistance to end her life led to a court case which resulted in the narrow rejection (5-4) of her appeal to the Supreme Court of Canada. It was a very public dying process, with extensive media coverage, an authorised biography, political and academic analysis during her life and afterwards. She was 44 years old when she finally died at her home in February 1994, allegedly with the assistance of an (unnamed) medical practitioner, in the presence of her prominent friend and supporter, Svend Robinson MP. The case was constructed around a claim that Sue Rodriguez's Charter rights under the Canadian Charter of Rights and Freedoms were infringed by the Canadian Criminal Code prohibition of assistance to commit suicide. The majorities in the three courts which considered her case argued that a blanket prohibition was appropriate and proportionate to prevent the harms that would be caused (to other members of society) if it were removed. They supported the doctrine of double effect as the major ethical underpinning of the distinction between palliative care and euthanasia. Claims of discrimination on the basis of her inability to kill herself without assistance did not prevail. Both chief justices (MacEachern CJ and Lamer CJ) involved dissented in her favour and laid down a series of safeguarding conditions which should be met before her request could be granted.

Canadian Senate Report

The Canadian senate report made recommendations under six chapter headings: palliative care, pain control and sedation practices, withholding and withdrawal of life-sustaining

treatment, advance directives, assisted suicide, and finally euthanasia (4).

Palliative care

The committee received considerable amounts of evidence concerning the present state of palliative care in Canada, with strong endorsement of what is being done already, but concerns about lack of coverage of services. It recommended that provinces make palliative care:

> "a top priority in the restructuring of the health care system."

It also specifically endorsed better training and research and the promulgation of guidelines and standards. However, the report expresses initial surprise that palliative care emerged as such an important practical issue at all:

> "The Committee began its hearings with the expectation that the large majority of its time would be spent on the ethical, social, legal and medical issues that have come to be associated with assisted suicide and euthanasia. However, at the outset of the hearings, it became apparent that a major and unanticipated issue was the question of alternatives to assisted suicide and euthanasia."

These words are highly significant, as they suggest that for this group of senators, which included a prominent medical practitioner, the departure point in public policy concerning death and dying was the necessity for euthanasia, absent any reference to palliative care. It was not that palliative care was failing, rather that its role was either unknown or under-estimated. The final report included a whole appendix on palliative care services which had not originally been scheduled.

Pain control and sedation practices

The Minister of Justice and Attorney General of Canada, the Honourable Allan Rock stated that palliative care practice was legal and that the distinction between palliative care and euthanasia is "relatively clear" in law:

> "The Criminal Code does not require futile treatment, nor does it require capable patients to accept treatment which they do not want. Similarly, necessary palliative care which is carried out in accordance with generally accepted medical practice is not prohibited by the Code whether or not this treatment results in the death of the patient."

However, he succumbs to the "morphine causation fallacy", but with regard to professional and public perception rather than the law itself:

> "When is it permissible to keep prescribing morphine when you know within the next six hours it will cause death? The underlying disease will not kill the person, however the treatment for the pain will. At present, that is shrouded in obscurity."

Witnesses seemed united in their agreement on the need for proper pain and symptom management, and how uneven this was due to lack of knowledge and fears of causing death or inducing addiction. One of the most influential palliative care physicians in Canada, Neil MacDonald addressed the assumption that morphine can cause the death of patients, by pointing out that tolerance occurs to the respiratory depressant effects of the drug. Nevertheless, the committee decided to operate on the assumption that palliative interventions may shorten life, and to recommend legislation to clarify the practice:

> "of providing treatment for the purpose of alleviating suffering that may shorten life."

The majorities in both appellate courts in Rodriguez, and the senate enquiry therefore maintained that a moral and legal distinction between palliative care and euthanasia could be upheld on the basis of double effect and intention, along much the same lines set out by the Law Reform Commission in 1982 (32). Mr Justice Sopinka, writing for the majority in Rodriguez states:

> "The administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes active contribution to death by any standard. However, the distinction drawn here is based upon intention – in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause death....In my view distinctions based upon intent are important, and in fact, form the basis of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear." (33)

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> "the practice of rendering a person totally unconscious through the administration of drugs without potentially shortening that person's life."

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treatment, such as the parallel with heavy sedation occasionally used for severe fitting, or when a person is being ventilated on an intensive care unit.

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Withholding and Withdrawal of Life-sustaining Treatment

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Minority recommendations were made by three (of the seven) senators on the committee to allow assistance in suicide and by two of those to allow euthanasia in certain highly regulated circumstances. Mullens has pointed out the significance of Senator Wilbert Keon, an eminent cardiothoracic surgeon from Ottawa, changing from opposition to qualified support for physician-assisted suicide, as a result of the hearings. He was apparently swayed by the poignant testimony of witnesses seeking this avenue for their relatives (34).

Australia

In July 1996 the *Rights of the Terminally Ill Act* (the RTI act) of the Northern Territory came into force, being the first such statute successfully enacted in the world (although the Oregon state law mandated as Measure 16 is now stated to be operative but subject to a US Supreme Court hearing). RTI had been passed by the Legislative Assembly by a margin of 15-10 after a legislative passage of only four months. This included a Select Committee and forty nine amendments during the Committee stage. In September 1996, the Liberal member for the federal seat of Menzies in Victoria introduced a private member's bill (the *Euthanasia Laws Bill 1996*) into the House of Representatives to override this act. It was passed by the House but was referred by the Senate Selection of Bills Committee to one of its standing committees: the Senate Legal and Constitutional Legislation Committee. This parliamentary enquiry received 12,577 submissions, a record, the majority (93.3%) of which were interpreted as being against euthanasia, a startling result from a country which expresses 70-80% support for euthanasia in opinion polls, which is indicative of an orchestrated anti-euthanasia submission campaign. The Committee made no recommendation to the Senate because the matters were the subject of a private member's bill and hence, of a "conscience vote". However, a majority of senators supported the bill and advised that the Commonwealth parliament had the requisite legal powers to override the RTI act. Minority reports against the bill were filed by several senators, including the only medical practitioner on the committee, Dr Bob Brown, Australian Greens Senator for Tasmania. He argued that palliative care and euthanasia lie on a moral or clinical 'choice' spectrum, and hence euthanasia is not different in kind in a moral or clinical sense (see also Russel Ogden from British Columbia) (35). The senate passed the bill and it was given royal assent in March 1997.

The Australian Attorney General's Department gave legal advice to the senate enquiry about the meaning of the term "intentional killing" in the *Euthanasia Laws Bill*, and whether the passage of the bill would generate legal "uncertainty" about end of life decisions. This passage of the evidence is revealing of the fragility of the legal understanding of palliative care:

> "The Attorney-General's Department noted that English cases refer to a rule that a doctor caring for a dying patient may lawfully administer pain-killing drugs despite the fact that he or she knows that an incidental effect of doing so will be to shorten the patient's life. The Department said 'it is uncertain whether the rule as stated is part of the law in all common law jurisdictions in Australia...(and a) degree of further uncertainty exists as to code jurisdictions....' The Department said if the rule were to be adopted (in Australia), 'which seems probable as to general principle, if uncertain as to reasoning and detail', many uncertainties remain on matters of significant detail."

Similarly to the Canadian report, in the Australian report palliative care is listed merely as one of a series of arguments against euthanasia. However, in the report's summary it is stated that:

> "Both sides of this debate recognise the fundamental importance of effective and available palliative care."

The continued federal funding for palliative care was the subject of questions in both houses and a motion in the senate during the passage of the *Euthanasia Laws Act.*

USA

The Supreme Court of the United States in a recent unanimous decision (9-0), has decided that state legislation prohibiting physician-assisted suicide is constitutional (7,8). Mendelson has pointed out that the court's decision-making was grounded in Anglo-American common-law tradition which has historically disapproved of both suicide and assisted suicide (36). Although at first sight this might seem to lay the matter to rest, commentators have argued that the judgments are less decisive than they appear, and still leave the way open for a different conclusion in future (37-43). Justice Sandra Day O'Connor indicated that if in a future scenario, a satisfactory way of relieving suffering (viz terminal sedation) could be demonstrated to be unavailable, then medical assistance to die might be permissible (44). Orentlicher has argued that by endorsing terminal sedation they are allowing a form of euthanasia which is less preferable than physician-assisted suicide because it can be applied to incompetent patients without their consent (45). The Court recognised the importance of palliative care and the need to remove any (state) impediments to its delivery, eg excessive drug regulatory bureaucracy and funding barriers (44).

Causation

Significant obstacles to the good care of dying people arise from deeply entrenched myths that morphine causes addiction and death if these false impressions are perpetuated in medicine, ethics and law (46,47). In particular, the notion that there is agreement about a "high" dose of an opioid drug such as morphine beyond which timing and possibly causation might be in question has permeated every legal deliberation on this issue since the 1957 instruction to the jury by (later) Lord Patrick Devlin in R v Bodkin Adams (48):

> "But that does not mean that a doctor who is aiding the sick and the dying has to calculate in minutes or even hours, and perhaps not in days or weeks, the effect on the patient's life of the medicines that he administers or else be in peril of a charge of murder. If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life. This is not because there is a special defence for medical men but because no act is murder which does not cause death. We are not dealing here with the philosophical or technical cause, but with the commonsense cause. The cause of death is the illness or injury, and the proper medical treatment that is administered and that has an incidental effect on determining the exact moment of death is not the cause of death in any sensible use of the term. But ... no doctor, nor any man, no more in the case of the dying than of the healthy, has the right deliberately to cut the thread of life."

Any therapeutic intervention in palliative or terminal care may potentially affect the timing of death, but the cause remains the underlying condition from which the person is dying. Lord Goff follows this line of argument in Bland (1):

> "As I see it, the doctor's decision whether or not to take any step must (subject to his patient's ability to give or withhold his consent) be made in the best interests of the patient. It is this principle too which, in my opinion, underlies the established rule that a doctor may, when caring for a patient who is, for example, dying of cancer, lawfully administer painkilling drugs despite the fact that he knows that an incidental effect of that application will be to abbreviate the patient's life. Such a decision may properly be made as part of the care of the living patient, in his best interests; and, on this basis, the treatment will be lawful. Moreover, where the doctor's treatment of his patient is lawful, the patient's death will be regarded in law as exclusively caused by the injury or disease to which his condition is attributable."

There is no empirical evidence that morphine causes death, if used with appropriate skill to palliate symptoms. Causation is not called into question by pain relief practices where the primary and sole intention is to relieve symptoms and the accepted principles of modern palliative care practice are followed. The Ontario coroner (Dr James Young, 1997) seems to have captured the essence of this well in laying down four conditions which apply for palliative care interventions to be legal in his jurisdiction, and these should be universally applicable:

> "(1) the care must be intended solely to relieve suffering; (2) it must be administered in response to suffering or signs of suffering; (3) it must [be] commensurate with that suffering; and (4) it cannot be a deliberate infliction of death. Documentation is required, and the doses must increase progressively." (4,49)

There are limitations to the use of empirical studies in this area. We cannot know when a particular patient would have died in the absence of palliative interventions or treatment abatement, particularly during the final dying process, and it would be unethical to design randomised controlled trials to find out. It is perhaps more helpful to consider that certain therapeutic actions or omissions in the setting of palliative care have the capacity to alter the timing of an otherwise inevitable death (although often not in a reliable and predictable manner), causation being predetermined by the underlying disease (see Keyserlingk below).

Like any class of drugs, the opioids are dangerous if used inappropriately. There is now a substantial body of clinical experience in palliative care about safe standards of practice, with particular regard to initial doses for 'opioid-naive' patients and subsequent dose titration according to the

person's pain or symptom reporting. The excerpts from the judgments and enquiries in this paper show that it is widely assumed that the morphine (or other opioid) *dose per se*, is the main determinant of whether the drug causes or hastens death. In fact there is no such determinative or threshold dose, and this approach is flawed. What matters is the present dose in relation to the previous dose. Gradual dose escalation by a factor in the region of 50-100% of the previous dose is usual practice, although substantially higher increases can usually be well tolerated by patients who are not new to the drug (that is they are no longer termed 'opioid-naive'). It is therefore the size of the initial dose, and the rate of subsequent increases which are important. Cancer pain management with morphine is unusual compared to most other forms of drug treatment in that there are no predetermined dose ranges to achieve satisfactory pain control for adults or children. Most adults will achieve initial pain control with a daily dose in the range of 30 mg to 200 mg (per 24 hours, orally), but the range of doses is very wide. The accepted practice (of which there is nearly 20 years of safe experience) is to adjust the regular dose upwards according to the requirements to keep the pain under control, balanced against incidence of side effects. Despite an extensive and sustained international campaign by the World Health Organisation (50-54), many doctors still believe that they are causing or hastening the death of patients by this process, despite a lack of any evidence to support this view (17,36).

It is clear that expert medical evidence given forty years ago has been incorporated into legal deliberations and public policy formulation ever since. The hospice and palliative care movement had not then commenced, and the standard medical view of opioids and care at the end of life were very different. Morphine and heroin were regarded as addictive in any setting, and at least contributory to bringing forward the time of death. The title for Patrick Devlin's 1985 book as a result of the 1957 Bodkin Adams case: "Easing the passing" (55), is perhaps illustrative of the prevailing views on palliative care at the time. The widespread use of the 'Brompton's Cocktail' also shows that the view of dying was that rapidity of death and oblivion were the goals of palliative interventions. This is no longer the case, and palliative care has expanded well beyond terminal care. Millions of patients worldwide have now benefited from the skilled use of opioids throughout the natural history of their disease process, without death causation or addiction being an issue, although older attitudes are still at work. Even in terminal care, medications are used to control symptoms, rather than to speed up the process of death (17,36).

Most people without a legal background, and hence most health care practitioners, will have a narrow medical view of causation, which approximates to the but-for test of causation[1]. In fact the law (particularly in Australia) looks at causation from the stand-point of determining liability and the possibility of the existence of multiple sufficient causes and by recognising the multifactorial nature of causation, no longer uses the "but-for" test as the sole legal standard for ascertaining or apportioning legal responsibility:

> "In law ... problems of causation arise in the context of ascertaining or apportioning legal responsibility for a given occurrence ... Thus, at law a person may be responsible for damage when his or her wrongful conduct is one of a number of conditions sufficient to produce that damage." (56,57)

Keyserlingk (30) in an argument against decriminalisation of assisted suicide based on an analysis of Rodriguez, proposes a move away from standard and but-for causality of death approaches in legal analysis, and the adoption of what he terms a normative causality approach, and what courts more commonly term the common sense and experience test of causation:

> "(this) position emphasises not simple scientific causality, the cause-in-fact of a death, but normative or legal causality as well. This more nuanced and comprehensive analysis holds that empirical, scientific or "but-for" causality cannot alone account for what distinguishes assisted suicide from voluntary euthanasia, or what distinguishes both from withdrawal of life support or appropriate pain control resulting in death."

This normative, or common sense and experience approach allows the but-for cause of death to be overridden as a cause of death if a society decides that the intervention or non-intervention in question not be viewed as a cause of death in law. There is no tradition (in Australia or elsewhere) of regarding the relief of pain and suffering in the setting of a terminal illness, subject to proper standards of palliative care practice, as causative of death.

In the absence of formal training in palliative care, doctors' attitudes and clinical behaviour are complex and variable, ranging from abrupt cessation of treatment, minimalist palliative care and treatment directed at bringing about a rapid dying process, to excessive caution about being seen to be instrumental in causing the death, particularly with regard to the provision of pain and symptom relief, cessation or non-initiation of artificial hydration and alimentation and cardio-pulmonary resuscitation. Whilst a doctor's intention may not always be easy to validate, evaluation of intention and motive are fundamental to legal analysis, and many would argue that intention is also determinative of the moral character of medical interventions.

A novel approach to these issues, in law, comes from South Australia. Double effect was put into statute law for the first time, with regard to the care of dying persons, with the *Consent to Medical Treatment and Palliative Care Act, 1995*. In Division 2 of this act, entitled 'The Care of People Who

[1] Causation is a complex phenomenon in the law, and it might be reasonably argued that it is misnomer in that context (Danuta Mendelson, personal communication). Legal causation is a process whereby courts look at the chain of events in a case, and then attempt to attribute legal liability. It differs from causation in medicine and science which is concerned solely with the facts (or data) and their relationship to each other. The 'but for' test in law asks whether the damage or harm would have occurred but for the (plaintiff's) wrongful act, and serves to eliminate matters which could not have been the causes of the (plaintiff's) damage (synonyms include *causa sine qua non*, literally 'the cause without which', 'proximate cause' and 'real effective cause'). It is not regarded as the sole determinant of legal liability, and is overarched or controlled by the test of common sense and experience. For further reading, see Mendelson D. Torts. Butterworths, 1997.

Are Dying', there is a non-culpability clause which specifically states that medical treatment for the relief of pain or distress, and the non-application or discontinuance of life sustaining measures (for people who are dying) does not constitute *an intervening cause of death* (*novus actus interveniens*, ie a cause that breaks a pre-existing chain of causation). A saving provision was inserted stating that the act does not allow euthanasia. The parliamentary select committee from which this piece of legislation emerged heard wide-ranging evidence, including assertions by palliative care physicians that death was not caused by palliative interventions and treatment abatement. Nonetheless, they heard sufficient professional and community concern about this issue to take the same view as the Canadian senate, namely that it was important to be specific in law, in order to prevent false perceptions of what the law had to say in this area from obstructing appropriate care of dying people.

The objects sections of the four Australian state and territory acts of parliament which have been passed over the last decade on matters related to death and dying all have significant comment to make about the issue of proper pain and symptom control, but only the South Australian act specifically articulates and codifies the principle of double effect in this context. This is not to suggest that there have been prosecutions of doctors for treatment abatement decisions or palliative interventions, which there have not, nor to propose legal remedies for clinical problems. Rather, if the law specifically articulates, in statute, the priorities and parameters it sets for the care of dying people and differentiates palliative care from euthanasia, this sends a powerful message to practitioners and their teachers which may fundamentally influence such care for the better. This holds even if the predicate about opioids and causation is inflated and unsubstantiated.

It is, nonetheless, important to note that the so-called 'doctrine' of double effect has recently been subjected to penetrating intellectual assault by a number of writers, despite the fact that courts and parliaments have endorsed it (58). Singer has suggested that it is 'figleaf' behind which decisions at the end of life which will have the effect of ending life are hidden. In the Bland case, he makes the irrefutable case that the intended outcome was clearly Anthony Bland's death (23). Jessica Corner, a prominent palliative care nurse, in commenting on the recent Annie Lindsell case in the UK, has made a plea for palliative care to recognise that there may be times when death is an intended outcome (59). Quill and coauthors have argued that patient self determination is more important than doctor's intentions as a guide to action in end of life decision making (60). This view has been shared by a South Australian palliative care specialist (Roger Hunt) (61), and another in Quebec (Marcel Boisvert) (34). It is clearly unacceptable to use double effect wrongly, and to pretend that death is an unintended and unforeseen consequence of certain courses of action, be they interventions or treatment abatement decisions, where the reverse is empirically true. Decisions such as the withdrawal of feeding in the Bland case (he was not 'dying', his condition was stable at the time of the decision) clearly need to be taken, and have very wide public support. However, it should be recognised that treatment abatement decision-making for dying persons represents a different type of clinical situation, in which the cessation or non-inititiation of medical treatment aimed at life prolongation is a commonsense recognition of relative or absolute futility. To call causation into question in these situations is unhelpful, as are arguments that all treatment omissions, no matter what the clinical circumstances, constitute "passive" euthanasia. It is surely not the purpose or the duty of medicine to provide all treatments which have any potential to prolong life to all patients in all circumstances. By embracing palliative care, medicine defines itself as more than mere death avoidance. Equally, narrow views of empirical causality in terminal care should not be mobilised to justify euthanasia, which surely has better arguments to put forward in its favour anyway.

The notion of death as a natural event is important. Justice Thomas throws light on the goals of medical care and the meaning of 'natural' death, in his judgment in a New Zealand court, where he authorised withdrawal of ventilation from a man rendered incompetent and completely paralysed by an extreme form of the Guillain-Barré syndrome:

> 'Medical science and technology has advanced for a fundamental purpose: the purpose of benefiting the life and health of those who turn to medicine to be healed. It surely was never intended that it be used to prolong biological life in patients bereft of the prospect of returning to an even limited exercise of human life. Nothing in the inherent purpose of these scientific advances can require doctors to treat the dying as if they were curable. Natural death has not lost its meaning or significance. It may be deferred, but it need not be postponed indefinitely.' (62)

This concept of 'natural' death requires a great deal more working through, and clearly there is now no broad consensus about its meaning (63). It is widely held that most deaths are 'managed' or planned in some way (64). Rachels has challenged the whole concept of human agency and natural death, and ascribed underlying religious connotations to the drive to demonstrate an absence of human agency in so-called 'natural' deaths (65).

Conclusions

In all the three major parliamentary reports and the various superior court judgments considered in this review, on balance, the status quo has been maintained, but all rejected a narrow interpretation of the principle of the sanctity of life. The Canadian report appeared to entertain the possibility of allowing assisted suicide or euthanasia at some point in the future if data were provided to support such a move. The majority of senators on the Australian committee took a more conservative and categorical stance against any present or future allowing of euthanasia. In the USA, the Supreme Court has ruled out physician-assisted suicide, but the judgments have been interpreted as being less decisive than they appear.

For all the select committees, palliative care evidence was particularly important, and was acknowledged to have changed the point of departure for the Canadian committee's deliberations. Palliative care was therefore endorsed and

distinguished from euthanasia, albeit on a predicate that death may be hastened or caused by palliative interventions and treatment abatement. This is a right outcome in the sense of promoting better palliative care, but still sends the community and the professions a mixed message with regard to causation and responsibility for death in the care of people who are dying.

Both public opinion in favour of euthanasia, and increasingly frequent acts of civil (or rather criminal) disobedience will combine to exert continuing pressure on legislatures. New approaches are required, which ensure that shared values about how care is delivered and decisions are made move the debate away from narrow empiricism to an acknowledgment that death is not medical defeat but an inevitable consequence of living. Stopping or not initiating treatment aimed at cure for people who are dying should not bring into question the issue of responsibility for death. Medico-legal and ethical dialogue should focus public policy more on practical care and the differentiation of palliative care and euthanasia is an ongoing imperative. Clearly there needs to be more dialogue on the 'naturalness' of death and decision-making at the end of life. While the 'morphine-causation fallacy' in pain control is dealt with, attention is also required for sedation practices in terminal and palliative care, about which there appears to be very diverse and confused views, including within the health professions themselves (Cherny, unpublished).

There are limits to the capacity of empiricism to determine moral and ethical issues (66). It is noteworthy that the Canadian report responded to most of the topics they addressed by calling for guidelines and more information. Whilst this is hard to disagree with per se, it is contentious that the rightness or wrongness of an issue such as euthanasia, can be (exclusively or predominantly) determined by empirical data. Similarly, in law, exclusive reliance on empirical analysis of causality is limiting. A balance needs to be struck between empirical and normative considerations.

It is finally concluded that the enquiries and judgments considered in this paper have been very important for the status and future of palliative care, as the practical response to suffering during the dying process was not as widely understood as many who work in the area might have hoped, including amongst public policy makers, judges and parliamentarians.

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ABSTRACTS

Deakin University

Symposium

Causation in Law and Medicine

FRIDAY 26 NOVEMBER
TO SUNDAY 28 NOVEMBER, 1999

PROGRAM

ABSTRACT 4

Causation in Palliative Medicine

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Analysis of causation is central to any deliberative process which has as its object the determination of the moral character and legality of medical decisions or palliative interventions at the end of life, but there are semantic, evidential and argumentation difficulties which require elucidation.[1] Anxieties about responsibility for causing death, and questionable assumptions about law and ethics permeate practice and debate related to death and dying. Dialogue between medicine and the law is hampered by the fact that the term causation in medicine and science is usually employed in a narrow empirical sense, a term with a complex history[2], but taken here to mean the facts or data pertaining to a given situation, and their relationship to one another. However, in legal usage it encompasses the facts *and* determination of legal liability.[3] It can also be shown that in a number of jurisdictions which follow the English common law tradition (Australia, New Zealand, Canada, the USA, and of course, England and Wales), the reference case is still R v Adams.[4] Whilst the judgement of (later Lord) Devlin J is supportive of palliative care, and expresses double effect in law for the first time in this context, much has changed in medicine (and society) since the expert evidence which would have informed that judgment in 1957.
The hospice and palliative care movement has driven fundamental change in care and decision-making at the end of life, and the assumption that the (appropriate and proportionate) use of opioid drugs (usually morphine and heroin) in pain relief is life-shortening has been shown, in nearly four decades of international clinical experience, to be flawed and inflated.

Modern palliative care practice standards are based on the notion that death is natural in the sense of being a universal and unavoidable consequence of having life, and that interventions or abatement decisions should neither hasten nor prolong the dying process. The intention is to relieve symptoms and suffering, not bring forward the time of death. Whilst this is sustainable in the palliative phase, it is susceptible to challenge in the terminal phase, when death is imminent (hours or days away).[5] It is acknowledged that as death approaches, abatement of life-sustaining treatment and terminal sedation may

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[1] See Ashby (1-3)
[2] See Raymond Williams' invaluable book "Key words: a vocabulary of culture and society" Revised Edition. New York: Oxford University Press, 1985, pp 115-117, for an account of the various meanings of empirical, and pp 219-224 for nature, see below.
[3] Mendelson D. Torts. Butterworths, 1997.
[4] R v Adams. [1957] Crim LR 365.
[5] For a description of these three phases of illness and goals of care: curative, palliative and terminal, see Ashby and Stoffell, 1991.(4)

indeed alter the time of death, although this matter cannot be verified scientifically, one way or the other, in a particular case, or in general.

There is almost universal support for the relief of pain and suffering, and avoidance of prolongation of the process of the process of dying. Public policy and the law has, without known exception, endorsed these common sense principles. There is also wide support for the cessation of life-sustaining measures in certain non-dying persons, where it is clear that the intention is to bring about death, as for instance those in a permanent and irreversible coma, or the persistent vegetative state, such as in the case of Anthony Bland[6]. However, there is deep division in societies about whether assisted suicide and euthanasia[7] should be made legal, and the fundamental question is causal. Those who advocate such changes often cite accepted palliative care practice in support of their position, on causal and consequentialist grounds. The line of argument runs something like this: "if you agree with the administration of opioids and sedatives, or treatment abatement which even have the *potential* to alter the timing, *and therefore the cause*, of death, how could you disagree with the administration of a lethal injection which has the expressed intention of causing death?".

It will be concluded that narrow empirical causality,[8] applied in the setting of terminal care, cannot alone account for the distinction between accepted palliative care practice and euthanasia. It is both false and unhelpful if appropriate and skilfully administered and monitored pain and symptom relief, together with the abatement of futile treatment in the context of a person's dying process, are seen as causing death. Self-willed and planned death, with or without third party assistance, surely has better arguments in its favour anyway.

In the experience of caring and being cared for, both intention and honesty are decisive. Palliative care must be clear about its intentions, and accept that there are some occasions when the process of death is hastened, either unknowingly or knowingly.[9] Far from subverting its practice, this acknowledgement might liberate it from wider claims of ambiguity on causal issues. No matter what one's view of euthanasia, it is important to unpack what is meant by the term natural death, which, it is argued, should move away from almost exclusive focus on human agency in death causation, crucially important thought this is, and embrace non-obstruction of the dying process and self determination as well.[10]

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[6] Airedale NHS Trust v Bland . [1993] All ER 821.

[7] Defined by the peak body Palliative Care Australia as "the deliberate action to terminate life by someone other than, and at the request of, the patient concerned" 1995.

[8] For a useful discussion of causation in end of life decision-making, see Keyserlingk, writing on *Rodriguez*. Causality is divided into three categories. Standard causality entails the characterisation of treatments (eg ordinary v extraordinary) in order to allow abatement. Cause of death is usually ascribed to the underling disease rather than the decision or intervention in question. But-for or empirical causality relies on the scientific cause. Normative causality allows a more comprehensive analysis including normative considerations and empirical data. (5)

[9] See Jessica Corner (6)

[10] See Stoffell and Ashby (7)

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ABSTRACT 5

Principles and Values Underlying the Concept of Causation in Law

Author: Professor Tony Honore, All Souls College, Oxford, United Kingdom

No values underlie the concept of causation in law as such. Causation is a general category employed in every sort of inquiry into the world around us. With its help we can find
out enough about the external world to survive in it.

The values underlying the concept of causation are objectivity, regularity and the possibility of cognition. To establish causal connection between events, however, presents greater difficulty in the organic (including the medical) sphere than in the inorganic, purely physical, owing to the greater complexity of organic processes.

The concept of causation is used as one of the bases of responsibility. It is in fact central to the basic type of responsibility that we have for our conduct and its
outcome. The values underlying the concept of responsibility are that it encourages good conduct and good outcomes of conduct and promotes a sense of one's own personal identity and that of others.

Law makes people in certain cases not merely responsible but liable to punishment or to pay damages for the outcome of their conduct and in particular for the harm they cause. When it does this the principle of corrective justice by which wrongdoers ought to make good the harm they have done to others is limited by legal values that depend on fairness to the wrongdoer. These aspects of fairness include (a) the requirement of notice (b) the

PARLIAMENTARY COMMITTEES
SUBMISSIONS AND REPORTS

APPENDIX 14

HOUSE OF ASSEMBLY

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**SELECT COMMITTEE
ON THE
LAW AND PRACTICE RELATING TO
DEATH AND DYING**

19 September 1991

Dr Michael A Ashby
Director of Palliative Medicine
Royal Adelaide Hospital'
North Terrace
ADELAIDE 5000

Dear Dr Ashby,

Enclosed is a copy of the evidence given by you to the Select Committee. Please make any grammatical alterations that may be necessary. However, you may not alter the evidence actually given. Please make any alterations in ink and do not obliterate the text.

The evidence should be returned as soon as possible, addressed to the Secretary of the Committee.

Should you wish to give any additional information please write to the Chairman of the Committee at Parliament House.

Thank you for your assistance to the Committee.

Yours sincerely

Anthony Murphy
SECRETARY TO THE COMMITTEE
PARLIAMENTARY OFFICER

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SELECT COMMITTEE ON THE LAW AND PRACTICE RELATING TO DEATH AND DYING

Minutes of Evidence,
Monday 9 September 1991 at 9.20 a.m.
at Parliament House, Adelaide

Present:

Hon. D.J. Hopgood, M.P. (Chairman)
Hon. Jennifer Cashmore, M.P.
Hon. B.C. Eastick, M.P.
Mr M.J. Atkinson, M.P.
Mr M.J. Evans, M.P.
Mr V.S. Heron, M.P.
Mrs D.C. Kotz, M.P.

Dr MICHAEL ANTHONY ASHBY, Director of Palliative Medicine, Royal Adelaide Hospital, North Terrace, Adelaide, 5000, recalled and further examined.

768 THE CHAIRMAN: Welcome to the select committee. You are no stranger to us, of course, because of your willingness to assist us wherever possible, for which we are very grateful. Please present your submission?---It is generally accepted that the management of pain (from all causes) has been an area of neglect until relatively recently (Melzack, The Tragedy of Needless Pain, Scientific American, 1990). Contrary to popular belief, the author says that morphine taken solely to control pain is not addictive, yet patients world wide continue to be undertreated and to suffer unnecessary agony.

Considerable efforts are under way to improve education and, hence, practice in the medical and other health care professions. South Australia has taken a leading role in this process, both locally and internationally (Pilowsky, An Outline Curriculum on Pain for Medical Schools, (Editorial) Pain 1988; and Loeser and Cousins, Contemporary Pain Management, Medical Journal of Australia 1990). Members of the committee will, no doubt, be aware of Professor Cousins, who recently left this State for the Royal North Shore Hospital in Sydney. That paper summarises issues in modern pain management. An important Australian document is the National Health and Medical Research Council (NH&MRC) report on the management of severe pain. Much of the work was done here in South Australia.

Cancer pain has been particularly problematical, and it is acknowledged that much remains to be done to improve the palliative care of patients with advanced incurable cancer pain (Stjernsward and Teoh, 1989). Dr Stjernsward is chief of the World Health Organisation (WHO) cancer and palliative care

unit in Geneva, and will visit Australia from 5 to 11 April 1992 during National Hospice Awareness Week. That will be a very useful event to address issues of public policy and palliative care in Australia, with him present on behalf of the WHO.

Although the main thrust of the WHO campaign for improved cancer pain control has been directed towards developing countries, it is clear that there are still major deficiencies in pain control and palliative care in all countries, for which policies are being developed (WHO Policy Statement on Palliative Cancer Care 1987; Griffin, Dying with Dignity, Office of Health Economics, London, 1991; and King Edward's Hospital Fund for London and National Association of Health Authorities, United Kingdom, 1987). These are all good examples of strategies that have been proposed and either partially or completely adopted.

This is certainly the case in Australia, despite the considerable recent progress and education initiatives. Most of those working in palliative care and pain units recognise that the process of change is slow because the main obstacles lie in the attitudes and myths surrounding the ethical basis of palliative care and the limitations of the curative medical model when addressing palliative care issues (Ashby and Stoffell, Therapeutic Ratio and Defined Phases: Proposal of Ethical Framework for Palliative Care, British Medical Journal, 1991). Pain is the most common symptom that afflicts patients referred for palliative care. The following table shows the commonest symptoms in advanced cancer patients from St Christopher's Hospice, a study done in 1990 on 647 patients.

Table 6 **Commonest symptoms in advanced cancer: St Christopher's Hospice 1979 (n = 647)**

Symptom	*Percentage*
Pain	69.5
Anorexia	64.75
Weight Loss	59.25
Weakness	49.0
Constipation	45.5
Dyspnoea	42.0
Nausea/Vomiting	36.75
Oedema/Effusion	30.75
Cough	29.0
Insomnia	27.0

Source: Walsh and Saunders, 1984.

The table shows that for nearly 70 per cent pain is a major issue; thereafter, it is anorexia, weight loss and weakness, constipation, shortness of breath, nausea/vomiting, oedema/effusion - that is, collections of fluid - cough and sleep disturbance.

769 THE HON. JENNIFER CASHMORE: Was that the rating system of patients themselves or of the medical profession in diagnosis? Is this how patients rated the severity of their symptoms?---No, these are the issues as perceived by the medical and nursing staff of St Christopher's Hospice. There is no scoring here: these are just problems as presented to the staff. They were issues in medical and nursing management. Other studies address the field to which you allude.

770 Do the other studies that look at it through the perspective of the patient differ very much in their outcomes from the perspective of the medical profession, in terms of percentage ratings?---Not in terms of issues. You would get a very similar list to this in publications that look at it from the patient's perspective. What differs is the reporting of the intensity of pain, but the issues are fairly consistent and, in most studies, what you find is that, if the pain issues are not addressed, it is very difficult even to evaluate the others. Pain is really a very dominant problem in palliative care, as one might expect.

771 THE HON. B.C. EASTICK: If one were to conduct an examination of patients generally in a hospital without the word 'cancer' involved, in a number of cases some of those factors would appear - and I am thinking of the person who goes down with a kidney stone or a gall bladder problem, pancreatitis and things of that nature - and would rate as pain, although for a shorter time, I take it?---Yes, what you say has a lot of validity. These are not just issues for the care of cancer patients. We can look at other common chronic and debilitating illnesses, afflictions such as dementia and dementing illnesses. I attended a seminar at Hillcrest Hospital recently, talking to the carers of demented people. We agreed that there was much commonality between the symptoms of a cancer patient and those of a demented patient. There are many overlaps with general care. These are not issues for cancer patients alone.

772 The very big difference as far as cancer is concerned would be the time over which the pain applied, although dementia is possibly the same?---Yes. Cancer pain control has been taught by the WHO using its analgesic ladder. This ladder is in some of the reference materials and books you have before you. The WHO analgesic ladder consists of three steps, mild, moderate and severe pain, for which a non-opioid, weak opioid and strong opioid drug is indicated sequentially and sometimes additively.

773 THE HON. JENNIFER CASHMORE: Will you define opioid and non-opioid?

---The opioids class of drugs is best exemplified by the drug morphine and a number of other drugs from that family which have similar effects in the body. For example, non-opioid drugs used for cancer pain are paracetamol and aspirin. Some examples of weak opioid drugs are codeine and oxycodone. New approaches are focusing more on pain mechanisms and the appropriate choice of drug class to match the mechanisms operative in a given patient at a given time.

774 THE HON. JENNIFER CASHMORE: What does the word 'adjuvant' mean?---Adjuvant refers to a drug that acts to help the main drug overcome the pain. The main drugs are paracetamol and aspirin in mild pain, codeine and oxycodone in the second step, and morphine in the third step, for severe pain.

774A What might be the chemical composition of an adjuvant?---It might well be a drug such as an antidepressant or an anxiolytic; a drug that relieves anxiety. It may be a benzodiazepam, one of the drugs that may well alter the pain threshhold perception in the brain. I dispute that term, and we are doing some work which may lead to us challenging the notion that these are truly adjuvant drugs.

775 THE CHAIRMAN: Does the plus and minus on the graph mean that there is an option?---Yes, there is an option. In our service we do not use the second step very often. We discourage the use of codeine and oxycodone because we find that they have high side effect profiles and limitations in terms of the doses that can be given. That is something that we do not find with morphine, and I will explain more about that later.

776 THE HON. JENNIFER CASHMORE: You say 'we'. I take it that means the hospice service that you are working in, and does not necessarily refer to South Australia or Australia? Is there much debate about limiting the second step in medical circles?---There is a bit of debate, but I think that most services are heading in the same direction. We were by no means being eccentric in this practice.

776A Are you referring to most services in South Australia or Australia?---I mean that, internationally in the hospice and palliative care movement, you will not find any support for the use of codeine, oxycodone and other drugs of that class, but there are a few individuals in a few services who advocate their use. The reason that they will remain in the armamentarium for the forseeable future is that in the third world many countries do not have access to morphine, but they may have access to codeine-like drugs. Therefore, to put up an international model that does not include that step would leave them rather in the cold. For the purposes of international teaching the step remains, but we believe that it has limitations. The drug classes used here, analgesics or adjutants (and I am not sure that I really differentiate between them) are drugs that we might

use for cancer pain. First of all there are the opioids of the weak or strong class. There is even some debate as to whether that distinction is a true one, but we regard the opioid of our choice as morphine administered orally, subcutaneously or intramuscularly.

777 THE HON. JENNIFER CASHMORE: When you refer to opioid morphine, do you mean that the difference between strong and weak is simply a diluted morphine or is it some other drug?---No, they are different drugs. Morphine is a strong opioid; codeine is a weak opioid.

778 MR HERON: When you say that morphine can be taken orally and in two other ways, what is the real difference? Must a certain patient take it in a certain way?---The World Health Organisation's approach to cancer pain control proposes as the first line route the oral route in all circumstances where the patient can swallow, or where they are not nauseated or vomiting. There may be times when patients cannot mechanically swallow because they may have an obstruction to the oesophagus, but otherwise the oral route is the first route that we use for all the medications.

No matter where the cancer is?---That is correct. Provided the patient can swallow, and provided that they are not nauseated, we would recommend starting on oral medications. This slide shows some of the drug classes that might be used in cancer pain: opioids, anti-inflammatory drugs both steroidal and non-steroidal, local anaesthetics, tricyclics, antidepressants, anticonvulsants, antispasmodics and anti-olitics. anxiolytics

779 THE HON JENNIFER CASHMORE: Is there any taste or odour that is unpleasant?---Some preparations can have an unpleasant taste, and pharmacists usually make an individualised effort to make up a solution that the patient finds acceptable.

779A Is it always in liquid form and, if it is liquid, what sort of liquid is it? Is it an oily liquid or a watery liquid?---Is depends on the basis the pharmacist makes up. Chloroform water has been the most popular basis. In the past there was a vogue of adding alcohol, which was part of the so-called Brompton Cocktail, and which has now been consigned to the history books. Some patients do not like either the taste or the idea of a mixture, and some patients find that taking a mixture every four hours triggers nausea. Patients on a stable dose of morphine are usually converted to slow release morphine tablets. This drug has just become available in Australia. It was put on the NHS under the PBS scheme in Australia. It is now available to the public and nearly all public hospitals in South Australia but, unfortunately, not in my hospital at the present time. This drug is taken twice a day in tablet form. I am sure that you can appreciate that it can offer very significant advantages in terms of patient convenience and acceptability.

780 THE HON. B.C. EASTICK: It is an early form of depot treatment. Is there any injectable depot treatment that is currently used by cancer patients?

(Continued on page 454)

---No, not at present, although that avenue could be considered in future research.

781 THE HON. B.C. EASTICK: Does the term 'depo' refer to pain being relieved over a protracted period, sometimes days, weeks or months?---The problem with cancer is that it must be treated with a fixed dose. If there were an escalation of the need for depo injections one week into a one month period, big problems could occur in terms of flexibility. Colleagues in Canada are considering a patch which is put on the skin and which utilises the transdermal route to administer a drug called fentanyl. Indeed, that is a marketable product in Northern America.

Most patients with advanced cancer pain will require opioid analgesia, and presently morphine is the chosen opioid in most palliative care programs. This has been a major contribution of the pioneer British Hospice and Palliative Care Movement. Details are well outlined in the work Twycross and Lack, 'Therapeutics in Terminal Cancer', 1984. Dr Hopgood, you have a copy of a book about morphine, which is written in question and answer style. Those questions and answers are also contained in the book, should members of the commitee wish to refer to them.

The book 'Cancer Pain Relief', which was written by the World Health Organistion, summarises the practical and policy aspects of cancer pain relief. Those books are worth looking at. Nearly everything I have said this morning is contained in these books. The areas of pharmacology and the discussion of opioids and their role in cancer and non-cancer pain relief are well covered by two British reviewers: Hanks and Hoskin 'Opioid Analgesics in the Management of Pain in Patients with Cancer - a Review'; and by McQuay 'Opioids in Chronic Cancer Pain', British Journal of Anaesth, 1989. Those works are referenced in the paper. For anyone wishing to look more at the basic pharmacology aspect, it is all explained in those papers.

Despite all the above experience and knowledge, one of the major impediments to effective pain control remains the wide-spread professional and public fear of addiction, habituation and side effects of morphine and the opioid class of drugs. Both Doyle and Zenz spoke at the First Asian Pacific Symposium on Pain Control in Sydney in February 1991. The reference 'Morphine Mythology, Morals and Money' by Dr Doyle, of St Columba's Hopsice, Boswell Road, Edinburgh, United Kingdom, states:

(Statement follows on page 454A)

DEATH & DYING pharmacodynamics M.A. ASHBY

By way of explanation, ~~pharmacology~~ looks at what a drug does when it arrives at its target receptor in the body, where it will do its job and where it will produce the effects, both beneficial and unwanted. Pharmacokinetics is the science of looking at how the drug gets there from its route of entry into the body until it reaches the target site, which can sometimes be very complex. The term 'parenteral' refers to all routes that are not oral.

Many of the issues raised by Doyle and Zenz are addressed in the paper 'Controversies in Cancer Pain: Medical Perspectives' by Kathleen Foley of ~~the cancer centre~~ Sloan Kettering Memorial Cancer Centre in New York who is an associate Professor at Cornell University and who is one of the leading advocates of good cancer pain control. Zenz, from Bochum in Germany, says:

(Statement follows on page 456)

(Continued on page 457)

(THE WITNESS continuing):

Zenz perhaps understates the side effects, which are problematical but manageable for many patients, but which may be unacceptable to some. Progress in this area may be reasonably expected from current research endeavours.

The main side effects of morphine are: first, with respect to the central nervous system: drowsiness, confusion, hallucinations, disturbed dreams and respiratory depression; secondly, with respect to the gastrointestinal tract: nausea and vomiting, and constipation. Itching, sweating, urinary disturbances and a dry mouth are occasionally reported. Most of these side effects are either transient, mild and tolerable, or amenable to preventative measures.

The fear of life-shortening, that the use of morphine for cancer pain may be a form of active euthanasia, is discussed and dismissed by Foley. The presence of pain appears to act as a counterbalance to both psychological addiction and side effects. That is an important concept, it is also a difficult one to document, but there is a lot of clinical evidence to support that statement. There does not appear to be an upper dose limit for morphine, and the dose required to control pain varies. Some patients do require very high doses for various reasons.

The next overhead is taken from the question and answer section in 'Therapeutics in Terminal Cancer' and 'Oral Morphine in Advanced Cancer', both by Twycross. The question is asked: why do some people need more morphine than others? There are differences in pain intensity. Sometimes other drugs will modify the way morphine is handled by the body. There may be individual variations in how we absorb drugs, how the liver metabolises the drug, how long the drug lasts in the bloodstream, the age of the patient, the patient's nutritional status, differences in the pain tolerance threshold, previously induced tolerance, and a number of other reasons that I will not go into now.

Is oral morphine really effective? The answer is 'Yes'. Oral morphine, given with a sulphate or hydrochloride base, has been used in four hourly doses ranging from as little as 2.5 mg to 1200 mg. Published data shows that the median dose is in the range of 15 mg four hourly and that few patients need more than 100 mg in four hourly doses, although some do. Patients, whose pain is poorly controlled on 100 mg four hourly doses, may sometimes obtain benefits at higher doses. whilst dose requirements may increase during the course of a terminal illness, there is no real substance to the notion that starting morphine prematurely leads to an inability to control pain before death. Despite overwhelming clinical evidence that morphine used appropriately for cancer pain is safe and

effective, there is still entrenched professional and public reservation about its use. As a result, far too many patients are deprived of the chance of optimal pain relief. A sustained educational and research effort is required to maintain and improve what has already been achieved.

That concludes my prepared submission. I have one further overhead on the classification of the different types of cancer pain, which I will leave to one side unless requested to present it.

782 THE CHAIRMAN: The nub of what the committee is interested in this morning is any suggestion that drug usage might hasten death. In short, the piece to which you referred is about pain management in the form of euthanasia. With respect to the Foley piece, which I have had a chance to quickly peruse, although emotionally I am on her side, I find what she says less than altogether convincing. On page 2258, under the heading 'Is pain management a form of euthanasia?', she says:

> Treatment of pain is never a form of euthanasia. Its intent, its goal, and the conditions in which physicians and patients interact are directed to the management of symptoms. More detailed discussions on this topic are beyond the scope of this report, but such a dialogue is critical if we are to educate both patients and health care professionals in clear differences between pain management and euthanasia.

Foley seems to be saying that there is a clear difference in intent, and there may be no argument about that, but I am interested in the difference in outcome.

(Continued on page 459)

---This probably leads us back to what I said about there being a balance between side-effects, psychological addiction and pain. It seems that different people require a different dose of morphine, as we have just said, to balance against their pain. Provided that the drug is being taken for pain, and provided that the correct dose has been found, there are neither overwhelming nor dangerous side-effects, nor is there any documented evidence of addiction; therefore any notion of causing death by opioid analgesics used in correct dosage and correct dose stepped up schedules for cancer patients is lacking.

There is no evidence for believing that morphine is causing the premature death of patients. However, it is an impossible study to undertake. How long would a cancer patient have lived had he or she been allowed to continue in pain without any form of opioid analgesia or any form of pain relief or, perhaps, with an alternative form of pain relief that might not be as effective? All of us who work in the area of cancer medicine would say that our observations lead us to conclude that a death may be more hasty if a patient is in overwhelming pain, and we have seen people who have presented in very severe pain who have had that pain controlled and have been able to go away and live for many weeks or months in comfort, without there being any issues of overwhelming side-effects of addiction.

However, some of our patients definitely have very severe side-effect profiles and, just as I do not think we should say to you that we can relieve all pain, because we cannot, equally, some of our patients have very big problems with side-effects, and that is a major area of focus of drug research in this area of medicine over the next few years.

783 THE CHAIRMAN: In the questions and answers are a couple of other references on which we should invite you to comment. The first is No. 33: 'Do patients die of morphine-induced respiratory depression?' There is a warning against what is called blunderbuss or shotgun therapy, and it goes on to say:

> We have seen patients whose death was possibly precipitated by an excessive initial dose of morphine.

Then there is No. 54: 'Don't patients die quickly once morphine has been prescribed?' It says:

> Whether the patient dies in a short time depends on at what stage morphine therapy is started. Circumstantial evidence suggests that many patients survive for a longer period because they are able to rest, sleep and eat more and take a renewed interest in life ... On the other hand, giving morphine to a patient totally exhausted by unrelieved pain and insomnia, especially if elderly, may lead to pneumonia consequent upon a combination of somnolence and cough suppressants when used in the way described in this guide. However, the risk is very small.

Will you comment on either of those?---No, I think that you have pulled out quite nicely from this question and answer technique used in this book some of the major anxieties patients and doctors may have. Certainly, we would not want to promote the idea that we are producing for you a generation of doctors who will be reckless with the use of opioid analgesics, because, like all classes of drugs, unquestionably they have their dangers.

The initial dose for a patient who has not received any morphine or other opioid class drug before has to be judged with some caution. Equally, we would not want to see those people who have respiratory failure, particularly people with exacerbations of chronic bronchitis and emphysema (a common chest condition in Australia), given large initial doses of opioid drugs. They could be quite dangerous in those circumstances. As with all these things, clinical judgment and care are essential, and the dose must be tailored to the individual clinical situation.

With regard to the other issue of patients possibly living longer in greater comfort when their pain is relieved, that is a statement I believe to be intuitively correct but not a study that is easily done, as patients would have to act as their own controls, in a sense. There is a lot of circumstantial evidence to show that they are not life-shortening.

(Continued on page 461)

(THE WITNESS continuing):

784 THE HON. B.C. EASTICK: In the documentation that you provided to us this morning, it talks about non-morphine responsiveness. To what degree, if at all, is that a personal idiosyncracy as opposed to an outright non-morphine responsiveness? Certainly, when it comes to species, there are some very major differences, but within individual species you sometimes obtain a variation of effect of the same pharmacological product. To what degree is that a problem in pain maintenance or pain palliative care?---I think that it is a potentially fruitful avenue to look at in our future research. Professor Bochum at the University of South Australia has done some interesting work that suggests that about one in 10 of the population may be unable to metabolise codeine. Codeine is what is known as a pro drug, that is, it is converted in the body to morphine, which is another reason why we do not recommend its use. If you want to give morphine, why not give it instead of going around the houses to use a pro drug? Professor Bochum has shown the way people fail to metabolise the drug. I wonder whether there are not also some effects of drug metabolism with morphine which we do not yet understand, and which may be variable from one individual to another and may be genetically determined. I think that there is still a lot of work to do in that area.

The subject of non-opioid responsiveness leads me to the slide I now show you concerning cancer pain mechanism. It is a very technical graph and is included in the document called Research Protocol. Please do not attempt to take all the information in at first hearing because it is very complicated. I think that it is fairly widely agreed that cancer pain is not just one entity. Cancers can spread to many parts of the body and produce pain by a large variety of mechanisms. There are two fundamental groups or types of pain: first, the so-called nociceptive pain, meaning a harmful or painful stimulus such as a cancer deposit in a bone, the liver or wherever; secondly, neurogenic pain, which is produced as a result of damage to the nervous system. Cancers, and sometimes their treatment, can lead to such damage. For instance, we know that tumours in the head, neck, pelvis or chest wall can grow into the nerves as well as the muscles, other adjacent organs, and part of the body lining. We believe that tumour growth into those structures leads to the production of pain by these mechanisms. Therefore, the principal subdivisions are nociceptive and neurogenic. Nociceptive pain refers to a normal, unattacked nervous system. Neurogenic pain tells us that the tumour has damaged the telephone network in the body. When the nerves are damaged, pain is produced. One group of patients on the graph represents our most difficult group of patients with whom we can achieve satisfactory pain control. We usually give them a trial of morphine and we often have to add other drugs such as steroids if we think there is an inflammatory component, or if we think there is a non-steroid component, we may add anticonvulsant drugs for shooting or lancinating pain as a result of spinal cord or other nervous pathway damage.

Antidepressants and anxiolytic drugs may also be required. Incidentally, nerve damage pain also has a lot in common with so-called phantom pain when a limb has been cut off, and it receives messages through the nervous system which are perceived in the brain. There is a lot that we do not understand about that.

When you look at nociceptive pain in different parts of the body you find two principal groups: somatic and visceral pain. Visceral pain comes from structures deep within the body such as large tumour masses placed deep in the body cavity, the intestines, the bile duct or the urinary tract. Someone earlier talked about urinary stones. The pain from a stone in your ureter going from the kidney to the bladder can be excruciating, and is known as visceral pain. Its wiring is different from somatic and more superficial pain, and we treat them entirely differently. We would also use an opioid drug for the pain of passing a urinary stone, and it responds very well to that. It does not respond at all to anti-inflammatory drugs, which would be our first line for superficial pain from, for example, a malignant ulcer of the skin or the mucosa of the mouth. Likewise, with the spread of cancer to the skeleton, called bone metastases, which is a very common situation and probably our most common subgroup of cancer pain patients, we would tend to use an anti-inflammatory drug as the first line drug and then add in an opioid drug if complete relief is not achieved with the anti-inflammatory. Radiotherapy is particularly useful for bone metastases and for malignant ulcers on the skin. They are not usually quite so effective for nerve damage pain, so now we are looking at a much more sophisticated model for cancer pain mechanism rather than saying that cancer pain is one type. We approach it in steps from one to three as on a ladder. Consequently, the group which might be referred to as pain that is poorly responsive to morphine in the opioids class of drugs is very often the nerve damage group. They are always said to be the ones that had pain which did not respond very well to morphine. That may be the case, but there is now increasing evidence that you should always try the opioid drugs and see the responses. Some people respond well.

(Continued on page 463)

(THE WITNESS continuing):

Having started with a simple model of cancer pain, we are now making life more complicated and difficult for ourselves. We are of the belief that it is a matter of horses for courses: that there is the right drug for the right mechanism. That is why I tend to reject the term adjuvant drug; I think many of those drugs have specific roles for specific mechanisms.

785 THE HON. B.C. EASTICK: It is important for us to continue research into the area of phantom pains. You have highlighted yet another area where the long-term palliative, hospice and medical approach to this whole matter does require assistance to fine tune and to eliminate some of the unknowns that currently exist within pharmacological treatment?---I think it is a potentially fruitful area of research. A good track record exists in matching drugs to mechanisms and in the better understanding of mechanisms. There is also a good track record in taking existing drugs and modifying their structures and profiles and their routes of administration to reduce side effects. An international effort is being undertaken to try to improve cancer pain and symptom control in general. I am sure that money spent in this area will be spent well because results will occur.

786 Antihistamines, when used to treat high fevers and so on, can have a completely different effect from one individual to another: they can send one individual into a deep sleep whilst they can cause another to have a high.

787 MR HERON: On the second page of your paper you state that the area of pain control caused widespread fear, both professionally and publicly, because of problems associated with drug addiction. Do some professional people not want to give morphine over the recommended 15 milligram dose because of that fear?---Yes, it is a fear. That indicates to me just how strongly implanted teaching in a medical school or training of any sort can become and how difficult it is to change once that message has been implemented, rightly or wrongly. It is a cohort effect. It is a gradual change that one will bring about in medical education, and it will not go away overnight.

Many of my colleagues, particularly the senior ones, went through medical schools when the world had a different view of opioid or narcotic analgesics and did not know how to use them properly. The area of cancer pain had not been focused on or looked at properly. One needs to have more than a few lectures or journal articles because they do not seem to be the most effective way to change the attitudes when these attitudes are deeply rooted. The best way to change those attitudes is with clinical experience. A doctor may refer a patient to me and say that either the dose of the opioids that the patient was on when he or she was referred is the problem

and, when the correct dose is given in the correct way, that patient will be happy; that can often be a better learning experience than any number of lectures or papers.

788 MR HERON: Is an upper dosage limit of morphine imposed on someone who is terminally ill, given that the idea is to get rid of pain?---Yes, obviously the dose is important. In fact, the initial starting dose is particularly important, and schedules now have been drafted for increasing the dose of the drug safely and effectively. Making doctors and the patients comfortable with using those dose calculation schedules is one of the fundamental factors of good cancer pain control.

I want to dismiss forever the myth that there is an upper safe dose limit. Because of variations in the intensity of pain, increases in pain during the course of a terminal illness and quite substantial differences between individuals in terms of the way they handle the drug when they take it, that is, how their bodies metabolise and process the drug, a big difference will occur in the number of milligrams of morphine that has to be prescribed over a period.

Some people will be able to tolerate high doses in numerical terms and, when that limit is reached safely, no problem will occur in relation to addiction, the shortening of life or side effects such as those I mentioned earlier. So, the removal of the idea of an upper dose limit is one of the fundamental educational aspects that we must address. The dose required is one that will safely abolish or substantially relieve pain.

789 THE HON. JENNIFER CASHMORE: When you were speaking to Doyle's paper, you said that morphine could be used to enable patients to be discharged from hospital and that they could lead useful lives. I think most people - including me - would be amazed to think that one could take morphine and still continue with employment or what we might describe as a normal life. In how many cases would that be possible, and over what period could a patient self-administer morphine to control pain and still maintain what we might describe as a normal or near normal lifestyle? In what circumstances would that be prescribed?---My colleagues who work in the chronic non-cancer pain field will say that it is possible for their patients to live many months - and indeed in some cases many years - on opioid analgesia. Some of my cancer patients end up having a more favourable outlook after referral to the program than was initially thought to be the case. Some of my patients have lived for years. A significant number have lived many months more than was expected.

However, from my perspective as a hospice and palliative care doctor, I deal predominantly with patients in the last few weeks of their life. I do not want to oversell the results of what I do because some of the patients are sick

and they remain that way. It is the downhill progress of the natural course of the disease that tends to influence so much of the patients daily life. However, by substantially reducing or abolishing the patient's pain with the help of my team I am able to contribute to a significant improvement in the quality of the patient's life. However, I do not project that as a return to normal living.

(Continued on page 466)

(THE WITNESS continuing):

While the other factors in the situation are static - a disease might go into remission unexpectedly or a patient with a disease in the earlier stages might require pain relief over a long period of time - you may well see people functioning reasonably normally on quite a high dose months or years after starting regular morphine use. Indeed, one of my patients has recently completed an overseas trip. This patient is severely disabled, but has static and good pain control on a dose of about 500mg of morphine a day in a syringe driver. That dose was recently converted to the MS content tablets at a dose of 700mg twice a day. One would not know that this person is taking an opioid analgesic. It is clearly documented that that person needed to be on the dose stated. It is a very large dose, but it has been static over many months.

790 THE HON. JENNIFER CASHMORE: The dose is 700mg twice a day?---Yes. The disparity between doses is because three times as much morphine is needed to be taken orally as when it is going in subcutaneously. There is a factor of three conversion because of the way the body handles the drug.

791 THE HON. B.C. EASTICK: Certainly, a patient would get a return to family life if not normal life?---Yes. For this person, in a sense, life has returned to normal in terms of what is possible within the context of the disease. The pain is no longer the major influence, neither is the dose of morphine: the morphine is relieving the pain but the dose is not causing any obvious deleterious effects to that person's quality of life - it is very stable.

792 THE HON. JENNIFER CASHMORE: A few years ago, the debate in Australia in terms of pain relief - certainly at the Ministry of Health level - was about promoting the use of heroin. Is that debate still going on; what is the relationship between heroin and morhpine; is morphine a narcotic drug in the same category as heroin, and has heroin become irrelevant in terms of pain control because of advanced knowledge in the use of morphine?---The two drugs come from the same family. Heroin, the pharmacological name of which is diamorphine, is converted to morphine in the body. The debate was certainly on. I think that one of the leading protagonists was Max Harris, who, every year, used to write a very angry column in The Australian saying how bad pain control was and that Australian doctors should grapple with the issues and sort them out.

One of the things that Max Harris has said on more than one occasion is that the unavailability of heroin in Australia is a major obstacle to proper pain control. I do not believe that to be the case, nor do the vast majority of doctors practising in this area in Australia or elsewhere. When I was training in the UK, and it still is the case, diamorphine was

available. There is some evidence to suggest that it has a greater effect on the brain when initially taken and that it produces more euphoria, but there is no evidence to suggest that it is superior in terms of pain control. One of its great advantages is its solubility. When high doses of an opioid are required, certainly in Britain we used diamorphine often because of its solubility factor. The drug can be put into a smaller volume of fluid for injection or for use in syringe drivers - it is a matter of convenience.

I do not know that anyone has ever done a randomised trial on diamorphine versus morphine, but it is the opinion of leading practitioners in this area that there is no substantial difference between the two drugs in terms of cancer pain control. I do not think that any professional in Australia in this area would campaign for the availability of heroin. Morphine is perfectly adequate, and it does the job very well.

793 THE CHAIRMAN: Members might like to look at page 27 of the Twycross ~~black~~ book which covers much the same territory.

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(Continued on page 468)

794 THE HON. JENNIFER CASHMORE: Would you say that it is extremely difficult for a patient or the family of a patient to identify the level of dosage required for a lethal dose of morphine?---Yes, I would say that it is extremely difficult because, when people are taking morphine or opioid analgesics regularly, the dose that would be required to bring about death through depression of the repiratory centre or other effects on the brain would be very difficult to judge and may be very high indeed.

795 THE CHAIRMAN: A strong element of advocacy comes through in your paper. It seems to me that you would be delighted if this committee were to make some recommendations that would encourage some of the breaking down of these prejudices about the use of opioids. To whom would we really be addressing ourselves? Do you discern that the prejudice, such as it is, is more or less entrenched in South Australia than elsewhere? Obviously, to a degree it is an international phenomenon: to what extent are we better or worse here, by your lights?---In South Australia we can take comfort from the fact that these myths are most, definitely not any more entrenched here than in any other State in Australia and almost any other country in the world.

Part of the problem is to do with medical education and a change in focus, and a genuine change in understanding of the way in which these drugs are used in cancer pain. That is a relatively modern phenomenon to do with the pioneering work of the British hospice and palliative care movement from the late 1960s onwards. The other factor is that, for all communities nearly everywhere in the world, drug addiction is a major social problem of the latter part of the 20th century, and is likely to remain so, unfortunately, for the foreseeable future.

It is quite understandable, therefore, that people in the community would find it very difficult to tease apart issues of drug addiction and using the same drugs for specific medical purposes. Given those statements, the only way to achieve better pain control is by education over a period of time both for the professions and for the community. This will not be achieved overnight: it will need a concerted effort, probably over a decade or so.

796 Can I press a little more closely: what practical effect does this have on our capacity to run good palliative care programs? Are the number of people who accept the philosophy that you and others have put before us in relation to the use of opioids so thin on the ground that we have trouble from time to time in attracting to these programs people who would be comfortable with the philosophy of the program? Is it as bad as that? I am thinking in terms of how we word a recommendation at this point?---Are you referring to patient referrals or to doctors working in the area?

797 THE CHAIRMAN: Doctors working in the actual area?---There are many other factors that would put off many of my colleagues from working in the area, and there is nothing particularly medical about that. Many people would feel that doing the kind of job I do, dealing mainly with dying people in the last few weeks and months of life, is generally a very difficult area to work in, for very obvious reasons. That is a significant influence on recruitment to the area and, possibly, to the attitudes to working with dying people.

However, it is important for the future that all doctors, nurses and other health care professionals going into the community and to hospitals from the tertiary education system should feel comfortable with this area, particularly with cancer pain control, because it is my opinion that, whilst for the foreseeable future there will be a need for programs such as ours and for roles such as mine in the major teaching centres, it would be quite inappropriate in every way for me and for my palliative care colleagues to suggest that a clone of us is required to give coverage to the people of South Australia.

That is clearly inappropriate, even in the metropolitan area. In country areas, obviously, it is not appropriate to have palliative care specialists widely distributed throughout the State. What we have to do is to make sure that colleagues in hospital medicine, and particularly in general practice, are comfortable with the attitudinal and ethical aspects of palliative care and of the clinical skills to control cancer pain safely.

That requires an education program, which to my mind should be a major priority. Most programs could do with more resources to improve education. I referred earlier to the fact that I should like to arrange for every student in our medical school to meet the family of someone dying of advanced cancer, as well as the patient himself, in order to see first hand what happens and how the issues are dealt with. It is not something you can teach by taking 20 students on a ward round: it is far too sensitive for that.

We could not do that in our hospice nor in the community, but on a one-to-one basis we could. If we had more resources, in terms of teaching time, we would be able to do a lot more.

(Continued on page 470)

(THE WITNESS continuing):

I think that we could do a lot more at undergraduate level, and certainly at postgraduate level where all the programs in Adelaide are now involved in teaching young general practitioners in training. We also need to consolidate in that area. I think that education is a major priority, otherwise, if we were to have this conversation again in 20 years time, that would be a pity.

798 THE HON. B.C. EASTICK: I was particularly interested to hear you say 'the professions' quite deliberately to Dr Hopgood when he asked the first of those questions. I would identify the professions that I would see involved in that collective as being medicos: the pharmacologist and the pharmacist (because they help set public perceptions and do more harm or good than they are sometimes given credit for), and the nursing profession. Would you include any other professions apart from those four, or would you exclude any of them?---No, I think that is a very reasonable list. However, in a hospital community such as a large tertiary 'referral institution like the Royal Adelaide Hospital, it is important that everybody in the health care team is familiar with the attitudes and philosophies.

799 Would that include the social workers?---Yes, and the speech therapists and physiotherapists. It would include everyone who works in the team, because they will know what drugs the patient is taking and what the problems are. They will know about the patient's pain. They also need to feel comfortable with what is going on, not so much in a practical sense, but maybe in an ethical sense. It is a very big teaching exercise.

800 Would you agree that it is something to which we must give a great deal of attention in any final report?---Yes, certainly.

801 THE CHAIRMAN: Thank you for coming and giving evidence today.

THE WITNESS WITHDREW

THE COMMITTEE ADJOURNED

HOUSE OF ASSEMBLY, PARLIAMENT OF SOUTH AUSTRALIA

SELECT COMMITTEE ON THE LAW AND PRACTICE RELATING TO DEATH AND DYING

SUBMISSION ON PAIN CONTROL IN PALLIATIVE CARE

M.A.ASHBY MB BS, MRCP(UK), FRCR
Director of Palliative Medicine, Royal Adelaide Hospital.
Medical Director, Mary Potter Hospice, Calvary Hospital, North Adelaide.
Clinical Senior Lecturer, Department of Medicine, University of Adelaide.

It is generally accepted that the management of pain (from all causes) has been an area of neglect until relatively recently (Melzack 1990). There are now considerable efforts underway to improve education and hence practice, in the medical and other health care professions. South Australia has taken a leading role in this process, both locally and internationally (Pilowsky 1988, Loeser and Cousins 1990, NH&MRC 1988).

Cancer pain has been particularly problematical, and it is acknowledged that much remains to be done to improve the palliative care of patients with advanced incurable cancer pain (Stjernsward and Teoh 1989). (Dr Jan Stjernsward is Chief, WHO Cancer and Palliative Care Unit, Geneva, and visits Australia from April 5th-11th 1992 during National Hospice Awareness Week).

Although the main thrust of the WHO campaign for improved cancer pain control has been directed towards developing countries, it is clear that there are still major deficiencies in pain control and palliative care in all countries, for which policies are being developed (WHO Policy statement 1987, Griffin 1991, NAHA 1987). This is certainly the case in Australia, despite considerable recent progress and education initiatives. Most of those working in palliative care and pain units recognise that the process of change is slow because the main obstacles lie in attitudes and myths surrounding the ethical basis of palliative care, and the limitations of the curative medical model when addressing palliative care issues (Ashby and Stoffell 1991).

Pain is the most common symptom which afflicts patients referred for palliative care (overhead). Cancer pain control has been taught by WHO using the WHO analgesic ladder (overhead). In this simple model non-opioid, weak opioid and strong opioid drugs

are recommended sequentially or additively for mild, moderate and severe pain respectively. (WHO, Geneva 1986). New approaches are focussing more on pain mechanisms, and appropriate choice of drug class to match the mechanism(s) operative in a given patient at a given time (Ashby and Fleming unpublished).

Most patients with advanced cancer pain will require opioid analgesia, and the opioid of choice is presently morphine in palliative care programmes. This has been a major contribution of the pioneering British hospice and palliative care movement (Twycross and Lack 1984). The pharmacology of opioid drugs and their role in cancer and non-cancer pain are well covered by two British reviewers (Hanks and Hoskin 1987, McQuay 1989).

Despite all the above experience and knowledge, one of the major impediments to effective pain control remains the widespread professional and public fear of addiction, habituation and side effects of morphine and the opioid class of drugs (Doyle 1991, Zenz 1991). The main side effects of morphine are: central nervous system: drowsiness, confusion, hallucinations, disturbed dreams, respiratory depression; gastrointestinal tract: nausea and vomiting, constipation. Itching, sweating, urinary retention and dry mouth are occasionally reported. Most of these side effects are either transient, mild and tolerable, or amenable to preventative measures.

Zenz perhaps understates the side effects, which are problematical but manageable for many patients, but may be unacceptable to some. Progress in this area may be reasonably expected from current research endeavours.

The fear of life-shortening, that the use of morphine for cancer pain may be a form of active euthanasia is discussed and dismissed by Foley (Foley 1989). The presence of pain appears to act as a counterbalance to both psychological addiction and side effects. There does not appear to be an upper dose limit for morphine, and the dose required to control pain varies, and some patients do require very high doses for various reasons (Twycross 1984) (overhead). The median dose required to control cancer pain has been quoted as 15mg 4 hourly, and it is unusual to exceed 100 mg 4 hourly. Whilst dose requirements may increase during the course of a terminal illness, there is no real substance to the notion that starting morphine prematurely leads to an inability to control pain before death.

Despite overwhelming clinical evidence that morphine used appropriately for cancer pain is safe and effective, there is still entrenched professional and public reservation about its use. As a result far too many patients are deprived of the chance of optimal pain relief. A sustained educational and research effort is required to maintain and improve on what has already been achieved.

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9th September 1991.

Eastern and Central Adelaide Palliative Care Service
in association with
ROYAL ADELAIDE HOSPITAL
MARY POTTER HOSPICE, CALVARY HOSPITAL
ADELAIDE CHILDREN'S HOSPITAL
ROYAL DISTRICT NURSING SOCIETY
EASTERN HOSPICE CARE ASSOCIATION
UNIVERSITY OF ADELAIDE
COMMUNITY VOLUNTEER SERVICE

Wednesday 27 February 1991

Mr G Thomson
Secretary to the Committee
House of Assembly
North Terrace
ADELAIDE SA 5000

Dear Mr Thomson

Re: Select Committee on the Law and Practice Relating to Death and Dying

I am pleased to submit evidence to the Select Committee in my capacity as the Medical Director of the above service. I wish to emphasise that the views expressed are personal. Whilst I am confident that in broad terms they are representative of those of many of my colleagues in palliative care, I do not presume to speak for them, especially on moral/ethical matters.

It is my understanding that the South Australian Association for Hospice Care (SAAHC), the Hospice Care Coordinating Programme Committee of the South Australian Health Commission (SAHC), and the Australian Nurses Federation (ANF) will be making submissions to which I and my colleagues will also be contributing, particularly with regard to resource allocation issues.

I would be pleased to assist the Select Committee in any other way it sees fit.

Yours sincerely

Dr Michael Ashby MBBS MRCP(UK) FRCR
Director of Palliative Medicine and Radiation Oncologist (RAH)
Medical Director of Mary Potter Hospice

MA:pc

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Parliament of South Australia. House of Assembly

Select Committee on the Law and Practice Relating to Death and Dying

Submission by **Dr Michael ASHBY MBBS MRCP (UK) FRCR**
Director of Palliative Medicine, Royal Adelaide Hospital
Medical Director, Mary Potter Hospice
Visiting Specialist in Radiation Oncology and
Palliative Services, Adelaide Children's Hospital
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ABSTRACT

The modern hospice/palliative care movement is well represented and established in South Australia. It aims to work with existing services in a harmonious and effective way. Limited additional resources should be allocated to the services as they are all working under considerable pressure, which is likely to increase as deaths (particularly cancer deaths) continue to increase. They particularly need more resources to undertake a wider and deeper educational role so that the messages can be permeated throughout clinical practice in all its settings. Public hospital strategies and procedural policies need to adapt to encompass palliative care issues more comfortably. Community and professional attitudes to opioid pain relief for chronic cancer pain need to be addressed by better education and understanding. Pain and symptom control in the clinical care of advanced cancer patients often require a special set of skills, which palliative care physicians and nurses possess, and this should be recognised.

Serious reservations must be expressed about the inappropriate and fallacious conflation of palliative care and euthanasia, and about the erroneous hope that legal measures can solve ethical and clinical issues. The South Australian community in common with all western developed societies might explore its ethical and spiritual horizons anew, and attempt to reintegrate death into life. A scientific study of The Natural Death Act should be commissioned.

a) the extent to which both the HEALTH SERVICES and the present LAW provide adequate options for dying with dignity

HEALTH SERVICES

Whilst the State of South Australia has an enviable record of pioneering work in the field of palliative care, there remain many areas of concern if this record is to be maintained. It seems that when the terminally ill are offered the full range and choices of a modern palliative care service, high levels of satisfaction are expressed. Expert symptom control, psychosocial and spiritual support, either in the home, hospice or hospital (or a combination of these at different stages of the illness) are essential components. A friendly and pleasant caring environment is provided with recognition of the patient's human context of family and/or friends. Medical interventions are kept to a minimum compatible with comfort and quality of life. Help is particularly provided to assist patients and families to come to terms with the realities of the situation - giving time wherever possible for anticipatory grieving and reconciliation. The acknowledgement of the dying process and the giving of permission to stop the fight against the natural history of incurable diseases are central to a more comfortable and peaceful death and quality of life until death. The majority of patients in palliative care programmes have malignant disease. The clinical (pain and symptom control) care of patients with advanced cancer often requires the advice and assistance of specialised palliative care doctors and nurses, in liaison with the general practitioner and relevant hospital cancer specialist(s).

Palliative Care Services

At present these small services are working well beyond capacity in most areas. There is a serious risk of overload and burn out for many dedicated team members. Special attention should be paid to the funding of the following:

- 24 hour medical cover and medical direction for all the services
- Support for the clinical nurse consultants in hospitals and community
- Improved coverage of services to those who require them
- Adequate levels of nursing staff in both hospital and hospice units in accordance with Hospice Standards documents.

Hospitals

The large teaching hospitals have a heavy load and a wide diversity of functions. Their procedures and philosophies are often not conducive to good palliative and terminal care. Rightly they are geared primarily to the delivery of high technology care aimed at saving life.

The chronically and terminally ill often do not have their needs adequately met in the acute care areas, and dying in a teaching hospital is often a more harrowing process then need be for all concerned: patient, relatives and nursing staff. Palliative care support and advisory teams in the hospitals can be of considerable assistance to hard pressed units trying to deliver palliative care. However more needs to be done in the training and support of the (often junior) medical and nursing staff to improve their skills and self esteem in this area of care.

The following suggestions are made:

(i) Educate staff to feel comfortable with a non curative model of care where appropriate. Emphasise that it is not palliative care "only" - some kind of second rate, minimalist care in the province of failure.

(ii) More team work to allow multi-disciplinary consultation in decision making and mutual support.

(iii) Set out guidelines of how to adapt hospital policies on observation, nutrition and hydration, and drug treatment of dying patients.

(iv) Provide adequate levels of suitably experienced nursing staff to deliver acceptable standards of palliative care nursing to dying patients.

(v) Each hospital should formulate a palliative care policy.

Community Care

In Adelaide the mainstay of community palliative care is the Royal District Nursing Society (RDNS) in partnership with general practitioners and hospice/palliative care outreach teams. The primary RDNS nurse in the field is assisted and supported by the clinical nurse consultant in palliative care in that area when required. The emphasis is on the use of existing services wherever possible. It is the policy of the palliative care teams not to take over care from the primary care team. However this does occur, sometimes appropriately with the consent of all concerned, but on occasions by default or misunderstanding. It is the world wide history of the modern hospice/palliative care movement that some opposition is encountered where doctors and nurses feel that they have always dealt with these issues and resent interference from palliative care teams.

The following suggestions are made:

(i) The reinforcement of the role of the primary nurse and general practitioners as the palliative carers, with the knowledge to appropriately consult, involve and on occasions hand over to the palliative care team. This is a more difficult model to work than one in which the palliative care team, takes over as a matter of course. It requires good communication, awareness and mutual understanding. ' It is a long term objective relying on education.

(ii) The role of locum cover in general practice for after hours calls is limited in palliative care. Such services do not have adequate prior knowledge of patients and of palliative care procedures to make effective interventions in most situations. Serious consideration should be given to the kind of service evolved in Western Australia (Silver Chain Nursing Service Hospice Care). General Practitioners with a special interest in palliative care take over the management of patients when requested to do so by the patient's own general practitioner - particularly where after hours care is an issue. This service should be discussed with the AMA and RACGP in South Australia.

(iii) The education of General Practitioners (both initial FMP training programme and ongoing postgraduate education) should include palliative care. FMP and RACGP have already been very supportive of this activity. FMP trainees rotate through some services, particularly through the special skills three monthly attachment, and regular lectures are now included in the FMP programme.

LAW

There are no obvious legal impediments to the delivery of a high standard of palliative care in South Australia. The main obstacles are inadequate resources and ethical attitudes. The Natural Death Act (1983) is almost never invoked in order to introduce palliative care. Laws will not assist in acknowledging the dying process, or in rendering it more comfortable or dignified.

(b) Whether there is sufficient public and professional awareness of pain relief and palliative care available to patients facing severe prolonged pain in a terminal illness.

Despite considerable activity and press coverage over approximately a decade there is still a surprising lack of awareness of what can be done. For many the issues involved are too difficult to confront and variable levels of individual and collective denial are operative. There are powerful myths both in the professions and amongst the public concerning the use of opioids for the treatment of chronic cancer pain. Morphine is seen as an addictive drug which is synonymous with 'the end'. Its appropriate and safe use in chronic cancer pain is still not acknowledged or understood by many. Others fear that if the drug is used 'too early' they will die a painful death without adequate analgesia, due to habituation.

(i) These attitudes are a generational or cohort effect and will require a sustained programme of professional and public education over many years.

(ii) Specialists and General Practitioners should be supported in the appropriate use of opioid pain relief, and to recognise that just as in any other area of medicine if simple measures do not produce good symptom control, then specialised assistance should be sought.

(b) continued

Whether there is adequate provision of such services.

Please see response to (a)

(b) continued

Whether there is sufficient public and professional awareness of the Natural Death Act, and if not, what measures should be taken to overcome any deficiency;

The Act is rarely mentioned in the palliative care setting. Its main effect might be seen as establishing the right of an individual to refuse treatment and the consequent change in medical and public attitudes generated. In the issue of patient and relative consultation for "not for resuscitation" orders, there may be considerable distress generated. There is no systematic way of recording or storing the forms, and of knowing whether a patient has completed a form prior to serious illness or loss of competence. A clearer definition of enduring power of attorney and clarification of next of kin/significant other/patient advocate or agent roles. Perhaps the palliative care perspective is not the best one from which to comment on these aspects of the Act as the decision to opt for palliative care has already been taken prior to referral. However the Act might be responsible for more patients being appropriately referred if these issues were addressed.

A properly funded and scientifically conducted study of the Natural Death Act should be commissioned.

It seems however unlikely that further legislation will lead to better or more compassionate, realistic and honest care of dying patients. This is more likely to occur when more ethical thought and awareness permeate the medical profession. The limitations of the traditional medical model need to be acknowledged and addressed in training. Attitudes cannot be legislated for.

. . . . . *and*

(c) to what extent, if any, community attitudes towards death and dying may be changing and to what extent, the law relating to dying needs to be clarified or amended.

More members of the public appear to be expressing the wish that when they are afflicted by incurable and terminal illness, professional carers be honest, that where burdensome and hopeless, continuation of active treatment is not pursued. There is considerable demand for high quality palliative and hospice care. However many people still have tragically unrealistic expectations of modern technological medicine. More public education about what medicine can and cannot achieve might be helpful. The views of Professor Alistair Campbell of Edinburgh and Otago that we live in a death-denying culture might be considered further. The more comfortable acceptance of death as part of life is an important step to a better quality of dying.

It is this term of reference which has generated concern amongst those who fear that the Select Committee will be facilitatory in the presentation of legislation to legalise voluntary active euthanasia to parliament.

I am opposed to any such move. In palliative care requests for euthanasia do occur from time to time. For some the process of dying is too slow undignified and miserable. Despite all attempts some patients do not achieve the sort of bodily comfort or mental peace to endure the natural process of slow death from advanced incurable diseases. For others prolonged static periods of severe physical and/or mental disability are intolerable. The views of those who sincerely feel that euthanasia is the only and ultimate answer to these situations need to be heard with compassion.

It is unfortunate that euthanasia commands considerable media and public attention, and that euthanasia and palliative care are often inappropriately and fallaciously conflated in argument. Palliative care in all its dimensions has much to contribute to those who might contemplate euthanasia or assisted suicide as an option for abolishing suffering in a terminal illness. It does not however operate in the argument for or against euthanasia as such. It does work from the principle that all aspects of an individual's suffering should be addressed, including mental suffering. The reader is referred to the accompanying discussion paper by Ashby and Stoffell to pursue this area further.

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(For information about the following please contact Dr Michael Ashby, PO Box 231, North Adelaide, SA, 5006)

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INTERIM REPORT OF THE SELECT COMMITTEE OF THE HOUSE OF ASSEMBLY

ON

THE LAW AND PRACTICE RELATING TO DEATH AND DYING

"...it would be a good thing if this State could maintain its strong track record in innovative social welfare and health legislation by having, at the end of this select committee, a policy on death and dying...That would certainly place South Australia amongst the world leaders of...public policy."

Dr Michael Ashby (Medical Director, Mary Potter Hospice, Calvary Hospital) - oral evidence page 19

Nevertheless, there is still a lot of work to do. Expert witnesses involved in palliative care have pointed out that when terminally ill patients are offered the full range and choices of a modern palliative care service, high levels of satisfaction are expressed.

Expert symptom control, psychosocial and spiritual support, either in the home, hospice or hospital (or a combination of these at different stages of the illness) are essential components.

However, many submissions stressed that there is insufficient public and professional awareness of pain relief, symptom control measures and palliative care available to people facing severe prolonged pain in terminal illness.

"From a country/rural perspective, lack of services means that clients do not have access to adequate pain relief, and due to professional isolation, health care professionals do not always keep up-to-date with latest "advances" in approaches to care."

Australian Nursing Federation (SA Branch) - written submission page 5

"...both nurses and medicos have a problem in that they think that if someone is dying and needs pain relief, if they are given too much of a narcotic drug they will become addicted. That is not the major priority if the person is dying."

"...when I worked with palliative care nurses and hospice care nurses...they stopped the curing, but the caring process that took place was really quite incredible."

Ms Elizabeth Percival (Nurses Board of South Australia) - oral evidence page 328, 325

"Despite overwhelming clinical evidence that morphine used appropriately for cancer pain is safe and effective, there is still entrenched professional and public reservation about its use. As a result far too many patients are deprived of the chance of optimal pain relief. A sustained educational and research effort is required to maintain and improve on what has already been achieved."

Dr Michael Ashby, - written submission on Pain Control and Palliative Care, tabled 9/9/91

Several witnesses expressed concern that dying has become an isolated process that takes place mainly in institutions, out of sight and out of mind of the community.

"There is an attitude in society that we must put people in institutions and hospitals in order to place death at arm's length."

"If we believe that death is part of life and...we talk about... healthy life styles, then maybe we should also talk about healthy death styles."

Mrs Joy Nugent (Director, Private Palliative Care Service) oral evidence page 344, 345

P.P. No. 185

Second Interim Report

of the

SELECT COMMITTEE

ON THE

LAW AND PRACTICE RELATING TO

DEATH AND DYING

- *would be entitled to an interest in the estate of another person on the death intestate of that person and*

- *who, by any deception, fraud, mis-statement or undue influence, procures or obtains, whether directly or indirectly, the execution by that other person of a medical power of attorney*

forfeits any interest under the will, instrument or intestacy, as the case requires. This should be in addition to any other penalty in respect of the deception, fraud, mis-statement or undue influence under any other Act or law.

(14) The law be amended to provide that the provision of palliative care (as defined), reasonably administered without negligence and with informed consent to a terminally ill patient, is not to carry any criminal or civil liability even if it has the effect of shortening life.

(15) The Natural Death Act should be repealed but any Certificates executed under the Natural Death Act should continue to have full force and effect notwithstanding the repeal of the Act.

'Good Palliative Care' Orders

(16) Hospitals in South Australia cease the practice of using coded instructions for "Do Not Resuscitate" orders and adopt instead "Good Palliative Care" orders based on consultation with the patient, the family,or other significant persons and the ward staff. These orders should be framed along the lines outlined in Appendix B.
Responsibility: Hospital Boards, in consultation with medical and nursing staff.
Timing: by June 30th 1993.

Provision of palliative care to carry no civil or criminal liability

The Committee was made aware of two circumstances in which doctors may feel at risk of prosecution, despite exercising the highest standards of clinical care in what they believe to be the best interests of the patient. The second is described in the next section of this report. The first is sometimes known as the principle of "double effect":

The principle of "double effect"

"Here there is administration of medication aimed at maintaining comfort for the patient, but having also the potential to cause death earlier than if it had not been used.

This is sometimes discussed as the 'principle of double effect'. A patient may have severe pain and restlessness which is able to be controlled only through large doses of narcotics and sedatives which cloud consciousness and impair other body functions to such an extent that the onset of death is accelerated.

Such an occurrence is not often necessary; usually the modern techniques of pain management available to experienced palliative care teams are able to control pain without significantly impairing other body functions. But when it occurs, palliative care doctors risk being charged with the administration of a drug which caused death, and in circumstances where the maintenance of life was judged to be less important and secondary to concern for the comfort of the patient and the assessed quality of that patient's life."

Professor Ian Maddocks Foundation Professor of Palliative Care, Flinders University of South Australia; President of the Australian Association for Hospice and Palliative Care - (written submission page 7)

Taking into account the evidence of Professor Maddocks and the opinions of other witnesses on this matter, the Committee recommends:

> ***the law should be amended to provide that the provision of palliative care (as defined) reasonably administered without negligence and with informed consent to a terminally ill patient, is not to carry any criminal or civil liability even if it has the effect of shortening life.***

"Do Not Resuscitate" orders - "Good Palliative Care" orders

The Committee received evidence on what are sometimes called "Do Not Resuscitate" orders. The evidence is best expressed as follows:

> *"The situation is generally that of a seriously ill person who is judged to be at risk of a further major deterioration, and particularly a sudden deterioration. This may occur through, for example, a cardiac arrhythmia and cardiac arrest, or a haemorrhage. In an otherwise-fit person such an event would immediately call for every effort at reversing the new pathology and restoring normal function. But if the patient has incurable disease, has already been resuscitated several times in similar circumstances ... and if the affected individual has indicated that he or she does not want further resuscitation or transfusion and been judged by the attending physician to be making an informed and rational statement to that effect, then the physician may indicate to the attending medical and nursing staff that it would be inappropriate to undertake resuscitation and write an instruction to that effect in the patient record.*
>
> *It will assist the doctor making such an order if the patient has previously left written instructions about his or her wishes not to be the subject of resuscitation efforts, but a witnessed record of a conversation to that effect written in the record may well be accepted by the courts. The recent advice of the Crown Solicitor is that the law cannot accept a 'do not resuscitate' order which is based only on either the family's or the doctor's perceptions.*

Professor Ian Maddocks, Foundation Professor of Palliative Care, Flinders University of South Australia; President of the Australian Association for Hospice and Palliative Care - (Written Submission page 7)

The goals of palliative care are outlined in the Hospice/Palliative Care Policy adopted by the South Australian Health Commission in March 1992 (Appendix C). Palliative care can be delivered through special hospice services, through hospitals, through nursing homes, or through community-based care delivered into the patient's home.

"Whilst the State of South Australia has an enviable record of pioneering work in the field of palliative care, there remain many areas of concern if this record is to be maintained. It seems that when the terminally ill are offered the full range and choices of a modern palliative care service, high levels of satisfaction are expressed. Expert symptom control, psychosocial and spiritual support, either in the home, hospice or hospital (or a combination of these at different stages of the illness) are essential components. A friendly and pleasant caring environment is provided with recognition of the patient's human context of family and/or friends. Medical interventions are kept to a minimum compatible with comfort and quality of life. Help is particularly provided to assist patients and families to come to terms with the realities of the situation - giving time wherever possible for anticipatory grieving and reconciliation. The acknowledgment of the dying process and the giving of permission to stop the fight against the natural history of the incurable diseases are central to a more comfortable and peaceful death and quality of life until death. The majority of patients in palliative care programmes have malignant disease.

The clinical (pain and symptom control) care of patients with advanced cancer often requires the advice and assistance of specialised palliative care doctors and nurses, in liaison with the general practitioner and relevant hospital cancer specialist(s)".

Dr Michael Ashby, Medical Director, Mary Potter Hospice, Calvary Hospital - (written submission, page 2)

Palliative Care Services

(See Appendix D for full details of the range of metropolitan and country services)

Hospice facilities for palliative care are located in all four metropolitan regions -

- Daw House Hospice - 15 beds (Southern Community Hospice Program)
- Philip Kennedy Centre - 10 beds (Western Hospice Palliative Care Service)
- Northern Hospice Service
  - Lyell McEwin Health Service Unit - 6 beds
  - Modbury Hospital Unit - 6 beds
- Mary Potter Hospice - 16 beds (Eastern and Central Adelaide Palliative Care Service)
- Royal Adelaide Hospital - 4 designated palliative care beds on a geriatic ward.

The Committee was told that most of these small services are working well beyond capacity with a consequent serious risk of overload and "burn-out" for dedicated staff. At present only the clinical nurse consultant in palliative care is deployed in each of the four metropolitan palliative care services to advise on all nursing aspects of patient care, assisted by a clinical nurse position which is temporarily internally funded by the Royal District Nursing Society.

Evidence indicated that locum cover for palliative care in general practice for after hours calls is inadequate. By their very nature, locum services do not have adequate prior knowledge of patients and frequently of palliative care procedures to make effective interventions in most situations. The Committee was told of the value of a service which has developed in Western Australian called Silver Chain Nursing Service Hospice Care. As part of this service, general practitioners with a special interest in palliative care take over the management of patients when requested to do so by the patient's own general practitioner. This is a particularly valuable service when after hours care is important to the patient but the regular general practitioner is not able to provide it.

The Committee recommends:

- ***the development of an after hours palliative care service to support general practitioners should be investigated and, if feasible, implemented***

  Responsibility: Australian Medical Association and Royal College of General Practitioners

  Timing: as soon as practicable

Pain Relief

Pain is the most common symptom which afflicts patients referred for palliative care.

It is generally accepted that the management of pain from all causes has been an area of some neglect until relatively recently. South Australia has taken a leading role to improve education and practice in the medical and other health care professions.

The Committee commends the work of the Pain Manangement Unit at the Flinders Medical Centre and other similar units in South Australia. We refer those interested in pain management to the National Health and Medical Research Council document entitled "The Management of Severe Pain" available from Commonwealth Government retail outlets.

Nevertheless, much remains to be done. The process is slow and the Committee heard substantial evidence that the main obstacles lie in attitudes and myths surrounding the ethical basis of palliative care and the limitations of the curative medical model when addressing palliative care issues.

Dr Michael Ashby, Director of Palliative Medicine, Royal Adelaide Hospital, presented written and oral evidence to the Committee, illustrated with information regarding World Health Organisation analgesic treatment models and by extensive references to medical literature. The Committee was told that cancer pain control has been taught by the World Health Organisation using non-opioid, weak opioid and strong opioid drugs sequentially or additively for mild, moderate or severe pain.

Most patients with advanced cancer pain will require opioid analgesia, and the opioid of choice at present is morphine in palliative care programs. This has been a major contribution of the pioneering British hospice and palliative care movement.

"What was a real boon to my mother was this pump. I couldn't have coped with my mother if she had been in constant pain or having to have injections all the time. Whoever invented it needs a medal."

Son of an 80-year old woman with colon cancer - "Survey of Attitudes of Bereaved Relatives to Terminal Care in South Australia" (March 1992 p.15) Appendix F

Despite all the above experience and knowledge, one of the major impediments to effective pain control remains the widespread professional and public fear of addiction, habituation and side effects of morphine and the opioid class of drugs.

"When he went into hospital they took him off his morphine. His pain became unbearable. I said, can't you give him something for his pain? - seeing him shake and grit his teeth. The male nurse there got Dr X and put in an injection. It helped."

Wife of a 77-year old man with lung cancer

"My mother refused most prescribed drugs ... no-one could convince her that she would not become addicted."

Son of a 70-year old woman with lymphoma

"Managing the pain at home was difficult for me to control ... I didn't know if I could increase the dose or even give it more often ... I was worried about overdosing her, so I stuck strictly to the prescription."

Daughter of a 79-year old woman with disseminated cancer

Appendix F p.16

"There are ... some very powerful myths in the profession and amongst the public about opioids. This refers to a family of drugs of which the best known would be morphine. Another is diamorphine, or heroin, which is not available in Australia and I do not believe there is a strong case for making it available. Morphine is seen as a highly addictive drug which is synonymous with the end of life. There are also natural concerns about drug addiction, particularly as opioid addiction in the community is such a big and sad present issue in the world. However, its appropriate and safe use for chronic cancer pain is still not acknowledged or understood by many, including some of my colleagues."

Dr Michael Ashby, MB BS MRCP(UK) FRCR, Director of Palliative Medicine, Royal Adelaide Hospital; Medical Director, Mary Potter Hospice, Calvary Hospital - (written submission tabled September 1991)

Dr Ashby told the Committee that he had heard the view expressed that "if one uses morphine now all of its analgesic properties will be used up and there will be nothing left at the end of life.". He told the Committee that these myths abound but that it is necessary to be realistic and accept that:

"... mythology is a powerful thing to overcome. One really needs to address it over a period of years. I think that that is what we are doing, particularly in educational areas. It has a cohort or generational effect. So, it will take a lot more education before those fears are a thing of the past."

The fear that the use of morphine for cancer may be life-shortening and addictive was discussed with the Committee by Dr Ashby. We were told:

"The presence of pain appears to act as a counterbalance to both psychological addiction and side effects. There does not appear to be an upper dose limit for morphine, and the dose required to control pain varies, and some patients do require very high doses for various reasons ... Whilst dose requirements may increase during the course of terminal illness, there is no real substance to the notion that starting morphine prematurely leads to an inability to control pain before death."

The Committee is concerned that despite overwhelming clinical evidence that morphine used appropriately for cancer pain is safe and effective, there is still entrenched professional and public reservation about its use. As a result far too many patients are deprived of the chance of optimal pain relief.

The Committee therefore recommends:

- ***a sustained education campaign be undertaken to improve professional and public awareness of availability of options for pain relief. The campaign should address:***

- *curriculum in medical schools and schools of nursing*

- *post-graduate education for doctors and nurses with particular emphasis on general practitioners*

  Responsibility - Deans of the University of Adelaide, Flinders University, University of South Australia Schools of Medicine and Nursing Royal College of General Practitioners

  Timing - as soon as practicable

- *public education through community health centres, voluntary organisations, aged care organisations*
- *media of all kinds, including film and television*

  Responsibility - South Australian Health Commission, Australian Medical Association, South Australian Association of Hospice Care

  Timing - as soon as practicable.

Care of terminally ill AIDS patients

The Committee made several contacts with the AIDS Council of South Australia (ACSA), seeking evidence which would assist us. As no response was forthcoming, the Committee contacted the Australian Federation of AIDS Organisations Inc. (AFAO) and subsequently received a joint submission on behalf of AFAO and the AIDS Council of South Australia.

SUBMISSION REGARDING THE EUTHANASIA LAWS BILL 1996.

TO THE SENATE LEGAL AND CONSTITUTIONAL LEGISLATION COMMITTEE

by
PROFESSOR MICHAEL ASHBY
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and
Department Of Medicine, Monash University.

This submission is respectfully presented to assist senators in their deliberations on the *Euthanasia Laws Bill 1996*. The author is a practicing specialist in palliative care who presently holds an academic chair at Monash University with responsibilities for the promotion of sound practice, research and education in this field of medical care. The author has worked in this capacity in South Australia (1989-1995) and Victoria (1995-present), and for three years (1993-1995) was employed as a visiting specialist in radiation oncology and palliative care by the Royal Darwin Hospital, being the first person to hold such a specialist position in the Northern Territory. The views expressed here are personal and professional and are not those of any organisation cited or not.

DEFINITIONS AND BROAD PRINCIPLES

The Australian Association for Hospice and Palliative Care Inc (AAHPC) issued the following position statement on voluntary active euthanasia on 27th October 1995, with which the author concurs, and on which this submission is based.

The Australian Association for Hospice and Palliative Care:

1. defines Hospice and Palliative Care as a concept of care which provides coordinated medical, nursing and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional and spiritual support for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement

support for the family and other carers during the life of the patient, continuing after death;

2. defines Voluntary Active Euthanasia (VAE) as the deliberate action to terminate life by someone other than, and at the request of, the patient concerned;

3. believes that dying is a natural process and that the refusal or withdrawal of futile treatment is not voluntary active euthanasia;

4. believes that legalisation of voluntary euthanasia is not a substitute for the proper provision of palliative care services to all Australians;

5. believes that public interest in voluntary active euthanasia reflects a concern about lack of adequate support for people who are dying, and will continue to campaign for improved services, education and research in all aspects of palliative care;

6. states that currently accepted palliative care practice does not include deliberate ending of life, even if this is requested by the patient;

7. asserts that palliative care experience shows that appropriate and effective use of morphine and other drugs for pain relief does not cause death;

8. recognises that there is a wide divergence of views about voluntary active euthanasia in Australian society, and also within the caring professions, including the palliative care community;

9. recognises and respects the fact that some people rationally and consistently request voluntary active euthanasia;

10. acknowledges that, while pain and symptoms can be addressed, complete relief is not always possible in all cases, even with optimal palliative care;

11. welcomes open and frank discussion within the community, and particularly with the health professions, about all aspects of death and dying, including voluntary active euthanasia;

12. nevertheless, due to the inherent risk to individuals and society, opposes all legalisation of euthanasia.

THE DESIRABILITY OF ENACTMENT OF THE PROVISIONS

Public Opinion Pressure

In common with the UK, Canada and the USA, it is clear that a growing majority of Australians say, in opinion polls, that they approve of euthanasia.[1] [2] Parliamentarians are, therefore, under considerable pressure from the general public and lobby groups to support legislation such *as Rights of the Terminally Ill Act 1995* (NT) (RTIA) and therefore to oppose the *Euthanasia Laws Bill 1996*. However, in palliative care practice only a small minority actually make persistent requests for assistance to die[3] and the Dutch experience similarly suggests that assisted death is uncommon, even when a legal channel for these practices exists.[4] Not unsurprisingly there is a substantial discrepancy between what people say when they are well and how they behave when affected by a terminal illness. Significant numbers of doctors and nurses state in confidential surveys that they have rendered assistance to die, but there is a much more reserved response from these professions with regard to legislation of euthanasia.[5] [6] [7] [8]

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[1] House of Lords Select Committee on Medical Ethics. 1994. HL Paper 21-I, II, III. London: HMSO.
[2] Morgan Poll: Majority support for euthanasia increases. Finding No 2250. Published in Time Magazine, May 25, 1992.
[3] Hunt R et al. The incidence of requests for a quicker terminal course. Palliative Medicine 1995; 9: 167. *Hunt found that 6% of patients in a hospice made serious requests for assistance to die.*
[4] Van der Mass PJ, Van Delden JJM, Pijneneborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. Lancet 1991; 338: 669.
[5] Kuhse H, Singer P. Doctors' practices and attitudes regarding voluntary euthanasia. Medical Journal of Australia 1988; 148: 623-627
[6] Kuhse H, Singer P. Euthanasia: a survey of nurses' attitudes and practices. Australian Nursing Journal 1992; 21(8): 21-22.
[7] Baume P, O'Malley E. Euthanasia: attitudes and practices of medical practitioners. Medical Journal of Australia 1994; 161: 137-144
[8] Stevens CA, Hassan R. Management of death, dying and euthanasia: attitudes and practices of medical practitioners in South Australia. Journal of Medical Ethics 1994; 20: 41-46.

The Rights Of The Individual Or The Common Good ?[9]

The title of RTIA specifically talks of rights in the plural, but only one right is legislated for, namely that of a terminally ill individual to request, and receive medical assistance in suicide or active medical assistance in dying. As such this is the first time that the so-called right to die has been enacted in statute law, although the Oregon (USA) *Death with Dignity Act 1995* (presently blocked on appeal) would allow doctors to assist in the suicide of a patient, but not administer the drug, and the non-prosecution stance in the Netherlands is well known. A right to die is not specifically articulated in any recognised national or international code of human rights. Those who drafted RTIA may well have been more swayed by Cory J's approach in Rodriguez, where she argues for a right to die by the inclusion of dying in the process of living. The right to life is, of course, already protected as the most basic of fundamental human rights, and in Canada specifically by the Canadian Charter of Rights and Freedoms:

> "The life of an individual must include dying. Dying is the final act in the drama of life. If, as I believe, dying is an integral part of living, then as a part of life it is entitled to the constitutional protection provided by s.7. It follows that the right to die with dignity should be as well protected as is any other aspect of the right to life. State prohibitions that would force a dreadful, painful death on a rational, but incapacitated terminally ill patient are an affront to human dignity."[10]

The supremacy of personal autonomy in decisions surrounding death is well expressed by Max Charlesworth in his book "Bioethics in a Liberal Society" :

> "We are on a slippery slope only when we move away from seeing the decision to end one's life as a moral decision belonging to the individual patient, ... In a liberal society then any legislation giving expression to a 'right to die' must relate essentially to the patient's autonomous right to control the ending of her or his life. Extraneous

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[9] Legislative Assembly of the Northern Territory. The rights of the individual or the common good? Volume One. Report of the Inquiry by the Select Committee on Euthanasia. (Government Printer, Darwin 1995)
[10] Rodriguez v BC (AG) SCR 1993; 3: 630

considerations, for example whether the continuation of a patient's life is a burden on parents, family or society in general, should not be taken into account."[11]

When considering the issue of the so-called principles or doctrine of the sanctity of life the drafters of RTIA might have also been influenced by Ronald Dworkin's approach in Life's Dominion, in which he argues that we all agree about the sacredness of life, but how we express that sacredness varies according to personal beliefs and world view :

" ... If people retain the self-consciousness and self respect that is the greatest achievement of our species, they will let neither science nor nature simply take its course, but will struggle to express, in the laws they make as citizens and the choices they make as people, the best understanding they can reach of why human life is sacred, and the proper place of freedom in its dominion."[12]

So for Dworkin, an individual who chooses assistance in suicide or voluntary active euthanasia (VAE), may be seen to be making an ultimate expression of autonomy, integrity and dignity, which is consistent with the way the person has led their life - rather than to be opting for a necessarily negative, desperate or hopeless last act:

"Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying - the emphasis we put on dying with "dignity" - shows how important it is that life ends appropriately, that death keeps faith with the way we want to have lived."[13]

As with Charlesworth the pivotal issue is the autonomous expression of personhood. There is clearly very substantial support in Australia for the principle of the right of access to medical assistance in dying, based on a recognition of the supremacy of individual autonomy over any notion of state's interests in preserving the lives of its citizens in the context of terminal illness. Any person or group who seek to thwart this primacy of autonomy will be in for a very rough ride in most western societies, and it seems likely from opinion poll trends that there is a generational cohort shift in action which very strongly

[11] Charlesworth M. Bioethics in a Liberal Society. Cambridge. Cambridge University Press 1993; 53.
[12] Dworkin R. Life's Dominion. An argument about abortion and euthanasia. Harper Collins, London, 1993; 241
[13] ibid 199

favours what is often termed 'choice in dying',[14] which presumably means choice in the manner and possibly timing of death, rather than whether death actually occurs. However it is also necessary to explore the limits of control which modern generations appear to think they have over all aspects of their lives, including death and dying. Michael Ignatieff sheds light on this when reflecting on the slow death of his own mother from Alzheimer's disease:

> "The real problem, of course, is what we are to think of death. People like us who live by the values of self-mastery not especially good at dying, at submitting to biological destiny. The modern problem is not death without religious consolation, without an afterlife. The problem is that death makes the modern secular religion of self-development and self-improvement appear senseless. We are addicted to a vision of life as narrative, which we compose as we go along. In fact we didn't have anything to do with the beginning of the story: we are merely allowed to dabble with middle; and the end is mostly not up to us at all, but to genetics, biological fate and chance."[15]

In rightly focusing public policy in health care firmly on individual choice, it is nonetheless essential to reflect on the individual's social context. The modern palliative care practice model is firmly based on acknowledgment of the centrality of the patient's autonomy in all decision making, but with due recognition and support for those family members and friends who are identified as being close and supportive of the patient. Autonomy is never absolute, and health care, particularly palliative care, cannot be conducted in an autonomous vacuum.

Euthanasia Debate Distracts Community Attention From Palliative Care

The euthanasia debate has become stagnant, circular and divisive and distracts our society from the on-going task of improving care and decision-making at the end of life. The

[14] Hunt R. Palliative Care - the Rhetoric-Reality Gap in Kuhse H (ed), Willing to listen, wanting to die. Penguin, Melbourne 1994; 133
[15] Ignatieff M. Scar Tissue. Penguin ,Toronto 1994; 68

common interest at stake is the promotion of the comfort, dignity and autonomy of people who are dying. Few would dissent from these goals.

Divergence about whether third party assistance (medical or non-medical) to die is permissible reveals a deep and complex fault-line in modern western democracies. It concerns religious beliefs and personal liberty. It is part of the challenge of the postmodern world to chart its course based more on individual liberty and autonomy than organised religion and deontologically-derived codes. This process is ongoing and will not come to a sharp resolution.

Societal energy should be more focused on palliative care, about which we can nearly all agree and where modest investments have already yielded excellent results for patients and families by improving care and decision-making at the end of life. If wholeheartedly supported they might also ultimately promote a more cost effective and appropriate use of the health care system.

Federal funding for palliative care is currently under review and the medium-term future of many services is under threat.

Limitations Of Palliative Care Acknowledged

Modern palliative care has evolved over the last three decades and a great deal of knowledge and expertise has been gained about how to look after people who are dying. There is always something that can be done to improve a person's symptom control, emotional, spiritual and psychological well-being. However, palliative care also has limitations and it must be acknowledged that the best efforts of multidisciplinary palliative care services do not always provide patients with what they wish or need.

The case of Sue Rodriguez, a young Canadian woman, with motor neurone disease, who sought assistance to die in 1994, demonstrates that certain such requests are unrelated to

palliative care or symptom control. They have more to do with loss of independence, dignity and role during a prolonged and inexorable dying process.[16] (Attachment II)

It is, however, quite inappropriate to fashion a legislative instrument such as RTIA on the basis of these 'hard cases', even more so when the systems required to care for people who are dying are so incomplete.[17] (Attachment V.)

Palliative Care Doctors Oppose Legalisation Of Euthanasia

Nearly all doctors who work in palliative care oppose legislation to allow euthanasia. Like any heterogenous group of professional people they have a range of reasons for doing so and these have not yet been systematically researched. One theme which does recur in discussions amongst us, is that there is an intuitive and affective aversion to the provision or administration of drugs or other measures with the intention of thereby ending a patient's life. This aversion has profound moral and professional meaning. For palliative care practitioners this is the firm line in the sand which clearly distinguishes euthanasia from palliative care in moral and clinical terms. Whilst this is weak ammunition in logic and ethics, it is important and should be respected. This is what Somerville calls the exercise of moral intuition (Somerville, personal communication).

Palliative care practitioners feel very uncomfortable with the real prospect of their specialty being used as a part of a quasi-bureaucratised 'rubber stamping' process for VAE, as set out in RTIA.

Ethical basis of modern palliative care practice propounded: the two fallacies

There are two major fallacies which confuse public debate concerning palliative care. Firstly, that pain and symptom relief measures cause death and, secondly, that treatment abatement is morally equivalent to the administration of (for instance) a lethal injection. The

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[16] Ashby M. The Rodriguez Case and Care of the Dying. Australian-Canadian Studies (1997 in press)
[17] Ashby M. Hard Cases, Causation and Care of the Dying *Journal of Law and Medicine 1995, 3(2):152-160*

danger of this first line of thinking is shown by this excerpt from the judgement of the Ninth Circuit Court of Appeal in the United States. This court recognised as part of its reasoning to allow "physician-assisted suicide" that :

> "as part of the tradition of administering comfort care, doctors have been supplying the causal agent of patients' deaths for decades"[18]

The second leads to the kind of confusion and misinformation which has led Cica and Williams to refer to the *Natural Death Acts of South Australia (1983)* (repealed 1995) and *Northern Territory (1988)* as allowing 'passive voluntary euthanasia'.[19]

The ensuing sections on causation and acts and omissions seek to redress these misunderstandings of the ethical basis of modern palliative care practice.

Causation : False Perceptions Of What The Law Requires Negatively Influence Medical Care And Decision-Making At The End Of Life

It is crucial to examine professional and community beliefs and understanding about causation and responsibility for death in health care settings. Doctors' attitudes and clinical behaviour are complex and variable, ranging from abrupt cessation of treatment, minimalist palliative care and treatment directed at bringing about a rapid dying process on the one hand, to excessive caution about being seen to be instrumental in causing the death, particularly with regard to the provision of pain and symptom relief, cessation or non-initiation of artificial hydration and alimentation and cardio-pulmonary resuscitation on the other. We know that doctors are more comfortable, for instance, about non-initiation of treatment than its cessation once initiated, and this can be interpreted as an expression of caution with regard to causation.[20] For some doctors then, a patient's terminal illness will remove any concerns about causation, for others such concerns will remain at an

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[18] Compassion in dying v Washington, 79F 3d 790 (9th Cir 1996). Quoted in : Amas GJ. The promised end - constitutional aspects of physician-assisted suicide. New Eng J Med 1996; 335: 683-687

[19] Cica N, Williams G. A Clumsy Attack on Territories. The Australian, 22 October 1996. *They write "Legislation has operated for some time in the Northern Territory and the ACT - as well as in Victoria and South Australia - explicitly allowing this kind of "euthanasia". One effect of the passage of the Andrews Bill could be that the territories lose the power to amend or replace their existing "passive voluntary euthanasia" legislation."*

[20] Christakis N, Asch DA. Biases in how physicians choose to withdraw life support. Lancet 1993; 342: 642.

unnecessarily high level. Nurses who experience high levels of anxiety when caring for dying patients may also do so as a result of a deep-seated fear of being seen to be causing death.[21]

Even if it were a fruitful path to follow, in practice it is extremely difficult to determine the precise cause of death, the causa sine qua non or the but-for cause of death in patients dying of a chronic malignant or non-malignant condition. Many factors come into play, and the use of drugs required to maintain patient comfort occurs against a background of multi-system organ failure. It is usually not possible to determine whether a particular drug has made a causal contribution to death. We have no way of knowing what the timing of the death would have been in the absence of a given drug, unless the prescription is transparent with regard to intention. These issues cannot, of course, for obvious ethical reasons, be the subject of any form of clinical trial.

It is a common belief, and the basis of a considerable body of legal and legislative opinion, that morphine (or other opioid) dose per se is the main determinant of whether the drug causes or hastens death.[22] In fact there is no such determinative or threshold dose, and this approach is flawed. What matters is the present dose in relation to the previous dose. Gradual dose escalation by a factor in the region of 50-100% of the previous dose is usual practice, although substantially higher increases can usually be well tolerated by patients who are not new to the drug (that is, they are no longer termed 'opioid-naive'). It is therefore the size of the initial dose, and the rate of subsequent increases which are important. Cancer pain management with morphine is unusual compared to most other forms of drug treatment in that there are no predetermined dose ranges to achieve satisfactory pain control for adults or children. Most adults will achieve initial pain control with a daily dose in the range of 100mg to 200mg (per 24 hours, orally), but the range of doses is very wide (Ashby et al in preparation). The accepted practice (of which there is nearly 20 years of safe experience) is to adjust the regular dose upwards according to the

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[21] Aranda S and O'Connor M. Euthanasia, nursing and care of the dying: rethinking Kuhse and Singer (1995) 3:2 Australian Nurses Journal 18. *This paper discusses the attitudes of oncology and palliative care nurses to decision making at the end of life, on the basis of repeating an initial study of nurses' attitudes to voluntary active euthanasia by P Singer and H Kuhse "Euthanasia, A survey of nurses' attitudes and practices" 1992; 21:8 Australian Nurses Journal 21. My interpretation of this work is that even a sample population of nurses with a special skills in dealing with death and dying is experiencing considerable difficulty in dealing with the moral and legal implications of situations encountered in their clinical practice, particularly on causation.*

[22] Mendelson D. Jurisprudential aspects of withdrawal of life support systems from incompetent patients in Australia 1995. Australian Law Journal 69: 267.

requirements to keep the pain under control, balanced against incidence of side effects. Despite an extensive and sustained international campaign by the World Health Organisation,[23] many doctors still believe that they are causing or hastening the death of patients by this process, despite a lack of any evidence to support this view. In the much quoted Remmelink report from the Netherlands, 17.5% of so-called MDEL's (medical decisions at the end of life) were attributed to opioid dose escalation by the treating doctor.[24] As there are no clinical data provided by which to judge the actions of the doctors who participated in this study, the report is reliant on their beliefs and interpretations of the consequences of their treatment, which may well have been mistaken with respect to causation.

It can be argued that an inappropriately high level of concern about causation is a common cause of poor care of dying people in our communities and constitutes the single most important attitudinal influence on medical decision-making at the end of life and provision of optimal symptom control. If a practitioner believes (however inappropriately) that he or she is (or could be) responsible for causing, or instrumental in causing the death of a patient, this could influence their clinical practice by two mechanisms. Firstly, there is a concern about possible legal proceedings and secondly such a belief may be inconsistent with the practitioner's personal ethics, although the legal concern may well predominate.

Most people without a legal background, and hence most health care practitioners, will have a narrow medical view of causation, which approximates to the but-for test of causation. In fact the law (particularly in Australia) looks at causation from the stand-point of determining liability and the possibility of the existence of multiple sufficient causes and by recognising the multifactorial nature of causation, no longer use the "but-for" test as the sole legal standard for ascertaining or apportioning legal responsibility:

> "In law ... problems of causation arise in the context of ascertaining or apportioning legal responsibility for a given occurrence ... Thus, at law a person may be

[23] Stjernsward J and Teoh N. The cancer pain relief programme of the World Health Organisation. Palliative Medicine 1989; 4: 1.
[24] Van der Maas PJ, Van Delden JJM, Pijneneborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. Lancet 1991; 338: 669.

responsible for damage when his or her wrongful conduct is one of a number of conditions sufficient to produce that damage."[25]

Keyserlingk, in an argument against decriminalisation of assisted suicide based on an analysis of Rodriguez, proposes a move away from standard and but-for causality of death approaches in legal analysis, and the adoption of what he terms a normative causality approach:

> "(this) position emphasises not simple scientific causality, the cause-in-fact of a death, but normative or legal causality as well. This more nuanced and comprehensive analysis holds that empirical, scientific or "but-for" causality cannot alone account for what distinguishes assisted suicide from voluntary euthanasia, or what distinguishes both from withdrawal of life support or appropriate pain control resulting in death.[26]

This normative approach allows the but-for cause of death to be overridden as a cause of death if a society decides that public policy on a certain issue requires that the intervention or non-intervention in question not be viewed as a cause of death in law. As stated above, Australian courts already recognise that the but-for test is too limited. There is no tradition (in Australia or elsewhere) of regarding the relief of pain and suffering in the setting of a terminal illness, subject to proper standards of palliative care practice, as causative of death. Examples of this (and hence vindication of Keyserlingk's proposition) in action would be the several judgements and legal reports which have dealt with the issue of pain control in a terminal illness, even if the underlying premise is a hypothetical and untested construct that the use of opioids (in particular) in accepted palliative care practice may hasten death. [27] [28] [29] [30] [31] [32]

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[25] Mason CJ in March v E & MH Stramare 1991 65 ALJR 334 at 335, quoted by Mendelson D: Causation and proof of breach (unpublished).

[26] Keyserlingk EW. Assisted suicide, causality and the Supreme Court of Canada. McGill Law Journal 1994; 39: 708.

[27] Devlin LJ in R v Adams. Crim LR 1957; 365: 375. *If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life. This is not because there is a special defence for medical men but because no act is murder which does not cause death. We are not dealing here with the philosophical or technical cause, but with the commonsense cause. The cause of death is the illness or injury, and the proper medical treatment that is administered and that has an incidental effect on determining the exact moment of death is not the cause of death in any sensible use of the term. But ... no doctor, nor any man, no more in the case of the dying than of the healthy, has the right deliberately to cut the thread of life. See also* Devlin P ed. Easing the passing. In: the trial of Dr John Bodkin Adams. London: The Bodley Head, 1985.

Whilst a doctor's intention may not always be easy to validate, evaluation of intention and motive are fundamental to legal analysis, and many would argue that intention is also determinative of the moral character of medical interventions. For 'hard cases' where all reasonable and available measures have failed there may be occasions where the timing of death of a dying patient may be hastened with the intention of abolishing suffering, either slowly by sedation or rapidly by the administration of a lethal injection. At present the law and prevailing codes of medical ethics draw a sharp distinction between these two acts. It is preferable that this continues to be the case for the sake of social solidarity and the practice of palliative care.

The objects of two pieces of Australian legislation[33] send a powerful message to health care professionals, and their educators, about the priority which the legislators wish to be given to pain and symptom control for dying persons. *The Consent to Medical Treatment and Palliative Care Act (South Australia), 1995* - CMTPCA - is a specific example of Keyserlingk's suggestion in action, where a public policy position is taken that if there is thought to be a conflict between hastening the timing of an inevitable death, and proper symptom control, then the latter should have priority. The doctrine of double effect is used to deal with the issue of causation in palliative care practice. If an incidental effect of accepted palliative care practice measures is to hasten the (inevitable and anticipated) death of a person, then this is not deemed to constitute a cause of death in law, because such practice does not constitute a new intervening act in a pre-existing chain of causation (novus actus interveniens). This provision helps to correct the widely held false perception that the heavy hand of the law is waiting to land on the shoulders of practitioners who administer morphine to terminally ill patients (especially "the last dose"), but this indemnity from civil or criminal prosecution only applies if the treatment has been "in accordance with the proper standards of palliative care",[34] and does not apply to circumstances in which the

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[28] Airedale NHS Trust v Bland 1993 1 All ER 821-896

[29] Thomas J in Auckland Area Health Authority v A-G. NZLR 1993; 1: 235

[30] Law Reform Commission of Canada. Report No 20 Euthanasia, Aiding Suicide and Cessation of Treatment. Ottawa 1982; 35

[31] House of Lords. Report of the Select Committee on Medical Ethics. Vol 1 Report HL Paper 21-1 (HMSO, London 1994): 58

[32] Of life and death.. Report of Senate Special Committee on Euthanasia and Assisted Suicide. Senate of Canada, Ottawa May 1995; 19.

[33] see objects of Medical Treatment Act 1988, Victoria, and Consent to Medical Treatment and Palliative Care Act 1995, South Australia

[34] see Part, Division 2, the care of people who are dying. Consent to Medical Treatment and Palliative Care Act 1995.

practitioner's use of drugs is transparent with regard to their intention to bring about the death of the person, even as a means of relieving the suffering of a person for whom other measures have failed. Proponents of RTIA would argue that this next step is essential, and would agree with Hunt that there is a 'rhetoric-reality gap' in palliative care practice, and that RTIA closes it, by allowing active assistance in dying.[35]

RTIA only deals with causation for those persons who wish to have their death caused by another. It makes no contribution to the issue of causation in palliative care discussed above, unless possibly by extrapolation. What is the position for the majority of persons, who do not want assistance to die but do want proper pain and symptom relief ? It needs to be at least considered that the presence of RTIA, and its formidable conditions, on the statute book of the Northern Territory may generate a higher level of caution and misinterpretation of legal imperatives amongst medical practitioners than that which existed before its passage, particularly if palliative care and VAE become conflated in public and professional consciousness.

It is essential that the whole society comes to a better understanding of the standards and processes which it wishes to see applied to the care of dying people. Correction of the wide range of false interpretations of the legal principle of causation is fundamental to this endeavour. The limitations of 'but-for' causality analysis in the context of palliative care should be recognised.

Acts and Omissions

The moral equivalence argument between acts and omissions which result in death advanced by Rachels,[36] Singer and Kuhse[37] have not found widespread support amongst practising doctors, nurses and other health care professionals. There is still a substantial body of medical opinion which defends the viewpoint that there are strong intuitive moral and clinical distinctions between stopping absolutely or relatively futile medical treatment and giving a lethal injection. For the omission to be morally equivalent to the latter act, it is

[35] Hunt R. Palliative Care - the Rhetoric-Reality Gap in Kuhse H (ed), Willing to Listen, Wanting to Die (Penguin, Melbourne 1994)
[36] Rachels J. The End of Life (Oxford University Press, Oxford 1987).
[37] Kuhse H. The Sanctity of Life Doctrine in Medicine: A Critique. (Oxford University Press, Oxford 1987)

necessary for the omission to be demonstrably still working to the patient's benefit in prolonging that person's life. In other words the moral equivalence argument cannot ignore the assessment of clinical proportionality and appropriateness. For a competent patient who expresses a wish to reject any medical treatment whatsoever this has been clearly accepted as morally and legally permissible, and the issue is not controversial. If the omission is made for an incompetent patient who is not in the process of dying, and the treatment to be omitted can be shown to be life sustaining in the circumstances, then the intention is to end that person's life, and it might be better to call this non-voluntary active euthanasia by means of an act of omission.

This was the situation in the Bland judgement, where Singer reiterates the point that the clearly intended outcome of the decision to stop nasogastric feeding and hydration was to end the life of Tony Bland.[38] ,It therefore appears that there are situations in which it is agreed that the life of an incompetent non-dying and permanently unconscious and insensate person may be intentionally ended. This practice should be clearly differentiated from that of palliative care for persons who are dying, where the intention of all therapeutic interventions is to relieve symptoms. Although palliative care measures may be applied to a patient such as Tony Bland, despite the fact that he is no longer sensate, the principles of palliative care practice do not underpin the decision to withdraw life sustaining measures and end of life.

In the Bland judgement their lordships decided that the cause of death was the initial injury rather than the cessation of artificial hydration and alimentation,[39] but this over-reliance on the underlying disease or injury as the cause of death has been disputed. Gerber has called it "the logic of Alice in Wonderland".[40] Collins writes that it is "susceptible to penetrating intellectual assault".

Both Keyserlink[41] [42] and Collins argue that act/omission distinctions should not be the principal determinative factor in assessing criminal or tort liability, and Collins particularly

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[38] Singer P. Rethinking Life and Death (The Text Publishing Company, Melbourne, 1994).
[39] Airedale NHS Trust v Bland 1993 1 All ER
[40] Gerber P. Withdrawing treatment from patients in a persistent vegetative state. Medical Journal of Australia 1994; 161: 715.
[41] Collins D. prescribing limits to life-prolonging treatment. New Zealand Law Journal 1994; 246.
[42] ibid

opposes the emphasis of this distinction in determining the legality of cessation of artificial hydration and alimentation in the Bland case.[43] Mendelson has pointed out that the reasoning in Bland was based not on causation, but what constituted an ethically acceptable limit to the medical duty to continue treatment.[44] Because it was shown to the court's satisfaction that it was not in Tony Bland's best interests to continue as he was in an irreversible persistent vegetative state, the cessation of life sustaining measures did not constitute a breach of duty to the patient as no such duty was found to exist in the circumstances. However, it is not a generalisable clarification of the distinction, and could not be applied to permanently incompetent non-dying persons who are permanently unconscious and insensate. Consequently RTIA does not take up the challenge issued to the British parliament made by their lordships in Bland, and so this area remains unresolved in the Northern Territory unless a notice pursuant to the *Natural Death Act 1988* has been completed.

Treatment abatement (with the intention of causing death) for incompetent, non-dying persons who are permanently unconscious and insensate should be clearly differentiated from palliative care.

It would have been preferable for the Northern Territory to address palliative care access and quality upgrading first, then promulgate and assess process and treatment guidelines for the care of dying people and medical decision making at the end of life. Legislation could have been considered to allow for advance directives, substitute health care decision making and clarification of causation in palliative care practice along the lines of the *Consent to Medical Treatment and Palliative Care Act (South Australia) 1995*.

Palliative Care Services In The Northern Territory

In an enclosed paper I have argued that the *Rights of the Terminally Ill Act 1995* (NT), in legislating for voluntary active euthanasia, should not be seen as a substitute for the

[43] ibid
[44] Mendelson D. The Right of the Terminally Ill Act 1994 (NT): Another perspective. Journal of Law and Medicine 1996;

provision of palliative care (Attachment IV). Palliative care services are very limited in the Northern Territory. Both access and quality of specialist services are now below levels which exist in most other parts of Australia. The promising comments which I made at the time of writing the paper about the focus which RTIA had brought to palliative care does not seem to have translated into improved funding or service provision.

The demographic and geographical realities of the Northern Territory dictate that most palliative care must be done by general hospitals and community services as part of mainstream health care. The community palliative care service in Darwin is the only specialist service in NT. It is under-resourced and has had a considerable turn-over of staff since its inception. There is no formal medical link with the Royal Darwin Hospital and the medical position is presently unfilled.

The main contribution which senators could make to the improvement of the care of dying people in the Northern Territory is to advocate for adequate resources to be made for the following:

- ***substantial palliative care specialist medical positions in Darwin and Alice Springs***
- ***expert palliative care nursing access (including deployment of specialist nursing expertise to patients in remote areas when needed)***
- ***palliative care education***
- ***back up consultancy from larger services in other states (notably in Adelaide where most of the tertiary medical input in the Northern Territory comes from).***

Senators might also reasonably ask for an independent review of present palliative care service provision, management and funding allocations to the Northern Territory.

Palliative Care Education

The draft Australasian Undergraduate Medical Palliative Care Curriculum is also appended (attachment IV). This document is being developed by a small working group of ANZSPM (Australia and New Zealand Society of Palliative Medicine) to promote better education in palliative care in the medical schools of Australia and New Zealand. A reading of it will hopefully demonstrate how much needs to be done, in educational terms, to redress past neglect of the needs of people who are dying by the medical profession and the health care system.

Senate support is sought for the provision of resources to provide palliative care education at all levels of the Australian health care system, including the Northern Territory.

THE CONSTITUTIONAL IMPLICATIONS FOR THE TERRITORIES OF THE ENACTMENT OF THE PROVISION

THE IMPACT OF THE ENACTMENT OF THE PROVISIONS ON THE NORTHERN TERRITORY CRIMINAL CODE

The major problem with the *Euthanasia Laws Bill 1996* is that it conflates two issues, namely euthanasia and the legislation scope of the territories of Australia. It clearly leaves the citizens of the territories in a different situation with regard to these issues to those of states, and this is unsatisfactory.

Professor Michael Ashby
MBBS MRCP FRCR FRACP MRACMA

11 December 1996
Word count : 5397

Mr STIRLING: We have heard much on the question of palliative care as the committee has travelled around the Territory. I can assure you that it will be a strong part of the report. There is a need to look at the needs of the terminally ill. The whole palliative care issue has to be addressed and given the proper resources that are required. I was interested in your comment that this committee had no power to make any recommendation. That is not the case. This committee is within its own power as to what form its report takes and what it states. I am not sure how you understood that?

Ms BERECRY: There was nothing in the terms of reference that said that you had the power to make recommendations to parliament.

Mr POOLE: We tend to be like most parliamentarians and utilise the unwritten word rather than the written word on things like that. We will certainly be making a report to the parliament. Now, whether or not ...

Ms BERECRY: But a report is not a recommendation, is it?

Mr POOLE: The report will contain a number of recommendations.

Ms BERECRY: Recommendations, I see. Thank you for that.

Mr POOLE: Now, we are not there to recommend to the parliament that the bill go through or not go through. We are there to recommend whether it is a good bill technically or is poorly drafted. We can highlight areas that we feel need to be addressed.

Ms BERECRY: I think that was the key area. Whether the bill should go through or not is another thing. You have not got the power to say ...

Mr POOLE: I guess, if we decided amongst ourselves, we could. We probably would not because we probably would not all agree.

Ms BERECRY: No, right.

Mr POOLE: I think the duty we have to the people of the Northern Territory and to the parliament is to make sure that everybody is aware of the pros and the cons and that they are properly debated so everybody does that from an informed position. We have already picked up things like the 12 month period, the possible need for a cooling-off period, those sorts of things. We have not come to a firm decision on them but they are all points that we will be talking about by ourselves in the committee process.

Ms BERECRY: Yes, I see. Thank you for that.

Mr POOLE: Well, thank you very much for appearing today. It was very clear and concise. Thank you.

SELECT COMMITTEE ON EUTHANASIA

PUBLIC HEARINGS

Elsey Room, Parliament House, Darwin

Monday 10 April 1995
Opened: 10.40 am

On the committee:

Mr E. Poole, MLA
Dr R. Lim, MLA
Mr M. Rioli, MLA
Mrs L. Braham, MLA
Mr S. Stirling, MLA

Ms P. Hancock, Secretary

Representative:

Professor Michael Ashby, Consultant Physician

Note: This is an edited transcript.

Issued: Thursday 4 May 1995

APPENDIX 18

Mr POOLE: I call to order this hearing of the Select Committee on Euthanasia and welcome Professor Michael Ashby, Director of Palliative Medicine and Radiation Oncologist, Royal Adelaide Hospital, who is appearing as a witness to give evidence.

Other than in exceptional circumstances witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that the committee has authorised, for the purposes of this inquiry, that the usual proscription on the disclosure or publication on material placed the committee does not apply.

Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case.

Professor ASHBY: There is no requirement on my part.

Mr POOLE: Thank you. For the Hansard record, could I ask you to state your full name and the capacity in which you appear today.

Professor ASHBY: Thank you. There has been a change of detail in that I have moved from Adelaide to Melbourne. My name is Professor Michael Ashby. I am a consultant physician and a Fellow of the Royal Australasian College of Physicians. My present post is Professor and Director of Palliative Care, Monash University based at the Monash Medical Centre in Clayton, Victoria.

Mr POOLE: Thank you very much. Professor, what we have been doing so far with witnesses is allowing them to speak to the committee, to make whatever submission they want to make. We then go into a question and answer format. We have allowed a fair length of time, so it is really up to you as to how much of that time we utilise.

Professor ASHBY: Perhaps the easiest thing for me to do at this point would be to say that I was involved with the drafting of a policy statement on voluntary active euthanasia for the Australian Association for Hospice and Palliative Care. I do not appear today as a spokesperson for that. Indeed, I hold no elected office in that organisation at the present time although I have in the past. I was requested by their executive to produce a discussion document and a draft policy. That has now been adopted in Victoria and I think is well on the way in other states and territories. As I was responsible for drafting that policy statement, it might perhaps be helpful if I briefly go over it because it does broadly define my viewpoint on this issue.

What we set out to do first of all was to define hospice and palliative care as a concept of care which provides coordinated medical, nursing and allied services for people who are terminally ill to live where possible in the environment of their choice, and which provides physical, psychological, emotional and spiritual support for patients and for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement support for family and other carers during the life of the patient, continuing after

death. We have defined voluntary active euthanasia as the deliberate action to terminate life by someone other than and at the request of the patient concerned. We believe that dying is a natural process and that the refusal or withdrawal of futile treatment is not voluntary active euthanasia.

We believe that legalisation of voluntary active euthanasia is not a substitute for the provision of palliative care services to all Australians. We believe that public interest in voluntary active euthanasia reflects concern about lack of adequate support for people who are dying and will continue to campaign for improved services, education and research in all aspects of palliative care. We state that currently accepted palliative care practice does not include deliberate ending of life even if this is requested by the patient. We assert that palliative care experience shows that the skilled adjustment of a morphine dose for pain relief does not cause death.

We recognise that there is a wide divergence of views about voluntary active euthanasia in Australian society and also within the caring professions including the palliative care community. We recognise and respect the fact that some people rationally and consistently request voluntary active euthanasia. We acknowledge that, while pain and symptoms can be addressed, complete relief is not always possible in all cases even with optimal palliative care. We welcome open and frank discussion within the community and particularly within the health care professions about all aspects of death and dying including voluntary active euthanasia.

You will seen from that that the position emerging amongst palliative care workers in Australia is that many of us now want to remove our specialist or sub-specialist area of medical or nursing multi-disciplinary practice out of the debate in a sense of not going to bat for one side or the other in a polar debate about voluntary active euthanasia. We believe that, when requested, we should provide committees like this with the information that you need about what we really do and what our intentions really are in the manner in which we treat our patients.

It would be wrong of us to use our skills and our special knowledge and experience on one side or other of the societal debate. I do not believe that it is any longer appropriate for palliative care workers to suggest that they can control all patients' pain, or that they can give meaning to the end of life when the patient feels that their quality of life is so poor that they do not wish to live any longer. I do not think that any professional person should be in the business of saying they can always turn that around and make what the person would want.

Just as palliative care is predicated on recognising the limitations of medicine and addressing the care needs of the patient when cure is no longer possible, so too we in palliative care have to recognise our own limitations. These include clinical limitation, and human and spiritual limitations. This includes recognising that some of our patients do wish to die and say so consistently.

Having said that, it is a relatively infrequent occurrence. In my experience, it would happen a handful of times a year - maybe 10 or 20 but no more. Most of those requests are modified a few days later by a change in the circumstances, either through symptom control, better emotional and psychological adjustment to the situation, or maybe some readjustment of family dynamics or support that was not apparent before.

However, I have to say that there are a few patients for whom that is definitely not the case. On a recent study tour last year to Canada, I came across the story of Sue Rodriguez. I believe that you have already received references to that Canadian case. I actually read the judgement. As a doctor, reading a legal case was quite a challenge. But it certainly assisted me greatly in my personal deliberations on the subject. I have submitted a copy of the full judgement to this committee to be photocopied and placed in evidence before you.

There is a book whose details I would like to place on the record for reference. It is Birnie L. and Rodriguez S. *Uncommon Will - The Death of Sue Rodriguez* (Toronto, Macmillan, Canada 1994). I do not think it is available in Australia at the present time. It is the authorised biography of Sue Rodriguez. I was particularly struck by the fact that she states on a number of occasions that the palliative care services in her area are not helping her in achieving what she seeks and she therefore distances herself from them. I think that we have to hear that there would certainly be a small part of our community here in Australia which would probably feel the same way.

It is also perhaps worth both pointing out that in many documented cases of medical assistance in dying, the patient is not actually terminally ill at the time of the request. Indeed, the reasons for making such a request may well not be just the objective tests of uncontrolled pain and suffering. There may be chronic disability or in some cases chronic mental distress, areas in which palliative care as such is very poorly equipped to assist. That is not to say that we would not try to help if such people are referred to our services. Obviously, however, in an area such as mental health, that lies completely outside the field unless the person has a terminal illness.

To just round off my verbal evidence today to you, which I will keep brief, I will say that I think there are many of us in palliative care who, if we were in your assembly when the bill came before us, would probably abstain rather than vote against it. I am speaking here as an individual and not for any organisation which employs me or of whom I am a member. My personal reason for doing that is that I think that I have no good argument against the kind of arguments that were put forward by Max Charlesworth in his recent book, *Bioethics in a Liberal Democratic Society* (Cambridge 1993). Charlesworth says that he can come up with no good argument in a liberal democratic society against individuals who consistently request active help in ending their lives. He could find no good argument not to allow them that right. As a palliative care practitioner and as an individual, I do not feel that I have any good arguments against that position.

That having been said, the really important issue for me is my professional role. Given my role as a professor of palliative care, one of a small number of people in Australia in that kind of academic position, I have to say to you that there still remains a lot to do in palliative care. I am sure you have already heard this more times than you want to hear it.

Here in the Territory, by virtue of distance, I suspect that a lot of patients do not receive optimal palliative care. The Northern Territory is not alone in that. There are many areas where the tyranny of distance does not rule and where, for other reasons, palliative care is not being delivered adequately. Coverage around this country is still patchy and indeed it is patchy in all countries. I do not think Australia should feel particularly singled out and I am sure that is not the case.

If you are a medical practitioner aged approximately 35 years or more, it is highly unlikely that you had any adequate undergraduate teaching in this area. It is possible, in fact highly probable, that your medical school had no curriculum to deal with chronic pain. I think that the reason for this was that medicine until very recently was solely focused on curative endeavours and all other endeavours were regarded as somehow disappointing, second rate and not worthy of scholarly and professional attention. I can still remember days in my own medical school in London in the late 1970's when doctors would regularly with the best of intentions lie to their patients in euphemistic ways, particularly about a cancer diagnosis, would not speak openly about death and dying, and would uneasily move away from the bedside of a dying patient because they did not know what to say or what to do.

You will hear from others before this committee and probably have already heard a considerable amount about the history of the hospice movement in the United Kingdom. It has spread right around the world, which has been a very remarkable change in focus of medical attention in the period of just over 25 years. There has been quite a dramatic change. However, the movement is not universal. For example, I do not think there is a single academic position in palliative care in a medical school in the United States of America. There are a few people with an interest but they do not actually put it up front. I know of one major US health care institution which will not allow its world class pain unit to be renamed a palliative care unit because that is not in the philosophy of the institution.

That is certainly not the case here in Australia. I am pleased to see increasing recognition for palliative at all levels of society and I believe that it has received good support from governments in this country. However, I believe that here in the Territory there are some important provisions to be addressed, notably the provision of dedicated beds. I do not believe it is necessary for it to be an expensive, free-standing, separate hospice facility. Indeed, given the population distribution and demographics of the Territory, and there will be something to be said for the beds actually being located in small strategic numbers in the major hospitals of the Territory.

Obviously, there is an urgent need to make sure that community medical and nursing skills are nurtured and supported so that people can die in comfort and dignity in the far flung corners of this Territory. Certainly, it is a deficiency in my view, for instance, that at the moment it would be very difficult for a specialised palliative care nurse to go to an outback location. He or she would have to vacate their position here in Darwin to do that. Some backup to be able to do that would be cost effective and would greatly assist in the care of the dying.

Without going into my view of how palliative care could be better done in the Territory in detail, which you would not necessarily want to hear, I think that there are areas of endeavour to be looked at. If the process of reviewing the bill allows a comprehensive review and improvement of palliative care facilities here in the Territory, that in its own right will be a very significant achievement which this Assembly could take pride in. If, however, the bill is just viewed as the matter in hand, the worst scenario of all in my view would be for the parliament to pass it and do nothing about palliative care. To do that would be to do itself and its community a grave disservice. The scrutiny of the rest of Australia and the world would shine very sharply on this Territory and I would suspect that there would be a lot of negative consequences.

I think I will leave it there. Now I would be pleased to answer any questions or hear any points that you want to make to me.

Mr POOLE: If I hear you correctly, even if we did live in an ideal world and the Northern Territory had palliative care facilities ranked with the best in the world, at the end of the day a small percentage of people still would not be kept in a comfortable or tolerable state by palliative care services and might well request assistance to end their lives anyway.

Professor ASHBY: I believe that to be a true statement.

Mr POOLE: You said only a handful of people, perhaps half a dozen or so in your personal experience, ask for that. Some of those obviously change their mind because of changes in their mental state or their physical condition. What total numbers are you talking about? Are you talking about a couple of hundred patients or ...?

Professor ASHBY: No. I would be talking about my experience in my last position, which I only recently left. We were getting approximately 800 referrals a year. Of course, as you will see in your evidence, people do not necessarily ask their doctor for assistance in dying. They may well feel that that person would be affronted or offended, or that there may be some legal implications. However, over the last few years since I came back to Australia in 1989, I have found that more and more people now are saying openly that they wish they did not have to go through the last bit of the illness. Gradually, patients themselves and families are talking much more openly about it. I think there was a feeling, particularly if you were in a Catholic health care institution, that you should not even mention the words.

If somebody raises the issue with me in a covert and subtle way, subject to the sensitivity of the circumstances, I would actually tease out what they are driving at and actually name the words. I would ask them: 'Are you talking here about voluntary active euthanasia? Do you want me to help you to die?' I think that if you can actually clarify what the person wants, we can have a conversation about what I can and cannot do and what their reasons for that might be. We can acknowledge that this is not an ideal world and we do not always get what we want. The idea that, in some cases, we can somehow sanitise and medicalise death and turn it into some kind of calm, peaceful event is probably seeking too much control.

I think that is a major issue for those of us who are the tail end of the baby boomers or the me generation, or whatever you care to call it. We are really used to having incredible control over our own destinies. We have a strong investment in our careers, our choices and our rights. I am not saying that that is bad. Most of us would say that it is a defining aspect of our existence that we are lucky enough to live in a time and a society where we have probably never had better recognition of our rights and probably never had more control over our choices in life. But the idea that we have control over everything is quite illusionary. It really is a transient illusion, and I suspect that it will be looked back on with some amusement by future generations, that somehow we can make the last bit of our lives as full of choices as the rest of our lives. I think that is fatally flawed.

I went to a meeting recently in Canada. One of the Canadians joked about the United States and said: 'I get the impression that, south of the border, there is a widespread view that death is optional'.

Mr STIRLING: Professor, I think that is a very interesting point. We have often said that the baby boom is a very selfish generation in Australia. By virtue of its size, it is able to dominate everything that is going on. It is interesting to speculate that this drive for choice may well have arisen from that. However, I want to refer to the Rodriguez case. She was suffering ALS which I took or understood to be some sort of MS.

Professor ASHBY: No, it is not. ALS is a form of motor neurone disease. In the US, it is known as Lou Gehrig's disease. That is like saying it is O J Simpson's disease. Lou Gehrig was a very famous baseballer. Everywhere in North America you will hear it referred to as that. ALS is just Amyotrophic Lateral Sclerosis, which is an old fashioned name for what the neuropathologists saw down the microscope when they dissected the nervous tissue of people who had died of this condition. The best term to use is Motor Neurone Disease or MND for short. Everybody in Australia will then know what you mean. There is an MND Society of Australia, which is the national association for patients and families.

It is a rare condition. If you want to know any more about its care in Australia, one of the places that particularly specialises in it is Bethlehem Hospital in Caulfield, Melbourne, close to where I am now working.

The feature of this disease is that it can have a very variable natural history. One of the longest stable sufferers is Stephen Hawking. A colleague of mine recently died of the condition within a few months in Adelaide, and that was a devastating course. It gradually robs the person of virtually all neurological function. Particularly early in the piece, it can interfere with speech and swallowing. It is quite a hideous way to die. Multiple Sclerosis can do the same thing incidentally, and a number of other neurological conditions can lead to the slow physical disintegration of person with comparative sparing of mental function.

What Sue Rodriguez was saying - and I really think her arguments were very powerful although the legal basis for it is more questionable and outside my area of expertise - was that she did not want to go through the last bit, even if she was not aware of it. She said: 'The

reason for that is that I do not want my 9 year old son to see it and I do not want my estranged husband to have to witness, even if I never know anything about it. It has no meaning to me. I want to say that up front and now because I know that, when I get there, I will be able to say nothing about it.

Mr STIRLING: This is the dilemma.

Professor ASHBY: It is the dilemma. I do not believe that any hospice or palliative care organisation could honestly say that they had a good answer for Sue Rodriguez' dilemma. As you know, she took it all the way to the top of the Supreme Court of Canada and she won very substantial sympathy. If you look at those judgements and read between the lines - and the Chief Justice of British Columbia and the Chief Justice of the Supreme Court of Canada both voted in her favour and gave dissenting judgements in her favour - you can see, according to my interpretation of what they are saying, that they would really like to help this woman and on humanitarian grounds they actually agree that it is reasonable for her to have a lethal injection. However, given that the case was framed in certain legal terms, how were they to get to the outcome that they would have liked to see? The tried many convoluted legal arguments to try to get from that point to this. (Reference: Rodriguez v BC (A.G.) [1993]3 SCR)

I think that happened in the Bland case too. No doubt you have received evidence about the House of Lords appeal decision in the case of Airedale and AHS Trust versus Bland in the UK. Similarly, you can see enormous sympathy from the judges on the bench for the dilemma that the family and the doctors are in. You can almost see them trying to make the legal deliberative process come to the conclusion that they would like to see from a human perspective. (Reference: Airedale NHS Trust v Bland [1993]1 All ER 801-896)

Mr POOLE: Looking at the Northern Territory from a current palliative care point of view, I guess it would be reasonable to assume that no matter what we did as a government, you would only ever expect to see palliative care centres in Alice Springs, Darwin and possibly larger centres such as Katherine and Tennant Creek. You would never see them in small settlements of a couple of hundred people. What sort of numbers are there in palliative care services in the larger centres down south. In a place such as Adelaide, are there 400 beds or 50 beds, for example? I am just trying to get some equation in terms of the population of the Territory.

Professor ASHBY: I am afraid that I do not have the precise bed numbers for metropolitan Adelaide. If you wish, I can provide that as separate written evidence or ask one of my Adelaide colleagues to do so. The Australian Association for Hospice and Palliative Care has a ideal figure which, if I recall correctly, is 50 beds per million of the population. Again, I would like the opportunity to cross check that. The association could submit it in evidence to you. In fact, if you have not received a formal submission from them, I think it would be important for you to request one and particularly to flag that kind of issue to ensure those figures are accurate. I am sure that can be done without any problem.

Mr POOLE: Using those figures as a rough guideline, are you basically saying that that is a sensible figure and the needs for palliative care, for example, in New South Wales are reasonably well serviced? Or would you say that they should have far more beds in an ideal world.

Professor ASHBY: I think it is not so much a question of bed number as bed distribution and bed function. If you are looking at acute hospice care, which is what I have mainly been involved in, I would say that for a community of the size of the Top End - say the greater Darwin area and the areas that it serves, possibly extending as far as Katherine and Tennant Creek - you would probably be looking at somewhere between 6 and 8 beds for specific symptom and pain control where patients could be sent for complex problems. I would suggest that that would be in the hospital, so that you could tap into all the resources and scales of economy that you get by being in a hospital rather than being in a free-standing site.

Respite, however, obviously has to be closer to the patient's home. So it might be important to have 1 or 2 beds designated, if not dedicated, in the other hospitals in the Territory. I guess you would be looking at Tennant Creek and Katherine, and naturally Alice Springs. You should have some designated beds and a skill base or area in the hospital where a patient with palliative care needs can go for respite or symptom control for that matter. It will not always be realistic or appropriate to fly very sick people or drive them long distances in the Territory.

The issue is not so much bed numbers as the skills that exist when the person gets there. I have seen this as a problem in a number of isolated regional centres in rural Australia. A palliative care room is put in and a lot is invested in the fabric. They make a lovely room and no doubt it is great. But then you ask: 'What kind of expertise is there? Do you have anybody who is really good at cancer pain relief on the staff?' The answer may well be: 'We do not actually have anybody with that particular interest.'

Mr POOLE: That is actually the situation in Alice Springs. Whilst the room is there, they really do not have the staff to provide the services.

Professor ASHBY: That is right. I am familiar with that situation. The anaesthetist who is director of intensive care is just so busy with desperately sick people on ITU and going to cardiac arrests and so forth. It is unreasonable to expect a person in that role to be able to give an hour or two a day to looking after palliative care patients, liaising with community workers and trying to put in a palliative care service. Obviously, there is some valuable work going on there, but when you are that busy and doing other things that will inevitably be more pressing, it does not work very well.

Mr POOLE: And as a general rule, are these people available? When you are involved with government in the Territory, you hear quite a lot about the difficulty of getting doctors to go to the more isolated areas. I am sure that the outback areas of New South Wales, South Australia and Victoria probably have the same problems. Are there people

available if you did go down that road, who could be slotted in reasonably easily? Or is there a great shortage of palliative care providers from a doctor's point of view in Australia?

Professor ASHBY: You framed the question entirely appropriately to the answer. No, there are not. It is well known that it has been difficult to fill palliative care posts in the major cities. In the northern area of Adelaide, there have been enormous problems in finding a medical director. There are sessional appointments at several Melbourne hospitals where the field of candidates has not been large. So, I just do not think that is the way you can possibly approach it here in the Territory.

What we need is a network which practitioners can actually plug into easily, and more training. Education is almost an insulting word, as if the doctors do not know how to look after their patients. Most doctors do have some of the basic skills. However, if they were never taught how to do it at medical school, there will inevitably be some gaps. These are best filled, I think, by a good collaboration without you looking after a patient. They actually first need to recognise that there is a problem.

I have been involved in seminars up here in the Territory. I have given a number of talks, and I actually see the same faces there all the time. They are all the people who are doing it wonderfully well already. There are a number of GPs in this city who have what I would call a significant interest in palliative care and are already doing it very well. The problem arises when a patient is being cared for by a doctor, who through no fault of his or her own, has been trained in the era when medical education did not even look at the area. Such people may feel somewhat affronted by the challenge that they are not actually doing as well as they might.

I feel that it would be important for an organisation like the AMA to say: 'Right, we need to recognise this as a responsibility. All of our members need to acquire some competency in this area'. I put it to you that, if it was a new cardiac technique, the skilling would be rapid. It would be considered to be almost culpable negligence if you did not know about a major new development in the treatment of heart disease, let us say. If you were found, in a small town here in the Northern Territory, not to be referring your patients for coronary artery surgery when they have severe angina, somebody would ask a question somewhere along the line, saying: 'You are really behind the eight ball here. What are you doing?'

It does not seem to be like that in palliative care. Somehow it is not deemed important enough. I think all of us in professions have a tendency to feel a little confronted and angry when the torch is shone on our ignorance. We do not like it. It dents the model, the mould, the image. I think my profession is the same as any other and I suspect that I am like that too. None of us like having our deficiencies pointed out.

Mr POOLE: My interpretation of what you said in relation to pain management was that, because of lack of training I presume, pain relieving substances are sometimes given and as a result of increasing the patient's tolerance level and the increased dosage, the side effect

can be that the patient actually dies. We have had comment made by doctors and nurses that this does happen but it has always been stressed that the intention is to give pain relief rather than to actively kill the person. There are cases around Australia, as in Victoria, where doctors are springing up out of the woodwork and saying that they have done it. Do you think that a lot of that that goes on?

Professor ASHBY: How would one know? You have probably come across the Remmelink Report from the Netherlands. (See Van der Mans P.J., Van Delden J.J.M., Pijnenborgh et al. Euthanasia and other medical decisions concerning the end of life. Lancet 1991; 338:669-674.) When you start to ask doctors how they treat patients at the end of life, the main methodology has just been to say: 'What did you think you were doing; what were your intentions?' There is no way of validating that. There is no way that you can find out what they really meant or really did, unless you went back to the cases and looked at all the records blow by blow and milligram by milligram. You may on occasions find that they stated to you that they wanted to actively end a patient's life and you find that they increased the morphine dose from 5 to 500 in one day. It might be transparent as to what they intended.

I put it to you that, in actual fact, when you analyse all of these surveys, studies and cases, in a small number the intention was active ending of life. However, if you look at the Remmelink Report, the data is very deceiving. The doctors said that they have actively ended life when they stopped treatment that was not working any more. Here in Australia, we would tend to regard that as normal and sensible medical practice. Yet they are saying that it is some kind of active decision at the end of life, which brought about the death of the patient.

Equally with opioid analgesia - with morphine - you hear an awful lot. There is a very long tradition, in legal judgments and in committees of this sort, that there is some kind of dose of morphine where the danger of death becomes paramount and that there is some kind of conflict going on between pain relief and active ending of life. I really do not believe that to be the case.

There are other drugs used to sedate patients - because they are confused, agitated or distressed in some way - where the line might be finer with regard to the cause or timing of death. But I do not think that is a conflict with morphine. I think we need to lay to rest this ghost of the large dose of morphine that causes death. You escalate up to the dose that the patient needs for comfort. If, as I said you move from 5 milligrams to 500 milligrams 4 hourly in one step, it is obvious what you are trying to do. We have worked out steps of increasing the dose and titrating it against the patient's level of pain. Although it sounds very scientific, it is more of a clinical art. There is some science in there but we do not understand it. For some reason, the level of pain balances out the side effects of morphine that might be seen to be life ending, such as respiratory depression.

Mr POOLE: It has been described by a good doctor, who is a member of our committee, as a window which gets narrower and narrower as you increase the dosage. Occasionally, I guess people cross the line and the patients die.

Professor ASHBY: I do not think that is a common occurrence in the good practice of palliative care.

Mr POOLE: That is an interesting statement. You are saying that, when that happens, more often than not despite the protestations of the good doctors, in actual fact the intention is to kill the patient.

Professor ASHBY: No, I do not think that is what I am actually saying. If you ask doctors what they thought they were doing in a particular situation, some of them will say: 'That dose of morphine killed the patient. I gave it and I am comfortable with that because I was trying to relieve pain'. I would have to see those doses and the charts before I could actually comment. But I wonder whether they really are doing that when they say they are. I suspect that often they are not. On the odd occasion, I am perfectly willing to accept that they have given very large step-ups in doses with an obvious intention of actively ending life. I am not saying that it does not happen but I would not want that to be seen to be a kind of everyday occurrence and a dilemma and problem for the practice of palliative care. It is not.

Dr LIM: If I can explain a bit more, I was talking about the window of safety of increasing any therapeutic drug where, as the level of pain increases, the level of complications from medication would increase. Therefore your window of safety in effect gets narrower and narrower. However, we are never sure of where the line is in terms of tipping a patient over into dying. If you can achieve the window of safety, so much the better. But the moment may come where in fact your level or dosage is in fact the dosage which tips the patient over.

Professor ASHBY: I do not think the window becomes narrower as the dose goes on. In fact, the time when you might be most vulnerable to serious side effects is your very first dose of morphine. Let us say that you are an elderly person in your 90s with an undiagnosed mild renal failure. If you have 10 milligrams of morphine, I would put it to you that you would be more vulnerable to respiratory depression after that first dose than you would if you started on it and you got up to 35 milligrams 4 hourly by step-wise increases to the dose and titration against your pain levels. So I am not sure that the window necessarily does narrow quite as you suggest. I do not think we have a lot of good information, to be honest.

To respond to your second comment about the line being a fine one in palliative care, the answer is yes. It is often fine. With palliative care interventions, I think that we probably both increase and shorten life in different situations and it is often not possible for us to predict how. I have seen people who have come in looking almost moribund. You find out that pain is the real issue. You relieve the pain and they actually go on for many more weeks. Equally some patients start on morphine, get fairly rapid pain relief and just fall asleep and die. Sometimes, the relief of pain is like the relieving of a large burden and almost a stimulus to stay alive. For some people, laying down that burden is just such a relief. That is a very subjective remark but I have actually seen it happen a number of times.

I was referring to the Remmelink Report and I wonder if I could just quote from a paper that I am in the process of writing. It is about what doctors report in medical decisions at the end of life. I talk about the potential for misinterpretation of the data categories in studies such as the Remmelink Report from the Netherlands:

In a study of doctor's opinions about the nature of their clinical decision making for dying patients, 38% of 9250 deaths studied involved a medical decision at the end of life, or MDEL. But true reported acts of voluntary active euthanasia constituted only 1.8% of cases. Considerable concern has been expressed about the 0.8% who report as being subject to that of non-voluntary euthanasia, although as it turns out nearly all of these have previously discussed euthanasia with their doctors, were terminally ill and incompetent. (Organic brain dysfunction is a very common problem in terminal care, see Bruera and Wood et al). (Reference Bruera E. Cognitive failure in patients with terminal cancer: a prospective study. J Pain Symptom Management 1992; 7:192-5.)

Concerns have also been expressed that cases of VAE are not reported and this may conceal acts of non-voluntary euthanasia, although this is not an exclusively Dutch problem. The vast majority of reported MDELs - 35% - were either non-treatment decisions, the withholding or withdrawal of treatment in situations where the treatment could have prolonged life - 17½% - or alleviation of pain and symptoms with opioids and such doses that the patient's life might have been shortened - 17½% of cases.

Allocation of patients to these categories was determined by the doctor's opinions about the supposed consequences of their management. The majority of these decisions can probably be located in the domain of good palliative care practice and the authors were careful to avoid the conflationary term of 'passive euthanasia'. In particular the notion that 'large doses of opioids cause death' per se is flawed, although the use of large initial doses in opioid naive patients or large dose increases in patients who are on regular opioid analgesia regimes may reveal an intent to end life rather than relieve pain, and as such would not be considered to be part of palliative care practice.

Mr POOLE: In debate before this committee, it has been argued in support of the bill that it would be preferable in our society to at least know what is going on and that is a good reason to allow euthanasia. At least we would know, presumably, the number of patients per annum who were dying, how they were dying and so on. Do you wish to comment on that?

Professor ASHBY: Well, let us take a parallel situation. Domestic violence is something that until recently we did not know very much about. Most of it went on in the privacy of people's homes and it was only when it spilt out into the street or a body emerged that the police were involved. Nobody suggested that, as a way of gathering information about domestic violence, we should actually legalise it. So I think that argument is totally flawed. You might say that back-yard abortion is a better analogy. When it was illegal, it was still performed regardless of the legal penalties. It had always been performed. By legalising it, you brought it out into the open and the safety of women was far better protected. I am not sure that those arguments hold sway in quite the same way in the issue of voluntary active euthanasia. I think that would be a poor motive to change the law.

Dr LIM: One of the comments made recently about the policy of the Australian Association of Hospice and Palliative Care is that there is a softening of its attitude towards euthanasia. Is there a softening? Is the association shifting towards a position which is more likely to assist patients requesting euthanasia?

Professor ASHBY: The answer is no. This policy statement is intended to be a conciliatory policy that helps the Australian community to see where its palliative care practitioners stand. It shows tolerance for all viewpoints including all religious and moral viewpoints.

I would have to say that the process of drafting this document met with a considerable amount of concern amongst my colleagues that it be seen to be a softening of the line that palliative care as presently practised did not include the active ending of life. We obviously had to make that clear in the drafting of the policy, and we did.

I think it would be fair to say the majority of my colleagues in this country are opposed to the bill that has been put before your Assembly. For many of them, that is based on a personal and usually Christian religious worldview. For others, it is a matter of individual medical ethics and what they see as the tradition of the ethical basis of their profession. There would be very few members of this association who approve of the legalisation of voluntary active euthanasia as proposed before this Assembly.

I do not believe that they have changed their line but what I have sought to do, with a considerable amount of support in the organisation, is to achieve a situation in which we do not use our skills and knowledge, and our privileged position in society, to actively campaign for or against. We hope that this debate will improve the care of dying people regardless of what is put on the statute books of the Northern Territory. I would have to say that a substantial majority of the members of this association, be they medical practitioners, nurses, allied and other health care professionals and volunteers, would be opposed to Mr Perron's bill. That is not to say that there would not be an increasing number, as in the community, who support it or would not be opposed to it. I do not think there is anybody in our association who thinks it is the major issue.

Dr LIM: We talk about some patients who would never be able to obtain adequate relief of their pain and suffering through palliative care. What do you do with them if they ask that they should be given access to euthanasia? What do you do with them?

Professor ASHBY: That is a fair question. From a medical colleague, I accept it in good part that I can be faced with a practical situation where my rhetoric and my position as presented to you today presents a gap between what the patient is requesting and appears to need, and what I have said I will provide and what the law allows me to provide. So what do I do?

I think the first thing is to recognise the request as a reasonable and sane request. Clinically, you obviously need to see whether depression is present. You need to see whether

there is some aspect of the person's medical care or of personal support mechanisms which you can assist to put right or to improve for them. Having done that, you may still be faced with somebody who is making a persistent request.

Perhaps I can give you a case history which is obviously scrambled so it cannot be identified on the public record. It occurred in another jurisdiction. A young woman, who had very advanced metastatic cancer in her chest, was severely short of breath at rest. She had 2 young children and a mother who came from a European country which had made any thought of active assistance in dying quite repugnant to her. I will not identify that country but you can imagine a few options that would readily come to mind. The husband was supportive of the woman's request.

She came into the hospice at which I was working and really bailed me up. She said: 'Look, you can see how short of breath I am at the moment. With oxygen and a bit of radiotherapy to this lumbar that is pressing on my trachea, I will probably be all right to get home. But I know this is going to get worse. It is at the limit of my tolerance at the moment and it is just about getting to the limit of your capacity as a medical practitioner to control the symptoms. When it gets beyond that, I want to die'.

We worked through what it was that she feared. It was not difficult to do that. She obviously feared being uncontrollably short of breath as she died in front of her family, feeling that she was drowning. She feared that that would occur at home and there would be no assistance to her, and that she might spend even a few minutes, which would certainly be too long, in that condition. Worse still, she might spend a few hours in that state, which would be just grotesque.

What I did was to explain to her the limitations that I felt were in front of me. I said that, if she was getting towards a stage where that happened, I would be happy to supply and if need be administer medication that would make her unaware of that condition. I said that there may be a fine line in terms of the timing of her death but that I did not believe I would be changing the cause of it, and that I believed that no judge, no jury and no parliament would want to deny me making her unconscious during that dying process.

In fact, that did happen. I was called to the house some weeks later. As a result of palliative care intervention, she did actually have a time that, without being able to be described as comfortable, was acceptable to her. It was a precious time with the children at home.

When she felt she was going under for the third time, she actually put her hand up and said: 'Can you come out here?' I went out there. She was already receiving morphine and I increased her morphine dose, although not by a large amount. I actually increased the dose of a sedative drug in her subcutaneous syringe driver, to a level where she became much more sleepy and indicated that she was comfortable. I also wrote up top-up doses so that, if she woke up in agitation, there would be a fairly sizeable dose that would hopefully make her unconscious in a few moments. Therein lies your fine line. It is a fine line. Roger Hunt will talk to you a bit more about that because he has actually written about it.

Dr LIM: The question is, then, if you were to put a patient into an unconscious state, what is the difference between that and euthanasia?

Professor ASHBY: Between that and voluntary active euthanasia? I would say ...

Dr LIM: Voluntary requested euthanasia.

Professor ASHBY: I keep coming back to that because I think it is important to have one clear definition. It stops this public debate being hijacked into all kinds of other totally unfruitful areas such as Nazi Germany and so forth, if we are clear that it is voluntary active assistance in dying. When I say there is a fine line, I believe that I have possibly affected the timing of the death. That is why I said what I did then.

The South Australian Medical Treatment and Palliative Care Bill has now actually got out of its deadlock through a conference of both Houses in the South Australian parliament. That is a problem that you will not have. It has been passed. It contains a clause about the care of dying people, which talks about not intervening in a pre-existing chain of causation. It is referred to in Latin legal terms: novus actus interveniens, a new act intervening in the chain of causation of death.

I would say that, in the example I gave, I did not introduce a new factor in the cause of that patient's death. But it is quite possible that I affected the timing. If, after due legal deliberation and consultation, it was believed that I had practised so-called pharmacological oblivion - a term which you may hear Roger Hunt refer to - there is a dilemma in terms of crossing the fine line. That dilemma in a sense brings this whole issue to the boil and is the reason why you are sitting there and I am sitting here. It is a fine line. Anybody who pretends otherwise is just kidding themselves. I would still say that my intention is to relieve her symptoms. In order to be able to do what I do within the existing law in all jurisdictions of this country, that is the way I defend myself in front of a court. I may or may not succeed.

Dr LIM: Accepting all that, the passage of this bill would take away that grey area. It actually would safeguard your actions.

Professor ASHBY: Yes.

Dr LIM: Some patients suffer from terminal hypoxia or just choking to death - which would probably be one of the worst types of dying I can possibly imagine. This bill will actually allow such patients a very comfortable way of dying. Marshall Perron might say to you that this is the sort of case which he is explicitly trying to help.

Professor ASHBY: Yes, and I accept that intention. However, it would not be fruitful for me to second guess the evidence that you will receive, far more articulately and appropriately put, by others who will be called before you. They will oppose that position very strongly and give you many reasons why that is not the case.

It seems clear to me that this legislation, if passed, would cover that eventuality and in a sense would regularise something that is already happening. That is if the interpretation and legal advice received is that it is cold comfort to say that the doctor in a double effect is protecting you in those actions, in those extreme cases where it could be argued that, in order to abolish the suffering by rendering somebody unconscious, you might as well say that is the same as administering a lethal injection.

The question could be asked: 'How do you know how many milligrams will make the person nice and sleepy and then they will naturally die, as opposed to the number of milligrams that will just stop the person breathing in a few minutes or half an hour or whatever, in which case you might have been said to have actively ended the life?' No doctor, I believe, could sit here in front of you and say: 'The answer is 50 milligrams of whatever drug for this outcome and 55 milligrams for that outcome'. That is not possible. But you will receive a lot of evidence to say that, if you want to legislate for those hard cases at the end of life, we can understand you wanting to do that. However, hard cases make bad law. Look at all the other consequences of putting in a law like that.

There is a precedent here that is well accepted virtually everywhere in the palliative care world. It had a very powerful impact on your colleagues from the ACT when they were looking at Mike Moore's bill. I invited them to a team meeting at the Mary Potter Hospice. They agreed, of course, to observe confidentiality and so forth, and just sat in on the team meeting.

One of the patients had a large mass in the neck which we thought might erode the carotid artery causing the patient would haemorrhage to death - an horrendous scenario. Going back 20 or 30 years, patients who are at risk of this complication, who are being looked after properly in cancer hospitals and head and neck units, would have a dose of morphine written up which is called a haemorrhage order. That haemorrhage order is clearly a lethal dose of morphine. If the patient is on 5-10 milligrams 4 hourly then this would often be for 20, 30, 40, or 50 milligrams. The idea was that, rather than let the person drown and haemorrhage to death, you would actually very quickly put them to sleep. That has been accepted practice. I am sure that, as I said before, the opponents of the bill before your Assembly would say: 'For heaven's sake, do not legislate on those hard cases. However, they are food for thought'. That has been accepted practice.

No doubt you have talked to that committee or received its evidence. The interesting implication for that committee was that, knowing that that could be done safely as part of existing practice and under existing law, presumably in South Australia and elsewhere, there was less drive and imperative to pass the Voluntary and Natural Death Bill that was proposed by Michael Moore in the ACT Assembly.

Mr STIRLING: Nevertheless, that does not solve the Rodriguez case.

Professor ASHBY: Quite right.

Mr STIRLING: There is always an exception. In terms of the bill itself, do you want to comment on any specific clause or on any weaknesses, deficiencies or dangers that you perceive?

Professor ASHBY: First of all, I just want to make a comment on the interpretation section. In part 1 clause 2, under the health care provider definition, I am not sure why you have lumped buildings and nurses together. No doubt the ANF will have already wondered why providers can be an institution or a nurse. I think you should clarify there that a nurse is a practitioner linked to a register. It might perhaps be better to define a nurse and give them the same recognition that you have given to medical practitioners. They are registered under the appropriate legislation in your Territory and no doubt they will be making separate submissions to you about the role of nurses in any proposed legislative changes. That is a trivial point but when I read it, it was immediately apparent to me that apples and oranges were being dealt with under the same clause. You have a drafting issue to be looked at.

Clause 6 concerns conditions under which a medical practitioner may assist. These strike me as being as reasonably stringent as they could be. You will no doubt be comparing them to the conditions that are imposed in Holland under the guidelines which have now of course been voted on by their parliament and adopted. It would certainly be interesting to compare them to the conditions set out by the Chief Justice of British Columbia and the Chief Justice in the Supreme Court of Canada. I think that they are roughly the same and in a sense, I think they show you just how hard this is going to be.

I know that Marshall Perron has been quoted in the press as saying that, if his bill was passed by the Assembly, few people would avail themselves of it. Presumably, his liberal democratic view is that they ought to be able to do so, even if the procedures that he has to draft in his bill are cumbersome and intrusive of privacy, as they are.

The idea of introducing a second medical practitioner into a home of a dying person for the sake of fulfilling the law is something that could on occasions be quite intrusive, disruptive and difficult for the patient and family. However, I am sure that it is essential to ensure that the clinical facts are as put to the patient and as quoted in the medical record.

In paragraphs (c) and (d), you have made the activating illness one that will end the patient's life in approximately 12 months. This is very difficult to determine. I appreciate that in drafting of law, you have to provide a number and be categorical rather than vague. You have left it open as to whether it is severe pain, suffering or distress. I assume that this could include mental distress, which makes it fairly wide, but still has to be in the framework of an incurable illness that will kill the patient within 12 months.

Mr POOLE: There has been some debate about 'distress' and whether it could be removed from it or not.

Professor ASHBY: If you look at the people who are reported to have received assistance in death, I am sure that there would be those, particularly in voluntary euthanasia

societies, who very much want to retain that breadth. When you really look at the number of cancer patients in 'excruciating terminal agony' who would be requesting assistance under the provisions of this bill, I suspect that it would be really quite small. There are, however, a number of people in Sue Rodriguez' position who no doubt would wish to avail themselves of it. It may well not be pain as such but loss of function that motivates them to make that request.

Mr STIRLING: Which is suffering and distress.

Professor ASHBY: That is right.

Mr STIRLING: In that Rodriguez case, it would be difficult to determine that 12 month period, I suppose. In those situations, there would be the dilemma of both remaining competent to make a decision under the bill and to be within the 12 month period in the opinion of a doctor.

Professor ASHBY: Yes. Within the reasonable body of medical evidence that is available on that particular topic, which would be substantial, the way you would probably address that would probably be to look at the rate of deterioration. With a recent case in which I was involved, I would have had no hesitation in a legal setting of saying that the overwhelming likelihood was that the person would die well within the 12 month period because of the rate of deterioration. At the end of the day, it is a clinical judgment. Like any other judgment, it could be wrong. I believe though, that in drafting the figure of 12 months, you have left yourselves open to assisting somebody like Sue Rodriguez.

I do not have any other comments about this bill which I received recently and have had an opportunity to read. Like many such documents, it is only many weeks later that you suddenly focus on something that you realise that you would like to reword. No doubt, in the process of your deliberations, aspects of it will become clear to you. In terms of meeting the objectives that it clearly sets out to meet, it seems to be a reasonable bill. To my mind, it does not contain any glaring errors from a palliative care physician's prospective, which is the prospective you asked me to present to you today. Obviously, you will receive other evidence on its legal implications.

Dr LIM: There have been suggestions that it might be open to abuse, that some general practitioners would go into collusion and start up an industry. Would you like to say anything about that?

Professor ASHBY: I do not believe that there is a danger of that. You would be talking about gross criminal activity. It is of course possible, but I think highly unlikely. I suppose it would not, in my view, necessarily be a reason for voting for or against this bill. You could argue that there are plenty of other statutes that 2 doctors could get together and fiddle, if they wished to, for some ghastly criminal motive.

Mr POOLE: Right. Is that everything?

Dr LIM: It would be an interesting question but I would not put it to you. It is just that you are asking us to abstain rather than to vote one way or another. I wonder how you would vote. That is all. But I do not think it would be fair to ask you that question.

Professor ASHBY: Well, I am happy to answer it and I do not think I should shrink from so doing. If I was sitting in your Assembly as a registered medical practitioner - as you are, Dr Lim - and as a palliative care physician, I think I would abstain on the basis that I actually do not think that this is the main issue with the care of dying people.

However, wearing my other hat as an MP representing a community where up to 8 out of 10 of my constituents say that they are in favour of this kind of measure - and certainly if I was not a medical practitioner in that particular specialised area of medical care - I think that I would probably vote in favour of it.

I would say that if it were voted in without adequate attention to palliative care, that would be a disgrace. As I have already indicated sufficiently, there is still quite a lot to do in this area of endeavour. I would say too that I think it is very important that palliative care services do not become known as euthanasia services. It needs to be absolutely clear to members of the public who very strongly oppose any move in this direction, that there is no way that they would in any way be coerced by any party into active assistance in dying. It would be quite a retrograde step if palliative care became the specialist service for active ending of life. There would be a lot of public mistrust of us if that were the case. I think it is important to keep clear about what we are doing and what our intentions are. I would have to say that I think that there are a lot of fears in the palliative care community of Australia that just that would happen if this were legalised in this Territory.

You obviously bear a very heavy responsibility in reporting this matter to the Assembly and the eyes of many other parts of Australia and the world will be upon you in your deliberations.

Mr STIRLING: Thank you very much. It has been most informative.

Mr POOLE: Yes. Thank you very much, Professor.

Professor ASHBY: I would just like to add that those last remarks are personal and do not represent the opinions of my professional body.

Mr POOLE: Yes, thank you.

SELECT COMMITTEE ON EUTHANASIA

PUBLIC HEARINGS

Elsey Room, Parliament House, Darwin

Monday 10 April 1995
Opened: 12.10 pm

On the committee:

Mr E. Poole, MLA
Dr R. Lim, MLA
Mr M. Rioli, MLA
Mrs L. Braham, MLA
Mr S. Stirling, MLA

Ms P. Hancock, Secretary

Representative:

Dr Roger Hunt, Medical Coordinator, Southern Community Hospice Program, Daw Park Hospice, SA

Note: This is an edited transcript.

Issued: Thursday 4 May 1995

Mr POOLE: I declare open this hearing of the Select Committee on Euthanasia and welcome Dr Roger Hunt, Director of Palliative Care, Daw Park Hospice, South Australia, who is appearing as a witness to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses however do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise if that is the case?

Dr HUNT: No. It is not.

Mr POOLE: Thank you. For the Hansard record, could I ask you to please state your full name and the capacity in which you appear today?

Dr HUNT: My name is Roger Wayne Hunt and I am a doctor who has been caring for terminally ill people. For the past 11 years, I have devoted my full time work to that. My current positions are: Medical Coordinator of the Southern Community Hospice Program and clinical lecturer at Flinders University of South Australia. I have been chairperson of the South Australian Association for Hospice and Palliative Care for 3 years. So my interest in terminal care has been long-standing. I see myself as an advocate for good terminal care for all patients.

Mr POOLE: Doctor, thank you for finding the time to appear. What we have been doing to date is inviting witnesses to either talk to a submission or make whatever comments they want to make. We then go into a general question and answer session, if that is agreeable to you. We have allowed a fair amount of time for you and will just play it by ear if that is all right.

Dr HUNT: Sure.

Mr POOLE: Over to you.

Dr HUNT: I guess this whole debate is happening in a society in which attitudes to this issue are changing quite rapidly. I included in my submission the Morgan Gallop poll results going back to 1962. A very straightforward question is asked about a patient who is in pain with absolutely no chance of recovering and who asks for a lethal dose so as not to wake again. Should a doctor be allowed to give a lethal dose or not? There has been a steady increase in the proportion of Australians who answer yes, that the doctor should be allowed to give the dose, and I would like to outline reasons for this.

I think people see it as a human rights issue in some respects. Attitudes have been changing because we have an aging population and old people tend to think more about death

and fear it less. We are having more and more deaths from cancer, whose terminal phase presents great challenges to health care professionals. There has been a growing disenchantment with medical efforts to keep people alive against their wishes. There are limitations on the ability of palliative care to relieve suffering and I would like to focus on that a bit more. The population is increasingly educated and assertive.

Often, 20 or 30 years ago, patients were not informed that they had a terminal diagnosis, so they were not aware of their options. They did not participate in the decision making. These days, we are hearing about informed consent and patients' rights. Many hospitals have patient advocates. Medical decision making has shifted from medical paternalism, with doctors determining what is right for you and what you are going to do, to patients wanting to have more say in what happens to them. Similarly, there is less traditional religious authority. In a more liberal society, there is a strong belief in the right to choose.

Palliative care has promoted the idea of passive euthanasia and autonomy, passive euthanasia being the withdrawal or withholding of life extending treatments if that is the wish of the patient. Palliative care has promoted the provision of comfort care rather than life prolonging care. It has promoted the idea of quality of life and of people choosing from a range of options for themselves. If anybody is going to judge the quality of life, it has to be the patient. So the patient is also in a position to judge what sort of treatment is likely to enhance their quality of life.

Those are some principles of palliative care that, I believe, are not in conflict with the principles of euthanasia. There are a range of options, focusing on the quality of life and what the patient wants. A lot of people portray this argument as one in which the euthanasia advocates are in one corner with the palliative care advocates in another. That is not the way I see it. I see that the basic principles advocated by both - autonomy, options for treatment, focus on quality of life - are similar.

In respect of the limitations of palliative care, I will focus on physical symptoms to begin with. This is an important topic because the palliative care community has traditionally said that all suffering can be controlled with good palliative care. I think that is a myth. In the past, it has been said that people who have good hospice and palliative care do not ask for euthanasia. That is another myth. They have also said that good palliative care would negate any need for euthanasia and the euthanasia movement only springs up when people do not have good palliative care. I think that is rubbish.

For example, in South Australia, where we had the rapid development of palliative care service to cover the whole state, there has been a parallel development of the euthanasia movement. The development of palliative care has not negated the euthanasia movement. In fact, both are growing together.

Perhaps it is worth exploring the history of the development of these myths in palliative care. I think the movement needed medical respectability and, in its beginnings, there was high idealism. The early leaders were Christian idealists rather than secular academics. As the

APPENDIX 19

LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

THE RIGHT OF THE INDIVIDUAL OR THE COMMON GOOD ?

VOLUME ONE

REPORT OF THE INQUIRY BY THE SELECT COMMITTEE ON EUTHANASIA

MAY 1995

[PP 186

Parliament of South Australia

INQUIRY INTO THE VOLUNTARY EUTHANASIA BILL 1996

Twelfth Report

of the

SOCIAL DEVELOPMENT COMMITTEE

Laid of the Table of the Legislative Council, and ordered to be printed 20 October 1999

THIRD SESSION, FORTY-NINTH PARLIAMENT

6 PALLIATIVE CARE

There remains a mystery about death, the way of death, the timing of death, the moment of death, which, in my view, deserves some respect. When death can occur in a context of family love, skilled support and clarity of mind, wonderful expressions of patience, love and generosity of spirit are often seen – these are all qualities which our society needs, and to cut them off quickly – for whatever reason, needs to be done with considerable caution.

Professor Ian Maddocks,
former Professor of Palliative Care Flinders Medical Centre

I shall not avoid illness by seeking death, as long as the illness is curable and does not impede my soul. I shall not lay violent hands upon myself just because I am in pain; for death under such circumstances is defeat. But if I find out that the pain must always be endured, I shall depart, not because of the pain, but because it will be a hindrance to me as regards all my reasons for living.

Seneca, Greek philosopher

Most of the evidence heard by the committee relating to palliative care was highly positive about what the movement had achieved in the short time of its existence. Divisions became apparent on closer examination of the testimony of those people who upheld it as best practice on the one hand and as no more than a step in the process of dying on the other.

A recent phenomenon, the palliative care and hospice movement in Australia and other countries in the western world originated in Britain in its modern form about three decades ago. Professor Michael Ashby, Director of Palliative Care at Monash Medical Centre, and Chair of Palliative Care, Monash University, told the Committee that palliative care had evolved from a strong, Christian charity ethos, and that its workers and organisations were generally opposed to voluntary euthanasia. He described the palliative care and hospice movement as a practical response " to the history of neglect of care needs at the end of life".

Ashby considered the central question in the euthanasia, physician-assisted suicide and palliative care debate to be whether it is permissible for a terminally-ill person to have third party assistance to die. He pointed out that many issues being raised today had been debated a decade ago at the hearings of the South Australian Parliament's Select Committee On Death and Dying, and elsewhere. In contemplating legislative reform on medical treatment relating to dying, courts and committees around the world had had to confront these issues:

> *A number of superior courts in the world...have made the assumption that palliative care interventions do actually on occasions constitute a cause of death but that those interventions are allowable because the overriding imperative has been seen to be the need to relieve suffering and to avoid prolongation of the dying process.* [Ashby, oral evidence, p 320]

He believed that South Australia should maintain its status quo and reject legalising voluntary euthanasia.

> *I think that the Consent to Medical Treatment and Palliative Care Act was very helpful and, indeed, unique in statute law in articulating what I have attempted to put to the committee today.* [Ashby, oral evidence, p329]

He told the committee that the only reason a voluntary euthanasia bill should ever be introduced was if it was believed it was "the right thing to do"; not to try and impose "some kind of quasi bureaucratic and legalistic process on the care of the dying" to stamp out any covert euthanasia that may be occurring currently.

Ashby agreed with the Ontario Coroner's definition of what legal palliative interventions entail. He said the care:

- must be intended solely to relieve suffering
- must be administered in response to suffering or signs of suffering
- must be commensurate with that suffering
- it cannot be a deliberate infliction of death. Documentation is required and the doses must increase progressively. [Ashby, oral evidence, p 321]

Ashby described this as being "all utterly germane to [medical] standard of practice", and argued there was a "defensible" distinction between standards of practice in good palliative care and the active ending of life. He expressed concern that many studies had deduced that medical practitioners were actively ending life behind closed doors. Ashby believed that far from clarifying the issues involved in palliative care, many of these studies on end-of-life decisions and medical treatment had "muddied the waters":

> *...In particular, they have made assumptions that the appropriate use of opioids and sedatives in palliative care already constitutes a form of euthanasia, and that the cessation of treatment that is not working and is not effective any more also constitutes a form of euthanasia.* [Ashby, oral evidence, p 320]

Ashby told the Committee the study of the attitudes and perceived practices of Australian medical practitioners by Kuhse, Singer, Baume, Clark and Rickard, revealed a disparity of perceptions among practitioners about what they were doing, and about their goals and approaches. He said this research was more indicative of the ignorance of doctors about palliative care than of signifying that up to 60 per cent of deaths in Australia involved medical intervention, or intent, to end the person's life. Moreover, he believed it reflected the differences in age range of today's practising medical practitioners and asserted that undergraduates, and recent graduates had a much better understanding of palliative care than most older doctors. He claimed that the younger generation of doctors would be less inclined to see end-of-life treatment in terms of drug dosages alone because palliative care was now part of the curriculum. However, he pointed out that:

The idea that pain relief treatment, for instance, in cancer, just involves doubling the morphine dose pretty well until the person stops breathing is never something that we have taught. [Ashby, oral evidence, p321]

Ashby told the Committee he believed a number of medical practitioners and many of the public misconstrued what palliative care was about. Although substantial progress had been made in palliative care education and its impact from both the medical profession's and the public's perspectives, he believed many doctors working in the system aged 40 or older would have had no academic tuition in palliative care because it had not been part of the curriculum when they were students. Ashby pointed out that postgraduate, professional education in most areas had been *ad hoc* and individual in the past, but was now regarded as a lifelong need and:

One of the problems we have is that some practitioners, particularly those who have been practising a long time, do not like to be told that what they have been doing for years could be done differently, that there are better ways of doing it. That is very confronting...

With symptom control at the end of the life, some profound attitudinal issues underpin the area, and those are related to the use of opioids. Doctors are trained to be rightly careful of powerful drugs, of course. They were taught that, if they gave morphine to somebody who had respiratory distress, they might stop breathing, so they would cause that person's death. Then there are the societal issues surrounding the use of opioids in a non-clinical setting, and nothing could be truer than in Australia at the moment, where the heroin debate is very alive. [Ashby, oral evidence, p 323]

Senior Consultant in Palliative Care and Clinical Lecturer, Daw Park Hospice Program, Dr Roger Hunt, who is an advocate for legalising voluntary euthanasia, told the Committee the mainstream palliative care position against euthanasia was summarised by the slogan "kill the pain, not the patient". Other arguments were that palliative care could make terminally-ill patients comfortable, therefore voluntary euthanasia was not required, or that patients receiving palliative care did not ask for voluntary euthanasia and that approving it would undermine palliative care development. However, Hunt said that:

Many patients say that weakness is the most distressing of all the symptoms; it causes an enormous amount of suffering, but we cannot do anything about it. Pain, yes; of all the symptoms, the treatment for pain is more effective than that for any of the other symptoms...but we cannot eliminate all suffering. [Hunt, oral evidence, p 25]

Asked the circumstances where pain relief by palliation would be ineffective, Hunt replied:

In conditions where it is a severe pain, for example, a tumour invading a nerve can be very difficult to treat; and some people are sensitive to pain relief medication, resulting in confusion, nausea and vomiting, particularly with morphine. [Hunt, oral evidence, p 25]

Ashby agreed with Hunt that palliative care was not effective for pain relief in some instances.

"There is no area of medicine that achieves perfect scores in anything. There is no area of life. For us to pretend that we can sort out everybody's pain in all the turmoil, physiological chaos and awful things that some of the diseases in our community, notably

cancer can produce, is not true. There are people whose symptom control is very difficult, whose symptom control is frankly unacceptable. [Ashby, oral evidence, p 325]

Mrs Janet Pfeiffer, whose husband, Rex, died "a terrible, lingering death" in 1997, supported this evidence. Mrs Pfeiffer described him as a living skeleton, weighing less than 30 kilograms when he died.

Some say that palliative care is the answer to all suffering. The palliative care people say their aims are to make their patients pain free and as comfortable as possible. My husband was never pain free because of his reaction to morphine and because his form of cancer is so painful, anyway. He was never comfortable because of his broken bones and because of his extreme emaciation. However he lay in bed, he could not be made comfortable. That is not a criticism of the palliative care he received but to stress that in my husband's case it was not the answer. Voluntary euthanasia would have allowed him to be in control of his life, to maintain his independence and to die with dignity. [Pfeiffer, oral evidence, p 101]

Dr Hunt said progress was being made in the elimination of pain but doubted whether suffering would ever be completely eliminated because it was part of the human condition. He said where pain was not regarded as a manifestation of pathology and a large psychological component existed, it was not possible "to realign people's minds to raise the pain threshold" [Hunt, oral evidence, p 25]. He went on to explain that everyone who had a terminal illness suffered from some kind of distress or another – psychological, emotional, spiritual or physical. [Hunt, oral evidence, p 26]

Dr Mary Brooksbank, Director, Palliative Care, Royal Adelaide Hospital and Medical Director, Mary Potter Hospice, argued the medical profession and the public were unable to deal with suffering adequately. She said:

...suffering may be related to physical illness but obviously can be precipitated by many other life events. For the patient...it is often the fear of what the illness might bring that produces the suffering – not the reality. The important thing is that suffering is personal. It is as human beings that we suffer.

Relief of suffering calls for more than a medical response: it calls for a human response. Although there is growing evidence in our medical schools of awareness of the human side of medicine, looking at communication skills and empathy, there is still an awful lot of competition within a very crowded curriculum. Our medical graduates are still ill-prepared to deal with chronic and terminal illness. (Brooksbank, oral evidence, p 230)

Brooksbank believed that although training for medical students in palliative care and pain management had improved, there was still insufficient emphasis given to preparing medical practitioners in being able to deal with patients with chronic and terminal illnesses. She pointed out that this was not an issue in Australia alone. She said it "horrified" her that the University of Adelaide was regarded as a world leader in this area.

...I do not think we have made anything like sufficient inroads yet. There is growing awareness among educators around the world, but you must have them in key places to battle for curriculum. [Brooksbank, oral evidence, p 240]

Hunt developed this argument that not all suffering could be relieved, saying some patients who received optimum palliation still requested euthanasia and therefore the palliative care position could not be sustained. He told the Committee he was hearing more requests for voluntary euthanasia now than he had in the past. He felt this was because people were becoming more assertive about what they wanted.

> *Similar forces, which drive the development of hospice and palliative care, are also driving the euthanasia movement. We have an ageing population. Older people tend to think more about death and to fear it less than young people. Our society is a lot more open about death and dying than previously. It used to be said that we were a death-denying society and discussions about death were taboo. That has all changed. Pre-paid funerals are now available and we see discussions about euthanasia on the front pages of newspapers...*
>
> *The major cause of mortality in our society is cancer. It used to be infectious causes. If we went back 100 years, death rates were very high among infants and young children. Now that those diseases have been controlled people are living long enough to contract diseases such as cancer. Terminal illness at the end of a full life span, I believe, is something that will drive both euthanasia and palliative care. In relation to disenchantment with life extending treatment, many people fear being connected to ventilators and life support systems when they have a terminal illness. Escalating health care costs are also a concern. There is a desire for more humane care of dying persons and for the rights of terminally ill people.* [Hunt, oral evidence, p 28]

Hunt said that although the hospice development had not silenced calls for voluntary euthanasia, the palliative care movement had received an injection of funding as a result of the voluntary euthanasia debate.

> *The debate about euthanasia...has stimulated palliative development. We saw what happened in the Territory when Marshall Perron first put his euthanasia Bill on the table. For palliative care services, annual funding was allocated at $100,000 a year and a couple of years later funding increased to well over $1 million. There was a 10-fold increase in palliative care funding in a short space of time.* [Hunt, oral evidence, p 28]

Both Ashby and Hunt confirmed that access to good palliative care had not curbed the numbers of people asking for voluntary euthanasia. Ashby said he had been approached by a "steady stream of people" who had asked him for assistance to die earlier than they would have otherwise, and that to pretend such requests did not exist was not right. [Ashby, oral submission, p 324]. Hunt agreed, claiming that the idea that people who had good palliative care would not ask for voluntary euthanasia was a myth.

> *We have looked at patients of our own state of the art hospice at the Flinders Medical Centre. At our weekly audit meetings we asked whether patients ever asked for the terminal course to be speeded up. The results were that some 77 per cent never mentioned anything spontaneously, 11 per cent said, "wish it would hurry up", 6 per cent asked staff, "could you hurry it up for me?" and a further 6 per cent were saying in a consistent and persistent way, "Please do something to hasten my dying".* [Hunt, oral evidence, p 26]

Contrary to evidence from some of the other witnesses, Dr Hunt said it was rare that a request for euthanasia emanated from the family rather than the patient.

> *...mainly it is the patient who is initiating the request. Often a request is made with the support of families and sometimes without the support of families. It would be very rare for families to be agitating for euthanasia with the patient saying, "No, I want to live".* [Hunt, oral evidence, p 28]

In response to a question from the Committee on whether there had been any change in the percentage of patients requesting euthanasia since the introduction of better treatment for depression, Hunt said:

> *The treatment of depression in the setting of terminal illness is a difficult subject... Certainly, requests for euthanasia have been associated with depression and lack of social supports...but not all patients who request euthanasia are depressed or have poor social supports.* [Hunt, oral evidence, p 27]

Ashby was unequivocal that voluntary euthanasia was practised in Australia, citing the evidence of published academic papers and ,a group of Melbourne doctors who had publicly admitted practising voluntary euthanasia in a front-page article in The Age. Elaborating on this issue, he said:

> *I would think that there are situations in which doctors and patients enter into a private covenant in which assistance will be given in a certain way at a certain time. The last thing you will do is then tell other people about that. It would be a betrayal of that covenant and the confidentiality.* [Ashby, oral evidence, p 328]

He believed further research in the area would be flawed because voluntary euthanasia was illegal, and that the potential to damage their professional status would prevent medical practitioners from being completely honest. Ashby suggested the way to improve end-of-life practices was the:

> *...education of the health care professions; by trying to take the community with us to understand the processes that happen when a person is terminally ill; to improve clinical care; to improve the consultation with patients and families; and to improve the education of practitioners.* [Ashby, oral evidence, p 329]

Professor Tess Cramond, Director, Multi-disciplinary Pain Centre, Royal Brisbane Hospital, also told the Committee the ignorance of members of the medical profession and the public about palliative care was of concern. She said it was a myth that morphine was the cause of death of "hopelessly ill" people and that:

> *...we have to get through to the public and refute...that morphine causes death. The progression of the patient's disease causes death and the morphine permits those people to die with comfort and dignity.* [Cramond, oral evidence, p 401]

Cramond argued that although not every illness could be cured, nor every pain relieved without side effects, 85 per cent of patients suffering from cancer could have the physical component of their pain relieved.

For 10 per cent of patients, more definitive treatment may be needed. That includes the interruption of pain pathways, and that is usually done in the spinal cord, or you can have morphine injected directly into the fluid that surrounds the spinal cord or into the cavities in the brain...where most of the cells where the morphine works are present...[Cramond, oral evidence, p 400]

She said about 5 per cent of patients endured pain and suffering that was difficult to control but in many of these cases there were complex psycho-social issues, which should have been identified earlier than at the terminal phase.

I certainly support the use of opioid drugs for pain that will be responsive to the opioid drugs, but the burning, neuralgic pain will not be completely responsive, and that is why you must have special access to the other drugs....it is not just a drugs or division of nerves treatment; it is a total patient care treatment, and the family is part of that. [Cramond, oral evidence, p 401]

A consultant physician in palliative medicine, Dr Leonie Zadow, also told the Committee there were some forms of suffering which were "almost" untenable to the human spirit. However, she opposed the legalisation of voluntary euthanasia on the grounds that society could lose the impetus to ensure that optimum care was being given, and that good palliative care had a significant role in redressing the perception of hopelessness and pain experienced by many at the end of life. [Zadow, oral evidence, p 283]

Like Ashby and Cramond, she believed the community was not well informed about the issues surrounding illness, treatment choices, and the experiences that may occur when they are patients or care givers, and that this needed to be redressed. She described palliative care as a rudimentary science, explaining that:

...good palliative care is still very young. We have only simple skills to tackle the complex physical issues of the dying. There are many physical experiences, which are quite horrendous. On every other level, from the physical and deeper to the psychological and spiritual, even though palliative care has some excellent ideals, we are still very poor at enacting those both within the speciality of palliative care and within the wider medical community. [Zadow, oral evidence, p 283]

Zadow went on to add:

I think we need to see that palliative care has a long way to go in addressing areas where distress is high...There are myriad areas where palliative care is not able to deal with things in a way that, for a lot of people, makes life easier. If we do not continue to see these areas as priorities we will never find solutions. [Zadow, oral evidence, p 283]

Ms Elizabeth Sloggett, Nursing Director, of the Mary Potter Hospice, told the Committee that although there had been deficiencies in the law in the past, the *Consent to Medical Treatment and Palliative Care Act 1995* in conjunction with the *Guardianship and Administration Act 1993*, had helped to rectify these deficiencies, and enabled people to make more informed decisions about treatment, and withdrawal of treatment, than previously. Like other witnesses, she believed there was a lack of awareness about palliative care services.

Mrs Elizabeth Keam, the Clinical Nursing Manager of the Mary Potter Hospice, said one of her regrets as a palliative nurse was that she could not deliver enough nursing care to patients and their families:

> *I speak for the majority of nurses working with dying people in hospices, hospitals, nursing homes and at home. The problems of dying in aged care facilities, I believe, are an enormous anxiety for most people, as they grow older. I teach and meet nurses working in this very poorly resourced part of health care who continue to give examples of dealing with poorly constructed end-of-life decision making, less than adequate knowledge about symptom control; and the lack of time and personnel to accompany the frail and frightened lonely person in this setting as he or she approaches death.* [Keam, oral evidence, p 216]

She agreed with other palliative care practitioners that the level of knowledge about basic principles of pain management in a significant number of medical practitioners and nurses was inadequate and placed:

> *...patients in great jeopardy through needless exposure to uncontrolled symptoms and the unwanted side effects of inadequate and inappropriately prescribed treatments. Nurses working in palliative care in South Australia are able to provide medications for the relief of pain and other symptoms without the fear of being prosecuted should their treatments inadvertently hasten the death of the patient. The first enactment in law of the principle of double effect is comforting in that it allows us to be active in managing symptoms. There is still, however, reluctance by some medical practitioners to do this* [Keam, oral evidence, p 217]

Keam contended that requests for aid in dying were a natural consequence of poorly managed or completely unmanaged symptoms. She said that changing the law to allow lives to be ended prematurely would signify the abandonment of all efforts to advance the ability to care and would be "colluding with hopelessness". [Keam, oral evidence, p 217]

Director of Medical Oncology, Royal Hobart Hospital, Professor Ray Lowenthal, who opposed the legalisation of euthanasia, was dismissive of any claims that palliative care was ineffective in controlling pain. He told the Committee:

> *When I read in the newspapers or see on TV cases of patients who are said to be dying an agonising death or in uncontrolled pain I wonder if I live on another planet, because I have been practising in this area for 25 years and this is something one virtually never sees. With modern palliative care these days it is possible to control virtually all the symptoms, particularly pain, in the overwhelming majority of cases. The Northern Territory cases where euthanasia was carried out...have now been well documented. The public documentation of these cases shows clearly that pain was not an issue — or not the issue — which led patients to request euthanasia.*
>
> *Pain can be controlled in virtually all cases. I admit there may be very rare difficult cases, but they really are few and far between. It depends how you define these difficult cases. Obviously, if a patient comes in in severe pain it may take one or two days or a little longer to get their pain under control. It is not an instant thing, and occasionally it takes longer, but in virtually every case it is possible to do that.* [Lowenthal, oral evidence, p 332]

Lowenthal considered palliative care to be one of the great triumphs of modern medicine. He agreed with other experts that there was a lack of understanding amongst some of the medical profession and of the public about what palliative care can achieve. Elaborating on this, Lowenthal said there might have been failures in some cases to refer patients to specialists in palliative care knowledge. [Lowenthal, oral evidence, p 332]

A view opposing Lowenthal's was expressed by Marshall Perron, former Chief Minister of the Northern Territory and instigator of the now vetoed *Rights of the Terminally Ill Act 1995*. Perron was forthright in his dismissal of palliative care being the cure-all for the dying. He described voluntary euthanasia as a "last resort palliative care option" and said it was a "total fallacy" that good palliative care removed the need for legalising voluntary euthanasia. In elaboration, he said:

> *The utopian palliative care service we hear about from time to time from our opponents exists only in the minds of the very religious. It does not exist in practicality.*
>
> *...Many people who seek voluntary euthanasia, or who believe that they would seek voluntary euthanasia if they were terribly ill, are people to whom the concept of total dependency for every bodily function from nutrition to mobility to removal of bodily wastes, and so on, is so abhorrent that they would rather be dead. Palliative care cannot help those people. And we must remember the common law right that we all have to refuse all forms of medical treatment, including medical treatment that might extend your life. Recently there was an example of that, of course, in Queensland, where a young woman refused a blood transfusion and died as a result. That was entirely under the law of Australia, and I think that most people would support that law. People have a right to refuse palliative care if they do not want to go through those processes. However, in all legislation put forward that I have seen, a patient seeking voluntary euthanasia is required to be informed about the palliative care options before they are allowed to proceed. So, they have to consider them.* [Perron, oral evidence, p 371]

The South Australian Voluntary Euthanasia Society [SAVES] was equally vehement in its rejection of palliative care being a solution to all end-of-life situations. In evidence to the Committee, the Vice President of SAVES, Dr Eric Gargett, stated that palliative care could not relieve all suffering:

> *...unless by terminal sedation or pharmacological oblivion, rendering the patient unconscious and ceasing life-prolonging measures until the patient dies. This is slow euthanasia, a subterfuge that relieves the consciences of some doctors, meets the requirements of the law, can only apply in certain cases and would not be regard by most patients, or those who love them, as a good way to die.* [Gargett, oral evidence, p 87]

Gargett also dismissed the notion that the *Consent to Medical Treatment and Palliative Care Act 1995* had made the legalisation of voluntary euthanasia unnecessary, claiming that although it was an important advance, it had unwittingly created two classes of patient.

> *There are those who can be helped to die, because they are receiving life-preserving treatment which can be discontinued or treatment for pain relief which can be increased—then there are all the others. This should not be glossed over as a grey area or excused as double effect, but acknowledged as a double standard.* [Gargett, oral evidence, p 88]

In response to a question from the Committee about the view expressed by some that palliative care was an alternative to voluntary euthanasia, Ashby said they should be seen neither as alternatives to each other nor as part of a package because active voluntary euthanasia was illegal. He said:

> *I believe the two should stand quite separately. If you ask me as an individual, I would accept that in a true, if you like, small 'l' liberal tradition, I do not think it is up to me to mobilise my professional weight, if you like, and say that as a result of that people should not be able to have assistance to die. I do not do that in front of you today. .... it is an individual decision. How I respond to that as a professional and as a member of a professional community within society is another matter altogether. I have very significant concerns about the way care of life is at the moment. That is why I do the job I do to try to improve it both in terms of its clinical content and its process...* [Ashby, oral evidence, p 326]

He was supported in this by Rosemary Dewick, nurse and former president of the Sunshine Coast Branch of the Voluntary Euthanasia Society, who told the Committee:

> *Excellent palliative care should not exclude the right to choose assisted dying.... It is very clear to me that the issue of voluntary euthanasia is completely separate from the issue of palliative care. Why are they linked? There is no way in which it can be linked because it is a different issue.* [Dewick, oral evidence, p 182]

In reply to a question from the Committee on clinical experience and standards of practice relating to palliative care, Ashby said it would be impossible to enshrine a suitable drug chart in law, because people responded differently to opioids and sedatives, and some people were more sensitive than others to drugs. He said part of the clinicians' skill was in knowing when to increase their patient's drug dosage. He agreed with Hunt that guidelines for the practice of euthanasia should be adopted if it were made legal, and suggested that principles of practice covering the ranges of drug doses used in particular clinical situations would be helpful. [See Appendix XI]

Hon Caroline Schaefer MLC
Presiding Member
18 October 1999

BOOK CHAPTERS

Palliative Care: Explorations and Challenges

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Palliative Care as a Medical Specialty

Michael Ashby

'Dying is not a subspecialty of medicine; it is our common lot . . . the aim is not a set of rigid structures committed to their own survival and enlargement, but a concentration of effort on achieving lasting change on the circumstances of death in post-industrial societies.' (Alistair Campbell, 1990)

'The world is come full circle; I am here.' Edmund. *King Lear*, 5.3.174.

Many people express surprise that a doctor would want to work with dying people ('it must be so depressing'), but all doctors have to at some stage in their careers. All interns, residents, registrars, many specialists and all general practitioners look after dying people. Those who do so effectively will tell you how professionally and personally satisfying it can be. As with most aspects of practice, doctors derive satisfaction from things they do well and, in order to do them well, some preparation and training is necessary. Historically, in regard to caring for dying people, this has been lacking, and students and doctors have tended to be cynical about the value of formal learning in this area. After all, people have always died and doctors have looked after them, so what is the problem? Until recently, most doctors had to teach themselves by 'learning on the job'; some did very well, but many struggled and patients suffered.

Social movement

This chapter is written with a background assumption that the Weberian charismatic social movement analysis proposed by James and Field (James & Field, 1992) is a reasonably accurate description of the social context and issues at play in the evolution of palliative care services in countries where the model is already well developed (Elsey, 1996). The

opening of St Christopher's hospice in Sydenham, south east London in 1967 is usually taken as the start of what has become known as the modern hospice and palliative care movement. Cicely Saunders and colleagues felt that they had to start up a specialised free-standing institution, on a 'green field' site, quite separate from the National Health Service in order to bring about a real change in the way dying people were cared for in Britain. She gathered around her a small group of dedicated supporters and, together with other pioneers in the field such as Robert Twycross (Oxford) and Derek Doyle (Edinburgh), developed a decidedly charismatic approach as a response to the enormous task which lay ahead. What was new about the approach of Cicely Saunders and co-workers was the focus on medical care, teaching and research. The movement developed as a response to the neglect of dying people in modern healthcare systems which evolved after World War II in developed countries. Medicine throughout the twentieth century had become focused on cure as medical technology had progressively opened up new therapeutic options. The stunning achievements of medical science in an age of scientific optimism had led to a level of expectation in the community that often significantly exceeded reality, particularly in common solid tumour oncology. Healthcare professions came to feel that death was medical defeat. At best perhaps, their contribution to the care of dying people was to know when to stop treatment aimed at cure. More often it seemed that they felt clinically, morally and perhaps legally bound to treat with curative intent no matter how poor the chances of achieving a favourable outcome. Palliative care has emphasised the need for the doctor to be able to 'accompany' a dying person, to be comfortable with the inability to provide a cure and with the uncertainty inherent in terminal illness—and to recognise that there is a significant medical contribution to the care of dying people.

The early developments in the United Kingdom consisted mainly of free-standing hospice and home-care programs together with the Macmillan nurse and medical initiatives. Over the next three decades there has been a remarkable growth in the number of specialist services for the care of dying people. The model spread first to the larger (culturally eurocentric) members of the old British Commonwealth (Canada, Australia, New Zealand in particular), then to a few pioneer programs in the United States, mainly outside mainstream academic medical circles, followed by rapid developments throughout Europe. By the late 1990s most countries of the world have attempted to address the issue in some way or another. Hand in hand with the development of services has been a trend towards professional sub-specialisation, notably in medicine and nursing. However, it is only in the United Kingdom that palliative medicine has achieved full specialty status and a recent bid in Canada has failed (Macdonald, N. 1996, personal communication).

Australian background

Originally most new initiatives in Australia attempted replication, to varying degrees, of the early stand-alone British hospice and home-care model. When palliative care services started to grow rapidly in Australia in the early 1980s, the area was dominated by a few large traditional hospice programs in capital cities, mostly with origins in established religious denominational healthcare facilities. These pioneering institutions mainly addressed the needs for terminal care (Briggs, 1992). Medical staff, including medical directors and specialists, came from general practice and a variety of specialist backgrounds (psychiatry, anaesthetics, medicine, oncology, surgery and several more). During the 1980s, there was considerable growth, with a wide variety of service configuration and models developing across the country, according to local needs, wishes and history (Allbrook, 1991). The medical role in these diverse hospital and community settings is well summarised by the medical leaders in the field in the late 1980s (Gunz, Kramer, Dwyer, Cavenaugh, Redpath, MacAdam et al., 1989). Although the issues raised were by no means uniquely Australian, these authors established a broad agenda for medical endeavour in teaching hospitals, home-care services, hospices and rural settings across the whole profession, with a strong emphasis on education, for the Australian context. There was a consensus of support among them for the establishment of a medical sub-specialty of palliative medicine.

The 'separatist' beginnings have been followed by a process of re-integration of palliative care initiatives into mainstream clinical services which James and Field argued was inevitable. Thus palliative care services are now seen as being in a continual dynamic state of development *within* health systems, which are themselves in a state of instability and rapid evolution. Higginson has shown that this process is well underway in Britain, where the hospice model always emphasised education and outreach, acknowledging that only a small proportion of patients actually die in specialist hospice units (Higginson, 1993). Australia has not built as many free-standing hospices as Britain and charitable funding support for services has been less. Palliative care units have been set up in a variety of different locations: general hospitals, private hospitals, nursing homes, other aged-care facilities. This pattern has influenced the way appointments to medical positions are made, with many of them in the mainstream public hospital and aged-care system. This process was also influenced in the same mainstream direction by federal funding allocations in 1988 (Medicare Incentive Packages (MIP)) and 1993 (Palliative Care Programme (PCP)). The result is that Australia appears to have avoided a phase of large investment in independent hospices (a 'big hospice' phase) and, consequently, fewer specialist positions have been

created than in the United Kingdom. Most of the present leaders in the area made a 'lateral entry' from other disciplines because no specialist training was available, or because the prospect of physician training in mid-career was unattractive. The drive for palliative care to be a separate specialty has also been less pronounced, and even now the pluralist background and lateral entry culture of Australian palliative medicine seems set to continue.

Maddocks' (1994) triangular model of home–hospital–hospice/in-patient palliative care unit is being widely implemented so that all dying people have access to optimal care to meet their needs. Location of care is not seen as being a competition between home (desirable) and in-patient sites (undesirable) but a (seamless) network of services where patients move from one setting to another depending on their needs and wishes. Access to beds is important because of the expertise and complexity of care that is sometimes required. It is also clear that where social and family supports are absent, there are serious limitations to home care, no matter how good and available the professional services are. In metropolitan Adelaide, a good level of access to palliative care expertise developed through the generic domiciliary nursing agency during the 1980s, with 56 per cent coverage of registered cancer deaths in 1990 by a hospice service (Hunt & McCaul, 1996). However, the rate of home deaths remained around 14 per cent between 1981 and 1990. The main change was the availability of hospice beds and deaths there rose from 5 to 20 per cent (Hunt, Bonnett, & Roder, 1993; Lickiss, 1993b; South Australian Cancer Registry, 1995). For some communities (particularly in non-metropolitan areas), the palliative care beds and the team will be designated rather than dedicated, with access to advice and back-up from larger designated services when required. The ratio of designated to dedicated staff in palliative care teams will usually vary according to the population served, ranging from a part-time co-ordinator and all other staff contributing on a sessional or as-required basis in a low population rural area, to a fully dedicated multidisciplinary team in metropolitan locations.

Palliative care as a medical specialty

The medical profession has an in-built response to new or redefined healthcare needs. Initially pioneers within the generic system take a special interest in the area. If service and academic needs appear to justify it, a process gets underway to form a separate specialty or sub-specialty. There is usually professional resistance to this budding off of a new specialty, but if the demand is there, official and academic recognition eventually occurs. The advantage of this is that a pool of expertise and research develops and (presumably) patient care improves. The down-side is that the specialty has a tendency to self-perpetuation,

with professional agendas of its own—in identifying with its patients' needs and wishes, it becomes substantially dedicated to its own professional agenda of self-preservation and expansion. It also tends to focus attention (and resources) on medical challenges, often the more difficult and unusual problems. A palliative care specialist is more likely, for instance, to find a challenge in neurogenic pain than improving carer support pensions. Specialisation can also be a disadvantage in any discipline by the encouragement of over-involvement with the area and the cause of the patients, with consequent loss of objectivity and context. In the complexities and stresses of modern healthcare systems, this can be problematic.

However, the need for medical expertise in palliative care is pivotal and unquestioned. For example, one of the commonest requests from nurses practising palliative care in the community is for improved general practice education in this area. Nurse consultants have played an enormous part in the improvement of the care of dying people. Frequently this has been a demanding and at times uncomfortable role for the nurses concerned and the doctors they work with. Over the last decade or so, these palliative care nurses have had to shoulder too much of the responsibility of palliative therapeutics and decision-making. Consequently some degree of medical sub-specialisation has been a necessary part of the medical response to patients' needs in terms of providing leadership, consultative support, education and research initiatives.

In Australia a watershed era has now arrived in which questions are being asked about the future of palliative medicine. While there are now four chairs established (at Flinders, Newcastle, Monash and Melbourne universities) and programs centred around most of the teaching hospitals, the number of doctors entering specialist training is low. The Australia and New Zealand Society of Palliative Medicine (ANZSPM) was founded in 1993 (Maddocks, 1994) and the Royal Australasian College of Physicians (RACP) offers an Advanced Training Programme in Palliative Medicine with its own Special Advisory Committee (SAC). This program of three years of supervised training at registrar level, with obligatory terms in palliative medicine, oncology and research or other approved elective activity (Lickiss, 1993a, b), has so far, been taken up by only a small number of doctors. There are significant difficulties in recruiting specialists for large and small programs alike, partly due to the absence of training posts. Until now there was only one registrar training program in Australia, run by Norelle Lickiss in Sydney (Lickiss, 1993a, b). Young trainees are not attracted to an area with such limited training posts, absence of clear career pathways and National Specialist Qualification Advisory Council recognition. The possibility is being explored of creating a Faculty of Palliative Medicine under the auspices of the Royal Australasian College of Physicians which would allow multiple

track entry with a final common pathway of clinically based supervised training.

Finlay and Jones have described three distinct but interconnected aspects of palliative care: the *palliative approach*, which should be a core skill-base of all clinicians; *palliative interventions*, which are often carried out by other medical or allied health specialists (e.g., radiotherapy, surgery and physiotherapy); and *specialist palliative care*, which is delivered by specialist clinicians in the context of a dedicated multidisciplinary team.

> The *palliative approach* is relevant to all patients with incurable conditions. It emphasises the importance of considering psychosocial and spiritual aspects as well as the purely physical. It includes consideration of family and domestic carers. Most specialities and all general practitioners look after patients with life threatening disease; attention to the patients' concerns and fears can guide management and ensure appropriate interventions. A palliative approach should be a core skill of every clinician, who may seek expert specialist help to ensure the best possible quality of life for the patient. (Finlay & Jones, 1995, p. 754)

This subdivision of palliative care is valuable insofar as it defines this core approach. But it might be read to mean that excellent care cannot be delivered by anyone other than a specialist team; this neglects the fact that the bulk of effective care is given by general practitioners and community nurses, particularly in rural areas, and this interpretation is not presumably intended by these authors.

It is clear that, given the diverse nature of service models required in a country like Australia, general practitioners will continue to provide the backbone of service delivery, including more specialised consultative support to colleagues, particularly in non-metropolitan areas. This role of general practitioners needs continued recognition in two respects. First, the vast majority of general practitioners want to be equipped and resourced to look after their own dying patients as a normal, integral part of general practice. Second, some general practitioners will elect to take a more than average interest in the area. They may look after patients in in-patient units and home-care programs on a sessional basis. In rural areas particularly, it is not uncommon to find that one general practitioner develops a special interest and assists others to care for their patients. This role has become formalised in some centres and some general practitioners have gone on to become directors of programs by this avenue. Each of these levels of involvement has different educational and credentialling requirements. Most resident medical officer posts in palliative care in Australian hospitals have been occupied by general practice trainees. In this way, the community has had access to a steady stream of doctors who have been exposed to the principles of palliative care practice. Similarly, consultative teams in teaching hospitals (Chan & Woodruff, 1991; Wood-

ruff, Jordan, Eicke, & Chan, 1991) are an important source of support and role modelling to young doctors. The cumulative result of this activity for approximately the last decade, together with undergraduate and postgraduate education, has been to contribute substantially to the process of 'normalisation' of palliative care.

It is the complexity of symptom management, multiplicity of symptoms and inherent fluctuations and instability experienced by patients with advanced cancer that have driven the development of specialist palliative care services. Hanks has argued that one of the major modern advances in cancer treatment in recent years has been the improvement of symptom management in patients with advanced or terminal disease (Hanks, 1994). Oncologists have a large role to play in palliative care development, as do pain specialists, who have done the bulk of significant research into pain. Over 90 per cent of patients presently seen by palliative care services have cancer but oncological expertise among palliative care workers varies considerably. The core clinical business of palliative care services is cancer symptom control. This is not to say that there is no role for palliative care skills and approaches for non-malignant conditions, quite the reverse. Most of the symptom control strategies for the care of terminally ill people have been learnt and extrapolated from the care of patients with cancer.

When the attributes of the modern palliative care specialist are unpacked, it is difficult to identify any element that is exclusive to the domain. Those who are not opthalmic surgeons do not remove cataracts and nobody would think of a renal dialysis program without nephrologists, but nearly all doctors may make a contribution to palliative care and many patients have straightforward deaths without specialist palliative care involvement. If the exclusive knowledge or skill litmus test is applied to palliative care, then it probably does about as well as geriatric or rehabilitation medicine. It is more realistic to view it as a unique attitude–knowledge–skill mix which requires both wide learning and experience but does not pretend to own an exclusive domain. Its main claim to existence is the historical neglect of dying people's needs and the need to refocus medical attention on clinical practice, educational and research issues of relevance to the care of dying people.

The future

For nearly all doctors, there is an undergraduate deficit in both experiential and theoretical learning in palliative care, and practising doctors who are approximately 35 years of age or older may well have had no teaching from a palliative care physician. Such a deficit cannot be satisfactorily redressed by postgraduate education without acceptance by the individual doctor that the deficit exists. Opportunities for clinical

experience have been limited, although consultation or shared care with a specialist service is probably the best way of improving clinical skills while enhancing the care of the doctor's own patients. Therefore, there clearly needs to be an urgent and sustained effort to improve undergraduate education in all medical schools, extending into the intern and resident years. Adequate exposure to palliative care in the mainstream medical system should, it is hoped, reduce rather than increase the amount of specialist palliative care expertise required in day-to-day clinical work. This would leave a nucleus of specialists who have predominantly academic and leadership roles.

However, it is not the goal of palliative care specialists to take over the care of all dying people, nor to appear to suggest that a terminal illness is only a medically defined event (so-called 'over-medicalisation' of death) (McNamara, Waddell, & Colvin, 1994, 1995). A commitment to a rounded multidisciplinary approach, with proper attention to spiritual and psychosocial issues, is generally accepted. The main goal of medical palliative care education should be to help doctors to become better doctors. In an ideal world, palliative care specialists would do themselves out of a job in a generation by following a consultative/educational model of activity. In reality, a core group of specialists will probably continue to be needed for many years to come. This is due largely to the time-lag between the introduction of widespread clinical activity, educational and research initiatives, and the consequent attitudinal changes within the profession and a real change in standards of practice.

A core of specialist expertise in palliative care has evolved in Australia and New Zealand in a semi-structured and eclectic manner since about 1980. This process will continue, but some form of collegiate status will probably occur in the near future. Services will most likely be developed more closely within mainstream structures, particularly oncology services. While a small number of physician trainees may elect to follow advanced training with the RACP, substantial numbers of people attracted to the area will come from non-physician backgrounds and this diversity will need to be formally accommodated within the evolving training structures. The involvement of general practitioners will continue to be central to home and nursing home care and some will develop a special interest, particularly in rural areas. Once the initial shortage of trained specialists is addressed, better general education in palliative care should lead to a diminished need for specialists over the next few decades. If this process appears to be circular, leading back into the systems whence the hospice and palliative care movement emerged three decades ago, it should not be seen as a negative result by palliative care workers. The question whether the process of 'mainstreaming' may have caused a loss of 'ideological purity', to the possible detriment of dying people, has been posed (Lickiss, 1993a). But surely the journey has

not been without considerable value, in that medicine in the last part of the twentieth century has been challenged to acknowledge its limitations and resume its proper place in the care of dying people. It became temporarily alienated from this by a transient illusion that science and technology could somehow cure all human ills—or rather that if cure was not possible, doctors had no further role or responsibility. The emergence of a sub-specialty of medicine is therefore seen as the means to this end of providing appropriate care for dying people, and not the end itself.

The medical care of dying people should not then be conceptualised as a 'specialist vs generalist' struggle in which territory is demarcated and defended. Instead, the shared short and medium term goals should concentrate on helping established doctors to care for their dying patients and to know when to refer for specialist help. The longer term goals should focus on undergraduate and postgraduate training to change the way the whole profession deals with death and dying.

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he was likely to be HIV positive.

In examining the protection of persons with HIV/AIDS it is important to avoid the problem encountered by *Ferguson*. HIV/AIDS is not a necessary incident of homosexuality. It is a disease which can affect anyone, but is more likely to affect persons in high risk groups. As such it is dealt with under various state legislation as a disability.[89] Discrimination on the ground of disability, and in some cases presumed disability(Ferguson's category) is unlawful. Each state, however, has permitted exceptions to discrimination, the relevant exception is the following contained in the New South Wales Anti-Discrimination Act:

> Nothing in this Part renders unlawful discrimination against a person on the ground of disability if the disability concerned is an infectious disease and the discrimination is reasonably necessary to protect public health.[90]

On the basis of earlier discussion regarding the limits of human rights, such a limit on the right to equality is probably justified. The question will then only ever be whether in practice the discrimination suffered is reasonably necessary to protect public health.

Conclusion

It has been argued in this chapter that much of the legal regime dealing with persons with HIV infection or AIDS disease is situated in public health legislation. Public Health legislative regimes exhibit their historical origins and are not efficacious in dealing with a modern infection and disease such as HIV and AIDS. An alternative approach based on medical science and legally recognised human rights is proposed. This approach comes very close to a medical ethics approach as commonly known.

Specifically, we argued that compulsory testing should have no place in a modern liberal democracy as Australia. It serves no identifiable or valid purpose. Similar criticisms were made of the power to control by detention, isolation and quarantine. On the issue of confidentiality, the role that the common law can played is limited and must be supplemented by statutory provisions. But the common law approach is no different from what obtains under a strict ethical rule of confidentiality. We also argued that criminalisation of transmission of HIV infection is illogical and should be abolished. The fact such offences exists serves as a figure of the deep rooted concerns (or obsessions) that the state or the ruling party has with sex, sexuality and cleanliness. Finally, with regards to the right to treatment, we conclude that at most it is illusory. It is not a fundamental human right and is thus subject to the vagaries of politics and budgets.

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[89] *Anti-Discrimination Act* 1977(NSW) s4(1), *Equal Opportunity Act* 1984(SA), *Equal Opportunity Act* 1984(Vic) s4(1), *Equal Opportunity Act* 1984 (WA), *Discrimination Act* 1991 (ACT), *Anti-Discrimination Act* 1992 (NT) s4.

[90] s49P.

Chapter 9

ON NATURAL DEATH AND PALLIATIVE CARE

Brian Stoffell and Michael Ashby

Introduction

Issues surrounding medical involvement in death and dying continue to be prominent in public debate. This stems mainly from sustained pressure to legalise euthanasia and assisted suicide, abetted by the quite normal journalistic preference for controversy and excitement. But in addition, modern medical practice is so dominated by the pursuit of cure that the plight of the dying appears to be obscured by the imperatives of technically driven curative medicine. Non-curative approaches are often described in purely negative terms: opting-out, withdrawal of care, or at best, allowing to die. In this climate palliative care challenges the curative assumptions and offers support for those who feel threatened by an unwelcome medicalized death. But what form of ethical framework, if any, operates with respect to palliative care?

The relationship between euthanasia and palliative care has tended to dominate political attention in Australia, being used in different ways both by those who support legalisation of euthanasia and those who do not. However, the moral propriety of requests for euthanasia/assisted suicide is a separate matter altogether, since their central arguments rest on the paramount importance of dignity, distress and compassion, not pain. The attention in this chapter is on the the ethical dimension to palliative care, but what we say is premised on something that should be blindingly obvious: palliation *is a treatment option, not an obligatory imposition.*

Clinical experience suggests that three modes or phases can be described in the management of life-threatening illness: curative, palliative and terminal. The terminal phase is a subdivision of the palliative mode, where there is evidence that death is imminent. Palliative care starts from a frank recognition of the phases of the dying process and death. The wilful obstruction of this process may well involve a futile denial of one of life's fundamental realities, and it can be argued that the consequences for both the patient and society are unkind and wasteful.

Taking a position on what interventions should or should not take place

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within the dying process clearly involves traversing territory similar to that which led to the coining of 'natural death' by legislators in the United States. Both South Australia (1983) and the Northern Territory (1988) followed California (1976) in using this terminology, although South Australia has since repealed its Act, subsuming both its aim and its living will instrument into The *Consent to Medical Treatment and Palliative Care Act* (1995).

It would be reasonable to expect the concept of natural death to resemble other concepts that have evolved to shape action in our inevitable confrontation with adversity. After all, this ongoing struggle is the crucible in which some of our major moral concepts are formed, particularly those whose object is the creation of human solidarity. If there are moral concepts governing the practice of palliative care, then natural death will be central among them. However, as will be made clear later, it is more accurate to say that natural death describes a moral reaction to facts about dying, rather than operating as a moral factor in the minds of palliative care providers. We treat natural death as an external descriptive moral framework for palliative care. In doing this the aim is to avoid confusing the external and impersonal moral framework with the internal and personal moral phenomenology of the carer's practice.

There are well-known philosophical difficulties with the term 'natural', but these should not block an attempt to analyse what was intended in the mid-1970's and early 1980's when legislatures first enacted Natural Death Acts. So, while agreeing that 'natural death' cannot be used without careful explication, it will be contended that the notion can be understood as a composite of two well known moral elements: (i) patient self-determination and (ii) the avoidance of harm; that is, the priority of patient choice in determining acceptable treatments in the terminal phase of an illness, plus the avoidance of certain obstructions to the process of dying. The first element is the one that the law is primarily interested in protecting, whereas the second demands closer clinical scrutiny of treatment decisions considered in light of the phases or modes mentioned above.

If our moral discourse shapes the way in which we operate as moral agents, then health care without a working notion of natural death is like travel with no recognition of journey's end. The journey is undoubtedly the main thing, but a refusal to think honestly about the moral shape of the terminus point is inexcusable, especially when dealing with those who are nearing their end.

'Nature and Natural Death

> 'For we all alike will die, although our fate is diverse' (Pindar, *Isthmian* VII, 44-45).

The senses of sameness and difference that can be aroused whenever we

concentrate attention on the place of humans within something called 'nature' is nicely brought out by Pindar (same end, different fates), as by others who have considered death and destiny: death in general as opposed to our personal deaths. The dichotomy here is intrinsic to our concept of nature (part of its nature as it were) because the deep etymology of 'nature' reveals notions of being and becoming, the static and the dynamic, the unchanging and the ever changing.[1] Further complexities emerge when the term 'natural' is employed to carry moral weight. These complexities within our concept of nature are sufficient to warrant the cautionary remark that, there is no *single notion here at all, but rather a cluster of related conceptions that are different enough to be kept apart*. We accept this view, and so an attempt will be made to set the parameters of usage which affect the main aims of the paper.

The two pre-eminent attempts to clarify the use of the term 'nature' in ethics are those of John Stuart Mill[2] and Jacob Klein.[3] Both agree that there is a global or all inclusive sense of 'nature' that denotes the sum of everything in the universe. This is nature with a capital 'N', and it may be useful in what follows to capitalise the word when this global sense is at issue. This sense of the term subsumes everything non-human and human under the concept of NATURE, excluding nothing; nothing that is, unless it belongs under the heading of 'non-natural', or 'non-NATURE'. For Mill and for Lucretius, the promulgator but not originator of the tradition, this non-natural class of things is empty, but for some others it presumably contains what they understand to be the supernatural. But consider for a moment the title of Lucretius's book, On the Nature *of Things*. The title hints at the complexity in 'nature' because it takes as its domain everything within NATURE; yet the book is really an account of *the naturalness of all things* (Jacob Klein's preferred translation of the Greek title). The title suggests we will be told something about what makes things - all things - what they are in their inner constitution. A seventeenth century contribution to the same tradition is found in Hobbes's materialism, especially his theory about the *conatus* motions of particles.[4] In this sense **'nature' means the inherent properties of something, the properties which allow it to act and react in the way that it does.** Micro-structure is obviously a good candidate for this role in material objects, but neither the speculation nor even the science are really germane here. What matters is that we grasp the fact that, 'NATURE' names 'all facts, actual and possible: or...the mode, partly known to us and

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1 Jacob Klein, *On the Nature of Nature, in Lectures and Essays*, Annapolis, Maryland: St. John's College Press, 1985, p. 224ff.

2 John Stuart Mill, "Nature", in *Nature, The Utility of Religion and Theism*, London: Longmans, Green, Reader, and Dyer, 1874.

3 Klein, *op. cit.*

4 Brian Stoffell, "Hobbes's conatus and the roots of character", in C. Walton and P. Johnson (eds.), *Hobbes's Science of Natural Justice*, Dortrecht: Martinus Nijhoff, 1987.

partly unknown, in which all things take place',[5] and that in another of its senses 'nature' refers to the intrinsic properties of things.

Death is a feature of NATURE that pre-dated the appearance of humans and will post-date them too. On the other hand conceptions of death are cultural creations, as are all concepts, including the concept of NATURE. This obvious point leads to a distinction between the natural and the non-natural within NATURE. The motivation for this new distinction comes from a desire to differentiate within the broad category or idea of NATURE, conceived of as the set of all causal chains, rather than as a catalogue of objects. Agency, the capacity to make things happen, is really the concern here, separating what flows from human action/inaction and what does not.[6]

Separating modes of agency appears in Greek thought as a distinction between art and nature (techne/phusis), but its more recent appearance stems from Sir Thomas Browne and Thomas Hobbes in their use (abuse?) of the distinction between the natural and the artificial: 'NATURE (the Art whereby God hath made and governs the World) is by the *Art* of man, as in many other things, so in this also imitated, that it can make an Artificial Animal...that great LEVIATHAN called a COMMONWEALTH, or STATE',[7] is Hobbes's application of Browne's, 'Now nature is not at variance with art, nor art with nature: they both being the servants of his providence. Art is the perfection of Nature...Nature hath made one world, and Art another. In brief, all things are artificial, for Nature is the Art of God'.[8]

The idea of agency is classically a forensic one, that is, one designed to allow apportionment of responsibility, praise and blame. So the distinction that Hobbes draws allows him to sheet home responsibility for revolutionary turmoil to the inadequacy of humans as designers and creators of stable government: revolution and strife arise from a design fault in the commonwealth structure, not a design fault in the nature of the creators themselves.

The class of the artificial embraces everything that resides in, or flows from, human agency, which in turn works with materials that come, ultimately, from nature; witness what we mean by *artificial insemination* and *artificial heart valve*. In the first case it is the process of fertilisation that is artificial, whereas in the second it is the object that is artificial (plastic). In its original sense the 'art' involved is workmanship, or the craft by which something is wrought through conjoining pre-existing elements. So every technical skill exercised, whether in health care or elsewhere, is artifice and hence non-natural in so far as its results do not flow directly from nature, but through that part of NATURE which is human. Human beings constitute,

[5] Mill, *op. cit.*, p. 6.
[6] D.G. Brown, *Action*, Toronto: University of Toronto Press, 1968.
[7] Thomas Hobbes, *Leviathan*, Oxford: Oxford University Press, 1929, p. 8.
[8] Sir Thomas Browne, *Religio Medici*, i sec 16.

at one and the same time, the dividing line and the conduit that separates/joins the natural and the non-natural, processing one into the other. Whilst the concept of NATURE is so all embracing that nothing falls outside it, and nothing save a demiurge can be contrasted with it, it should be stressed that this second sense of 'nature' actually implies a form of contrast.

While there is a difference between what flows from human intervention in nature and what does not, reflection will show that the elements this distinction sets in contrast are not stable, they are interacting in a progressively complex way. Increments in technical capacity diminish the extent of the purely natural, understood as processes operating beyond human ken and agency. The media preoccupation with using the 'playing god' theme in their dealings with topics like nuclear physics, IVF and molecular genetics, is in one respect mere laziness of mind, but it can also be taken as a demonstration of the mixture of awe and foreboding that people feel when confronted with deeper insight into, and control over, hitherto impenetrable natural processes.[9]

This sense of dread was once an omnipresent feature of our ancestors' confrontation with natural agency, particularly in its threatening and deadly forms - lightning, volcanic eruptions, landslides, storms at sea, as well as droughts, floods and insect plagues - but its appearance for us is largely symptomatic of the degree to which the balance of power within NATURE has shifted. Of course, even when humans were largely impotent with respect to nature, attributing its processes to the gods (this was the busiest period in history for religious myth making), they were certainly not powerless in their dealings with one another. From the great Hammurabi (1728-1668BCE) forward, tribal and civil codes have marked the distinction between deaths that were treated as natural, that is, of no legal concern, and those that were considered not natural. The latter were brought about by proscribed forms of direct human intervention (murders and manslaughter) and thus of direct concern to the law. The Mosaic code in the Pentateuch marks a related distinction between permissible and impermissible killings (do no murder).[10] The first of these distinctions can also be found at work in the current Dutch criminal code, where even cases of euthanasia that strictly follow the state mandated guidelines and thus are lawful, are still classified among the non-natural deaths that require the coroner's attention.

The moral significance embedded in 'natural death' as it appears in contemporary medico-legal discussion has connections with both the ancient forensic interest in human agency, and with modern fears about the impact of technical skill on nature and natural processes, inclusive of those that are taking place in our bodies.

[9] Brian Stoffell, "Playing god?", *Monash Bioethics Review* 13:4 1994, pp. 14-19.
[10] Brian Stoffell, "Three Forms of Vountary Death" in Peter Singer and Helga Kuhse (eds.), *Companion to Bioethics*, Oxford: Blackwells Books, 1998.

Natural death is not a part of nature in the way that death is a part of NATURE. Natural death is an ethico-legal construct, that is, an idea created through a negotiation between our appreciation of the workings of nature and the powers of human artifice. In one respect this is a trivial, purely logical point, because the human, and all that flows from human intervention in nature, is conceptually distinct from pure nature unconnected with our concerns: this is simply what the distinction between nature and artifice amounts to. But non-trivially, it is the needs which result in negotiation or compromise between our powers and what they work upon that generate the concept of natural death. As an ethico-legal notion natural death is expressive of our concerns with each other, not with nature. Subsequently, natural death does not function in the way that natural beauty does (denoting a pristine landscape), nor in the way that *natural law* was designed to do; namely to give certain moral qualities (virtues) or moral directives greater impact, suggesting that they were design features in human nature, which was itself assumed to be an artefact of divine craftsmanship. The attempt to give moral notions added force by connecting them with something beyond human contrivance is well known in philosophy, but in the case of natural death no such allusion is intended. The 'nature' in natural death is not there to signal that we should take nature as a moral guide, although there are those who pine after such guidance.[11]

NATURE, the universe, the cosmos, the whole shebang, is neither a lesson nor a tutor, it neither guides nor teaches. We are part of it in the same way that the asteroid belt is. Nature, taken as everything non-human, is similarly neither a lesson nor a teacher, but it is the primary source material for human education. There is no paradox here, we simply draw lessons from nature and some of those lessons may be applicable to human affairs. Aesop was an expert at this. We provide moral guidance to one another on the basis of what we learn from natural processes and events, but except in the case where interests are specifiable - those of other animals and ecosystems for example - the moral content is not in nature. We guide each other and merely use natural events or processes as examples.

However, even if nature is not a moral guide, it has proven almost impossible for some people to accept this, and for others to write as though they accepted it, even when they do. The term 'natural' is part of the conceptual dyad natural/artificial and operates, like its partner, comparatively. The comparison is the entire point and neither partner has a separate existence, unlike NATURAL for example which has only the figurative supernatural as a conceptual counterpart. Employment of the term 'natural' signals a comparison the writer has in mind: with the artificial, the unnatural, the unpalatable, the uncommon, the prodigious,

[11] L. Kass, B. Norton, S. Donnelly, "Can Nature Serve as a Moral Guide?" *Hastings Centre Report* 26:6, 1996, pp. 22-27.

the monstrous, the uncharacteristic, the unconventional, or the foreign. So far our comparisons with the natural have all been by reference to the artificial, but usage would allow all of these other comparisons. Analysis, of course, dissolves many of them into nonsense or mere abuse.

So, if appending 'natural' to another term serves to overtly contrast it with something non-natural, then the writer who employs it owes us an account of what the natural is being set against. Greek usage contrasted laws of nature (*phusis*) with social conventions (*nomos*) or descriptive laws with prescriptive laws; jurisprudence since the Romans recognises both natural (humans) and artificial (corporations) persons; and what people find beautiful can be divided into the natural and the products of art/craft. A presumed understanding of what is common, everyday, the norm, popularly acceptable, conventional, or mundane, is working when the variant senses of unnatural are employed, but of course these uses are themselves merely conventional (not natural) and not based in any defensible form of the natural/artificial distinction.

When 'natural' is joined to 'death' the result should be understood as conventional, that is, the implied comparison *is not* between what happens in nature and what happens with human intervention. If that were the case then a natural death would be one untouched by the involvement of others. That conception is clearly coherent, but it rules out medical treatment altogether. Natural death is closely related to the idea of natural food, whose proponents argue plausibly that our food sources should be as free from additives and processing as possible. They are not against farming, that is, active human participation in the production of what we eat. Nutrition has a point, good health, and so those who promote forms of natural food are doing so on the assumption that food that is free from certain things is better for health. Taking this as a parallel, we should ask what it is that proponents of natural death think that our dying should be free from.

Rather like the moral notion of justice, the concept of natural death is utterly conventional (contrived for a purpose) and best approached via the negative: identify and rectify the injustices and justice will take care of itself (if its not unjust then its just).[12] Equally, if we identify and rectify the things that render dying burdensome for people then natural death will be served. Natural death, like justice, seeks to arbitrate within the arena of human and institutional actions, but according to what criteria?

The common law right of competent patients to accept or reject any proffered treatment is argued for morally by reference to self-determination: because competent people are capable of determining their future on the basis of their own estimations, some of their choices in medical matters should be protected by the law. An obvious extension of this into palliative

[12] Robert Ewin, "On Justice and Injustice", *Mind* 1970, pp. 200-216.

care gives primacy to the wishes of competent adults (or their appointed proxies) in the evaluation and choice of treatment or non-treatment options when death is imminent. Palliative care is not special in this regard, since the right is utterly general and applies to life prolonging therapies at any stage of life. The Jehovah's Witness who rejects essential blood products and dies in the exercise of this common law right, does not have some special legal protection for acts inspired by religious beliefs. It is not *particular* beliefs that are treated as sacrosanct by the law, but rather a social space is created and protected. Within this space citizens may exercise deliberation about medical matters. The space shrivels and dies under some regimes - especially the religious and political tyrannies - but stands a chance of flourishing under liberal democratic forms of polity that respect the civil domain and enhance personal sovereignty.

One of the two major components of natural death is a legal reaffirmation of the moral claim to a sovereign role in decision making about medical matters in one's own life. The other is a straightforward application of the harm principle in medical matters.

Avoidance of harm or damage (*primum non nocere*) has some claim to being the primary precept in medical care, if only because it operates even when the patient is not competent and thus holds sway in all possible cases of care, whereas respect for autonomy normally assumes competence or advanced directions. Harm is not the same as injury, since I may injure or damage myself in the pursuit of exercise without anyone doing me harm. However, if I suffer an injury or damage because of someone else's actions/inactions and there are grounds for claiming that they were obliged to protect my interests, then harm may be established. My reputation as a full forward for the Immanuel Kant Eagles might be irreparably damaged if I am thrashed by a ring-in fullback from the under 10's, but no harm has been done. Many of the things that occur in open competition cause damage to reputations and fortunes, but unless there is a duty to the contrary operating it is not obvious that harm has been done.

The doctor/patient relationship is one where such duties do exist and hence where the charge of harm is a live prospect. The difficulty of course is deciding what is in someone's interests, since without that information any further weighing of risks and benefits is difficult and sometimes impossible. For example, because the Jehovah's Witness judges an early death (followed by salvation) an acceptable consequence in comparison to a later death (followed by everlasting torment), it would follow that a blood transfusion is not in her interests, judged on her criteria. On the other hand, for a patient who has permanently lost consciousness it is difficult to envisage what would count as an interest at all. Continuing the patient's biological existence through medical means is prolonging one sense of life - the biological - but is futile because it cannot affect their autobiographical life. No harm can be done to them either by ceasing to maintain them or, for that matter, by continuing to maintain them; so the sense of futility is

manifest here: there is nothing that we can do that makes any difference to them.

These two cases are at opposed ends of a spectrum, with competence and non-competence as the end points. Where there are clear patient wishes expressed on the basis of information, then harm and benefit are easy enough to determine, since their component elements have been identified by the patient. In palliative medicine these elements are not identical to those in curative contexts. For example, longevity cannot be taken as a given in treatment plans because many patients choose to avoid procedures that may lengthen life but only at the cost of surgery and severe post-operative restrictions. Quality of life and not longevity will often dictate treatment plans, suggesting that there will be cases where prolonging dying by obstructing death entails harm.

Up to this point we have been essaying a position on how the notion of natural death might plausibly be constructed. What a concept is and what purpose it serves are connected issues.[13] Our conclusion about the formation and content of the concept demonstrates that it is clearly ethical, but in a way pertaining more to the framework than the experience of ethics in palliative care practice. In the sections that follow the social context and more intimate elements of palliative care ethics will be described.

Modern Death and Dying

Three significant changes have occurred in the cause of death and setting of dying in this century. Firstly, the widespread availability of medical technology and its innovations, have led to a perceived legal and moral pressure to use them, even in situations where the results are likely to be very poor. Secondly, death and the dying process have become progressively institutionalised in hospitals and nursing homes throughout the century.[14] Thirdly, the nature and epidemiology of disease has changed, with a shift away from the infectious and acute to the degenerative and chronic.

Observation of medical vocabulary shows that the dominant approach is curative, with palliation presented in negative terms of disappointment and failure. Patients are referred for 'palliative care only', and 'all that can be done now is to offer comfort measures', whereas potentially curative treatment is referred to as 'active', 'state of the art' or 'aggressive'. The rhetorical force of these terms is clear and they are transparent with regard

[13] Ludwig Wittgenstein, *Philosophical Investigations*, Oxford: Basil Blackwell, 1968, 11ef; and J. Kovesi, *Moral Notions*, London: Routledge and Kegan Paul 1967, pp. 37-66.

[14] Ivan Illich, *Medical Nemesis*, New York: Pantheon Books (Random House), 1976; and R. Hunt, M.J. Bond, R.K. Groth and P.M. King, "Place of Death in South Australia, Patterns from 1910 to 1987", *Medical Journal of Australia*, 155, 1991. pp. 549-553.

to their real meaning. Ivan Illich sounded the alarm about the danger of the medical model of illness and death,[15] and Susan Sontag has illuminated the nature of metaphor in the language used to describe and discuss illness.[16] Death has also been subjected to redefinition and subdivision. There is 'brain death', 'medical decisions at the end of life',[17] and 'abatement of treatment with the critically ill... ethical and legal limits to the medical prolongation of life'.[18]

The history of modern cancer treatment provides an interesting illustration of some of these trends. With the advent of effective chemotherapy for haematological malignancies and some of the rarer solid tumours, the scene seemed set for the discovery of new drugs and combinations to 'conquer' the common cancers.[19] The language was martial: to fight disease, 'anti' cancer foundations were set up, and in France the regional treatment centres are called 'centres de la lutte contre le cancer' (literally, centres for the struggle or battle against cancer). The medical and research communities enticed the public with the prospect of defeating cancer, and in the process have generated inappropriately high expectations, with consequent disappointment and anger when cure is not possible. There has been significant progress in understanding of the biology of cancer, imaging, improvements in surgical and radiotherapeutic technique, new chemotherapeutic agents, bone marrow transplantation, biological response modifiers, and better prognostic information to select patients for more intensive treatment. All this endeavour has produced definite improvements in prognosis for certain sub-groups of patients ,[20] but the bigger picture is still of negligible impact on survival for the common solid tumours,[21] despite very substantial treatment related morbidity, and vast expenditure on treatment and research.

Medical Decision-Making

Medical decisionmaking is influenced by all of the following: ethical or moral reflection (what ought one to do?); religious influences (I must obey god's will or law); medico-legal issues (will I be sued if I do, or do not do

[15] Illich, *op. cit.*

[16] Susan Sontag, *Illness as Metaphor*, New York: Farrar, Straus and Girouw, 1978.

[17] P.J. Van der Maas, J.J.M. Van Delden, L. Pijnenborg and C.W.N. Looman, "Euthanasia and Other Medical Decisions Concerning the End of Life, *Lancet* 338, 1991, pp. 669-674.

[18] Robert F. Weir, *Abating Treatment with Critically Ill Patients*, New York: Oxford University Press, 1989.

[19] Sontag, *op. cit.*

[20] A. Bonett, P. Dickman, D. Roder, R. Gibberd, and T. Hakulinen, *Survival of Cancer Patients in South Australia 1977 - 1990*, South Australian Cancer Registry, 1992; and R. Doll, "Are We Winning the War against Cancer? A Review in Memory of Keith Durrant", *Clinical Oncology* 4, 1992, pp. 257-266.

[21] J.H. Kearsley, "Cytotoxic Chemotherapy for Common Adult Malignancies: 'the Emperor's New Clothes' Revisited?" *British Medical Journal* 293, 1986, pp. 871-876.

this?); technological imperatives (the technology exists, and therefore I should use it whenever there is any chance of benefit, however small) and economic considerations (can we afford to do this?). From the Hippocratic/ Pythagorean tradition onwards the preservation of life has been cast as the highest ideal among those guiding medical practice, and decisions about death and dying have become a matter of arguing down from a position of doing all things possible to save life in all circumstances. Many practitioners erroneously believe that this is also what the law requires.

The real or apparent difficulties involved in the opting-out of active treatments occupies a disproportionally large part of the attention of those who are involved in medical ethics. This subject is sometimes represented as though it was a series of ingenious expositions of autonomy, beneficence, non-maleficence and justice in particular health care contexts.[22] However, too much has been expected of this approach, and these principles should be viewed more as a shorthand means of clarifiying issues rather than solving them.[23] Komesaroff reminds us that ethics is an intrinsic and inseparable part of the clinical process, and that 'ethical practice in medicine cannot be described adequately in terms of conflicts of theoretical principle; nor can it be guaranteed by the generation of sets of rules to be followed in all circumstances'.[24] It will be asserted below that focus on process is a central tenet of hospice and palliative care.

Hospice and Palliative Care

The modern hospice and palliative care movement is usually regarded as beginning in 1967, with the opening of St Christopher's Hospice in Sydenham, London, UK, through the pioneering work of Dame Cicely Saunders. She addressed the spiritual and physical needs of dying patients because they were being substantially ignored by modern medical practice. It was not merely because treatment had become more complex or technological. Palliative care did not develop just because of the ability to keep people alive longer; its genesis had more to do with the dawning recognition that medical success was obscuring the more humane concerns at the heart of medical practice. Death had become failure, and dying patients uncomfortable reminders of the reality of death. From its earliest days the hospice movement concerned itself with improvement of medical care for dying patients, with pain and symptom control based on

[22] Raanan Gillon, *Philosophical Medical Ethics*, Chichester: John Wiley and Sons, 1986; and Tom L Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, New York: Oxford University Press, 1989.

[23] K.D. Clouser and B. Gert, "A Critique of Principilism", *Journal of Medicine and Philosophy* 15, no. 2, 1990, pp. 219-236; and Brian Stoffell, "Ethical Praxis, *Health Care Analysis* 2, no. 4. 1994, pp. 14-19.

[24] Paul A. Komesaroff, "Ethics and Clinical Medicine", *Australian and New Zealand Journal of Medicine* 23, 2993, pp. 3-5.

pharmacological principles, and a commitment to teaching and research. The psychosocial aspects of care were integrated into the clinical approach, but there was a clear acknowledgement that patients with uncontrolled symptoms could not deal with other issues until they were more comfortable. Hospice and palliative care must be based on sound clinical practice, but its broader tenets could well be adapted as guiding precepts for all medical practice:

- ***patient-centred***: it concerns itself primarily with the expressed and perceived needs of the dying person;
- ***family centred:*** it extends to those who are also facing imminent loss, embracing carers;
- ***comprehensive:*** it seeks to address the full range of physical, emotional and spiritual needs;
- ***continuing:*** it aims to provide support throughout the whole period of terminal illness and beyond into the time of bereavement, wherever that support is required.

As these approaches demonstrate, there is an obvious emphasis on self-governance, expressed in a way sensitive to the context of the patient's family and social circumstances. Although the primary moral relationship of team members is with the patient, important duties are owed to the family and friends. These duties are complexly related to the condition of the patient, but cannot be ignored, particularly if the patient is incompetent. If family members are to care for a patient at home, their wishes, needs and limitations are integral to the interests of the patient and must be considered. Teamwork and communication are prominent features of the model. Palliative care teams aim to work with a process of negotiation and dialogue between all parties involved. The patient's autonomy is the central presumption, but the wishes and needs of all parties are considered. Family meetings are common, particularly where a transition from curative to palliative or terminal modes is occurring, or where location of care and placement are issues.

The principal characteristics of the hospice approach can be summarised as: honesty, realism, compassion, consultation and awareness of what people experience as spiritual.

The Natural History of a Disease

The course of a disease process, from preclinical undetectable stages right through until remission, recovery or death is often referred to as *the natural history of that disease.* It is usually understood that the natural history describes the course of biological events without modification by treatment, and there are notorious cases where patients have merely been observed in order to study the unhindered disease process. But the natural history of a disease can just as easily encompass the course which proceeds relentlessly

when treatment is ineffective. In palliative care there is frank acknowledgement of the terminal nature of the disease process, occasioning the following analysis of loss:

- ***behavioural***: overt and covert acknowledgement by the patient that death is both inevitable and imminent, with anticipatory grief behaviour on the part of patient, family, significant others and carers.
- ***clinical evidence***: weight loss, recumbency, lassitude, physiological systems failure and disease progression, plus loss of appetite and decrease in oral intake which usually ceases altogether as the patient's conscious state lapses.

If a dying process is recognised, it can then be proposed that any medical intervention which is not for a comfort endpoint represents obstruction of this process, and may be seen as unduly burdensome and futile. Futility may be absolute (that is the procedure proposed has no chance of achieving benefit) or relative or situational (the procedure might be temporarily successful in achieving its technical objective, but is disproportionate to the underlying clinical situation). The chances of a favourable outcome from a given treatment may be low, but are rarely non-existent. The therapeutic ratio may be unfavourable per se, or unfavourable in the circumstances, due either to prevailing factors which result from the disease, or other aspects of the patient's situation. Medical decision making is based on an evaluation of proportionality and careful assessment of the therapeutic ratio (of desirable beneficial effects weighed against unwanted side effects). The use and location of the therapeutic ratio in three different modes of care: curative, palliative and terminal has been proposed to assist in ethical deliberations in palliative care .[25]

The key question becomes the cut-off between reasonable and realistic medical treatment, and its corollary of futile, intrusive or burdensome treatment which obstructs the dying process. The decision is usually the patient's, but therapeutic privilege should allow a doctor to advise against, and ultimately to decline to administer treatment which is considered to be absolutely futile. Relative or situational futility is more difficult because this will often concern consideration of quality and value of life issues, which cannot be determined unilaterally by the doctor. Resource factors also emerge when futile treatment is requested.[26]

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[25] Michael A. Ashby and Brian Stoffell, "Therapeutic Ratio and Defined Phases: Proposal of Ethical Framework for Palliative Care", *British Medical Journal* 320, 1991, pp. 1322-1324.

[26] R.D. Truog, A.S. Brett and J. Frader, "Sounding Board. The Problem with Futility", *New England Journal of Medicine* 326, 1992, pp. 1560-1564; S.H. Miles, "Informed Demand for 'Non-Beneficial' Medical Treatment", *New England Journal of Medicine* 325, 1991, pp. 512-515; and M. Angell, "The Case of Helga Wanglie. A New Kind of 'Right to Die' Case", *New England Journal of Medicine* 325, 1991, pp. 511-512.

At what level of the therapeutic ratio do we eschew treatment, and what degree of influence does the setting have on decisions based on the same therapeutic ratio? A 10% five year survival might be regarded as a poor outcome, but could be more acceptable to a 35 year old than an 85 year old. Much hangs on the absolute as opposed to relative levels of toxicity for older and frailer patients, which is to say that a given level of treatment-related morbidity may be unacceptable, whatever the outcome. This is shown by Molloy, where a substantial proportion of older persons did not want any surgical intervention, even when the condition was thought to be reversible.[27]

An Unobstructed Death

The previous two sections have described the moral world of palliative care practice. We have deliberately avoided the use of the notion of natural death as a clinical guiding precept, and nor have we put a lot of stress on substantive concepts like autonomy or beneficence. The reason is straightforward, but contentious. We believe that the moral world of palliative care practice is not well represented through reference to the standard set of moral principles operative in bioethics. Their role is not as first order moral motivators but as second order justificatory principles. A person's dying wishes are seldom met because of the principle of autonomy, but more likely because of their needs and expressed wishes. Sympathy, kindness, compassion and avoidance of harm do not flow because of the requirements of beneficence and non-maleficence, but because of the plight of those in our care who are suffering. A distortion in medical ethics is created by forcing these high level justificatory principles into the clinical encounter where they are largely alien.

Natural death, as a medico-legal construct, is not designed to accurately describe the clinical moral encounter. A complex set of descriptions about moral sensitivities and their opposites might be a better vocabulary for that task. Natural death is *a stranger at the bedside*, but not an unwelcome stranger. There is a legitimate role for the concept of natural death outlined in the second section of this paper. It supports the legal right to determine treatments in the light of our developed views about life and its significance to us personally. Furthermore it helps to chart the incedibly difficuly area where obstruction of death entails harm. Finally, it is *individualistic* in the very best sense of that much maligned term, because it acknowledges that lives are lived by individual human beings; individuals are not infused or inhabited by anything named with the abstract noun 'life'.

The reintegration of dying into a developed world view is certainly a personal endeavour, and one which may have spiritual or religious

[27] W.D. Molloy, G. Guyatt, E. Alemayehn and W.E. Mcilroy, *Humane Medicine* 7, 1991, pp. 285-290.

significance for some. This personal odyssey should not be overtaken by a medical speciality; rather, medicine can rediscover this heartland and better understand its ethical imperatives and legal obligations. Medicine is misrepresented when its aim is seen as universal curative competence. This transient illusion is at best an understandable extrapolation from some of the century's more striking successes, but illusion it is, and a dangerous one at that. The law has been somewhat wiser here, and no law demands that curative measures must be administered irrespective of the therapeutic ratio or biographical setting of the patient. The sobering challenge for late twentieth century medicine is to embrace those practical limitations which have some claim to be seen as natural limits on the appropriateness of interventions. This implies no barrier to the spirit of research, nor a nihilistic denial of the power of science. In summary, our claim is that medicine should be engaged in a more honest dialectic about its place in life and its role in our collective confrontation with our nature, inclusive of death.

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Chapter 10

JUSTICE IN THE ALLOCATION OF HEALTH CARE*

Christi Dawn Favor

Introduction

When it comes to political philosophy, perhaps the most significant theorist of our time is John Rawls whose primary work *A Theory of Justice* has been read throughout the Western world by philosophers, sociologists, theologians, economists, political scientists, and ethicists, in short by those interested in questions of distributive justice. Distributive justice might be defined as the study of how to divide up or distribute the benefits and burdens in a society in a way that is just or fair to everyone. Two of Rawls' most quotable statements in A *Theory of Justice* help to explain why the way health care is allocated in a society is so important to whether it is a just society. The two statements are "Justice is the first virtue of social institutions," and "The subject of justice is the basic structure of society."[1] The first of these statements says that while justice is not the only virtue for social institutions, it is probably the most important and the first we should hope to achieve. In the second statement, Rawls means to identify just what it is that is supposed to be "just." By "the subject of justice", Rawls means to refer to those parts of our society we should rightly evaluate according to principles of justice, those parts of society we should attempt to design according to the standards of justice. He identifies the subject of justice as the "basic structure," by which he means the whole range of major institutions in a society - such as the family, the market, the political system, educational institutions - which determine in significant ways what prospects of success people will face in life. These institutions are the subject of justice for two reasons: their effects are profound and often present from

* The argument regarding need and deserving in Section 4 of this paper is influenced substantially by work done with the support of the United States National Endowment for the Humanities in 1995.

1 John Rawls, A *Theory of Justice* , Cambridge,Mass.: Harvard University Press, 1971, pp. 7-10.

CANADA-AUSTRALIA

Towards a Second Century of Partnership

Edited by Kate Burridge, Lois Foster
Gerry Turcotte

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MICHAEL ASHBY

THE *RODRIGUEZ* CASE AND CARE OF THE DYING

INTRODUCTION

Sue Rodriguez, a 44-year-old woman from Saanich, British Columbia died on 12 February 1994 after losing her appeal to the Supreme Court of Canada for medical assistance in dying. This paper is the result of a three week study trip to Canada in the fall of 1994, which permitted simultaneous access to three important sources: the posthumously published authorised biography of Sue Rodriguez — *Uncommon Will* (Hobbs Birnie and Rodriguez, 1994),[1] a moving CBC documentary — "Witness: Sue Rodriguez", and the decision of the Supreme Court of Canada — *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519. It was also possible to attend a debate on Sue Rodriguez' case at the Faculty of Law, McGill University. Participants included Svend Robinson, the MP from British Columbia who became so publicly and personally involved in Sue Rodriguez' last few months of life and her legal struggle for permission to have medical assistance in dying.

From these and other sources,[2] I have attempted to tell what I know of her story by integrating relevant extracts from her biography with the course and arguments of her legal case. Whilst there may be several specialist or professional "angles" of her "case", for Sue Rodriguez there was only one angle — the story of her life and its end.

Sue Rodriguez was 41 years old in August 1991 when she found out that she was suffering from motor neurone disease (MND) which gives rise to progressive disability and inevitable death.[3] She made contact with the Right to Die Society of Canada, whose executive director John Hofsess happened to be based in Victoria, British Columbia — near to Sue's home. Sue had already decided to seek assistance to end her life, but it was her relationship with Hofsess which would set her on the legal

path which was to become so public. This relationship came to an end when he forged Sue's signature in a letter to a newspaper and began speaking for her in public. Hofsess' motives in supporting her are revealed to be political, her dying process being one of the best opportunities to date to further the aims of the Right to Die Society in Canada. This event provides clear evidence that whatever public and political pressures were upon her, Sue Rodriguez did what she did for herself, of her own free will, without coercion from others. Svend Robinson MP then became her major public supporter, together with her lawyer Chris Considine, during the remaining months of her life. Whilst Robinson clearly wanted to back her cause as a way of changing the law to allow voluntary active euthanasia, his deep personal concern and friendship are always apparent.

The fundamental question of Sue Rodriguez' case was whether it was or could be lawful (in Canada) to permit a terminally ill person to have medical assistance with the intention of causing her death by suicide. This is part of a universal ethical and legal question, namely can one person (usually a medical or health care practitioner) cause, or be party to causing, the death of another person in the circumstances of a chronic progressive, irreversible and incurable illness which will eventually result in death anyway. The intention is then to avoid either further suffering or a process of progressive physical or mental deterioration, with consequent loss of independent function and activity. Sue Rodriguez did not want to wait until she was in the terminal phase of her illness course, but rather to choose a time before she was left without any control of events; that is, she wished not to have assistance to die in her terminal phase but to avoid this phase altogether. Her purpose is clearly summarised in this quote from the dust jacket of *Uncommon Will:*

> I want to be in charge of my life and my death ... I feel that it is my right to die with dignity.
>
> I do not want to die of pneumonia or choking, and I do not want my family to endure the stress of watching me slowly deteriorate and die. I do not want palliative care, which would involve injections of morphine to relieve pain. I choose to be alert and aware of my surroundings before I go ... I feel it's a choice I should make myself. (Hobbs Birnie and Rodriguez, 1994)

In all such arguments it is the individual's consistent and competent request for such assistance which is pivotal to its ethical justification: namely, that it is the person requesting who makes the quality and value judgements concerning their life and death. The Rodriguez case brings into sharp legal focus the conflict between a state's perceived interests in

maintaining the lives of its citizens and the individual's autonomy as expressed in a wish for assistance in dying. This is the main issue at stake in the societal debate on voluntary active euthanasia.[4]

PART I—THE LEGAL CASE

The legal process started in the provincial jurisdiction of the Supreme Court of British Columbia. Sue Rodriguez applied to the court for an order that s. 241(b) of the *Criminal Code* of Canada, which prohibits the giving of assistance to commit suicide,[5] be declared invalid on the grounds that it violated her rights under ss. 7, 12 and 15(1) of the Canadian *Charter of Rights and Freedoms*,[6] in so far as it precludes a terminally ill person from committing "physician-assisted" suicide, and is therefore of no force and effect by virtue of s. 52(1) of the *Constitution Act, 1982*. Melvin J. dismissed this application, as did the British Columbia Court of Appeal by a majority of 2–1 (Hollinrake and Proudfoot J.J.A., with McEachern C.J. dissenting) (*Rodriguez v British Columbia (Attorney General)* [1993] 79 C.C.C. (3d) 1). The further appeal to the Supreme Court of Canada (*Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519) was dismissed by a majority of 5–4 (La Forest, Sopinka, Gonthier, Iacobucci and Major J.J. in the majority, with Lamer C.J. and L'Heureux-Dubé, Cory and McLachin J.J. dissenting).

Sopinka J. (for the majority)

The majority judgment rejecting Sue Rodriguez' application in the Supreme Court was delivered by Sopinka J. Her case is summarised by him as follows ([1993] 3 SCR 519, 583):

> The appellant argues that, by prohibiting anyone from assisting her to end her life when her illness has rendered her incapable of terminating her life without such assistance, by threat of criminal sanction, s. 241(b) deprives her of both her liberty and her security of the person. The appellant asserts that her application is based upon (a) the right to live her remaining life with the inherent dignity of a human person, (b) the right to control what happens to her body while she is living, and (c) the right to be free from governmental interference in making fundamental personal decisions concerning the terminal stages of her life. The first two of these asserted rights can be seen to invoke both liberty and security of the person; the latter is more closely associated with only the liberty interest.

The conditions which the Chief Justices of British Columbia and the Supreme Court had proposed in order to grant the application, by the striking down of s. 241(b), were rejected by the majority as too broad and unenforceable. Reliance on ss. 7, 12 and 15 of the Charter to support the granting of the application was also rejected (582–83).

The most substantial issue in the appeal was identified by the majority as being whether s. 241(b) infringes s. 7 in that it prevented Sue Rodriguez from controlling the timing and manner of her death. Sopinka J. disagreed with the trial judge (Melvin J.), who had concluded that it was the illness from which Ms Rodriguez suffered, not the state or the justice system, which had impeded her ability to act on her wishes with respect to the timing and manner of her death (534). Sopinka J. accepted that the Criminal Code's prohibition of assistance in suicide did indeed impinge on Sue Rodriguez' security interest (584):

> As a threshold issue, I do not accept the submission that the apellant's problems are due to her physical disabilities caused by her terminal illness, and not by governmental action.

However, he held that any resulting deprivation was not contrary to the principles of fundamental justice and the same was true of her liberty interest in the case. Sopinka J. accepted that the prohibition would contribute to her distress and dismissed the argument that s. 7 could not be activated because she was not engaged with the criminal justice system.

The lynch pin of the majority's holding is that the security of the person cannot encompass the right to end one's life. They argued for the continuation of a blanket prohibition on assistance in suicide, despite recognising that it may cause suffering in some cases. They based this position on the fact that other countries and many health care professional bodies support such a prohibition (605):

> Overall, then, it appears that a blanket prohibition on assisted suicide similar to that in s. 241 is the norm among Western democracies, and such a prohibition has never been adjudged to be unconstitutional or contrary to fundamental human rights.

They also found no evidence that there had been a change in public opinion on the issue (585):

> At the very least, no new consensus has emerged in society opposing the right of the state to regulate the involvement of others in exercising power over individuals ending their lives.

A blanket prohibition is mainly defended on the grounds of the "slippery slope" argument and that even if certain individuals suffer as a result this is the lesser harm, preferable to the potential abuses that might occur if it were permitted (613):

> ... [t]his protection is grounded on a substantial consensus among western countries, medical organisations and our own Law Reform Commision that in order to effectively protect life and those who are vulnerable in society, a prohibition without exception on the giving of assistance to commit suicide is the best approach. Attempts to fine tune this approach by creating exceptions have been unsatisfactory and tended to support the theory of the "slippery slope". The formulation of safeguards to prevent excesses has been unsatisfactory and has failed to allay fears that a relaxation of the clear standard set by the law will undermine the protection of life and will lead to abuses of the exception.

The distinction between acts and omission was defended as the main means of determining the legal and moral character of medical decisions at the end of life. The majority concurred with the conclusion of the House of Lords in *Airedale NHS Trust v Bland* [1993] 1 All ER 821, that the principle of the sanctity of life may not be an absolute one but it forbids the taking of active measures to cut short the life of a terminally ill patient ([1993] 3 SCR 519, 598–99). The majority also maintained the basis of intention and the doctrine of double effect in relation to palliative care practice (607):

> The fact that doctors may deliver palliative care to terminally ill patients without fear of sanction, it is argued, attenuates to an even greater degree any legitimate distinction which can be drawn between assisted suicide and what are currently acceptable forms of medical treatment. The administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes active contribution to death by any standard. However the distinction drawn here is one based upon intention—in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause death.... In my view distinctions based on intent are important, and in fact form the basis of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear. The fact that in some cases, the third party will, under the guise of palliative care, commit euthanasia or assist in suicide and go unsanctioned due to difficulty of proof cannot be said to render the existence of the prohibition fundamentally unjust.

The proposition that the state's prohibition of assistance in suicide constituted "cruel and unusual" treatment was not accepted and so Sue Rodriguez' Charter rights under s. 12 were not violated in this regard. The majority assumed that there was discrimination under s. 15(1) in view of her disability but that this was justified as being reasonable and proportionate under s. 1 of the Charter.

Lamer C.J. (dissenting)

The Chief Justice's dissenting judgement centred on the view that s. 241(b) of the Criminal Code infringed s. 15(1) of Sue Rodriguez' Charter rights to *choose suicide* because her physical disability prevented her from performing the act herself and she could not have assistance and this was not justifiable under s. 1. Lamer C.J. made a long analysis of the nature of discrimination and applied a two-branch test of the validity of the legislative objective of s. 241(b) and the validity of the means chosen to achieve that objective. He found that s. 241(b) was over-inclusive in that it was not necessary to restrict the rights of a competent terminally ill person such as Sue Rodriguez in order to protect other vulnerable persons in society from being subjected to such assistance against their wills or feeling coerced into ending their lives. In other words he did not accept the "slippery slope" arguments that the majority found more compelling (567).

But by recommending that s. 241(b) be struck down in view of its Charter violation he recognised that this would indeed leave too wide a gap in the law and so he proposed that the section be rendered inoperative for one year to give Parliament an opportunity to revise the section in a more tailored manner. During that year the applicant, and others in a similar situation would be able to have medical assistance in suicide subject to restrictive guidelines.[7]

McLachlin and L'Heureux-Dubé J.J. (dissenting)

McLachlin and L'Heureux-Dubé J.J. (two female members of the Supreme Court of Canada) did not base their dissent on discrimination under s. 15 of the Charter, but saw the case as being (616):

> about the manner in which the state may limit the right of a person to make decisions about her body under s. 7 of the *Charter*.

The judgment of McLachlin J. (L'Heureux-Dubé J. concurring) is based on the reasoning in the landmark decision by the Supreme Court of

Canada in *R v Morgentaler* [1988] 1 SCR 30, which struck down the Criminal Code's abortion provisions. In *Rodriguez*, McLachlin J. concluded (621) that:

> it does not accord with the principles of fundamental justice that Sue Rodriguez be disallowed what is available to others merely because it is possible that other people, at some other time, may suffer, not what she seeks, but an act of killing without true consent.

McLachlin J. held that the principle of the sanctity of life is not an absolute one in law, quoting the example of self-defence (623):

> Criminal culpability depends on the circumstances in which the death is brought about or assisted. The law has long recognised that if there is a valid justification for bringing about someone's death, the person who does so will not be held criminally responsible. In the case of Sue Rodriguez, there is arguably such a justification—the justification of giving her the capacity to end her life, which able-bodied people have as a matter of course, and the justification of her clear consent and desire to end her life at a time when, in her view, it makes no sense to continue living it.

McLachlin J. also argued that the Criminal Code afforded adequate protection for the vulnerable and pointed out that Sue Rodriguez only sought a declaration of unconstitutionality for s. 241(b) which forbids aiding and abetting suicide, and that s. 241(a) would remain in force, forbidding the counselling of a person to commit suicide.

Cory J. (dissenting)

In a short dissenting judgement, Cory J. argued that a *right to die* exists by virtue of being *included* in the *right to life* which is constitutionally protected under s. 7 of the Charter. Section 7 is, according to Cory J. (630–31), a provision which:

> emphasises the innate dignity of human existence.... The life of an individual must include dying. Dying is the final act in the drama of life. If, as I believe, dying is an integral part of living, then as a part of life it is entitled to constitutional protection provided by s. 7. It follows that the right to die with dignity should be as well protected as is any other aspect of the right to life. State prohibitions that would force a dreadful, painful death on a rational but incapacitated terminally patient are an affront to human dignity....

> I can see no difference between permitting a patient of sound mind to choose death with dignity by refusing treatment and permitting a patient of sound mind who is terminally ill to choose death with dignity by terminating life preserving treatment, even if, because of incapacity, that step has to be physically taken by another on her instructions. Nor can I see any reason for failing to extend that same permission so that a terminally ill patient facing death may put an end to her life through the intermediary of another, as suggested by Sue Rodriguez.

Despite her narrow failure to obtain the legal sanction for the assistance to die which she sought, Sue Rodriguez was indeed helped to die by an unidentified medical practitioner, peacefully in her own home on 12 February 1994, in the presence of Svend Robinson. Robinson announced her death at a press conference in Ottawa on 14 February.

PART II—COMMENTARY

A Right to Die?

Rodriguez is an example of the *Charter of Rights and Freedoms* "in action". The opportunity to observe the practical operation of formal legal protections of the rights of individual citizens is particularly valuable in a country such as Australia, where the merits of constitutional enshrinement of its citizens' rights is a subject of on-going debate. It would be worthwhile asking whether the existence of the *Charter* — and the consequent framing of the legal application — contributed to both a fair hearing and outcome for Sue Rodriguez as an individual Canadian citizen, and a healthy and appropriately profound consideration of the public policy issues at stake for Canadian society.

The majority relied cautiously on the principle of the sanctity of life, the acts/omission distinction and "slippery slope" arguments. From medical and ethical points of view they brought no new evidence or arguments to bear on the case and may have misjudged public opinion, although they acknowledged that the assessment of public opinion and legislation are Parliament's business. The case brought by Sue Rodriguez' lawyers and supported by the minority — based on discrimination and security of the person — was framed in terms of violations of her *Charter* rights but could be interpreted as stretching the intended scope of the *Charter* and the human rights tradition from which it is derived. In respect of discrimination, it is noteworthy that neither able-bodied nor disabled persons in Canada may have assistance in suicide, that is s. 241(b) applies equally to all Canadians.

To argue that Canada imposed "cruel and inhuman treatment" on Sue Rodriguez by retaining its prohibition on assisted suicide seems far-fetched and counter to the scope and spirit for which this term was originally adopted, namely to promote the humane treatment of those engaged with justice systems.

The central issue in *Rodriguez* is whether a sustainable argument can be constructed for a *right* to commit suicide or to have medical assistance in dying (Ashby, 1995), and what duties the recognition of such rights might impose on individuals and societies. It is certainly contentious to argue that there is a right to commit suicide as such. It is doubtful whether common law principles can be argued to include a right to suicide or a right to die (Tribe, 1988).[8]

Societies make every effort to prevent suicide and it is a major public health issue in developed countries, especially for young people in countries like Australia and Canada, who at present have alarmingly high rates of suicide and attempted suicide. The purpose of decriminalising suicide was not to enshrine such a right, nor to encourage suicide, but to correct the wrong of involving the law in the tragic situation of a decision to end or attempt to end a person's life and thereby to inflict more suffering on survivors or families. This reform also sought to remove the moral judgement which had thus been hitherto visited upon them by society ([1993] 3 SCR 519, 561).

A key argument made by the majority was that there was no evidence of a shift in community or professional opinion to allow any form of assistance in suicide. This does not appear to be the case in the frame of a terminal illness, and it is hard to believe, in view of the opinion poll trends in other western societies (House of Lords, 1994), that there has not been a very marked shift away from the argument which they made.[9] However, they ascribed to Parliament the duty of assessing public opinion and taking any ensuing legislative action.

There are certain similarities here (and in several other respects) between the decision of the Supreme Court of Canada in *Rodriguez* and the decision of the House of Lords in *Airedale NHS Trust v Bland* [1993] 1 All ER 821. In both cases the highest court in a jurisdiction received an application by an individual (or on behalf of an individual in *Bland*) for a declaration which would have the effect of conferring indemnity from future civil and criminal proceedings on a person or persons for a future act (or omission in Bland) performed with the intention of bringing about the death of the applicant. These are unusual and challenging requests for courts to consider.[10]

In *Rodriguez* and *Bland* the judges drew attention to the problems which face courts at the complex and contentious interface between

judicial interpretation of existing laws and the legislature's responsibility to amend existing laws or consider new ones. Both courts sent powerful messages to their respective parliaments to assess public opinion and consider the social policy issues which arose from the particular cases under consideration. Both parliaments have responded with select committees of their upper houses which have recommended against any change in the law which would allow any form of voluntary active euthanasia, including medical assistance in suicide (House of Lords, 1994; Canada, Senate, 1995).

The lynch pin of the majority's holding was that the security of the person cannot encompass a right to die. This argument is clearly diametrically opposed to that quoted above from the dissenting judgment of Cory J. in which the right to assistance is argued to be, perhaps somewhat paradoxically, included in the right to life. This inclusive argument centres on the process of dying as part of the process of living rather than focusing on the event of death (with particular regard to agency and causation) and places more emphasis on the former. The majority argued for adherence to a fairly rigid interpretation of the so-called principle of the sanctity of life ([1993] 3 SCR 519, 585):

> I find more merit in the argument that security of the person, by its nature, cannot encompass a right to take action that will end one's life as security of the person is intrinsically concerned with the well-being of the living person. This argument focuses on the generally held and deeply rooted belief in our society that human life is sacred or inviolable (which terms I use in the non-religious sense described by Dworkin [(1993)] to mean that human life is seen to have a deep intrinsic value of its own). As members of a society based upon respect for the intrinsic value of human life and on the inherent dignity of every human being, can we incorporate within the Constitution which embodies our most fundamental values a right to terminate one's own life in *any* circumstances? This question in turn evokes other queries of fundamental importance such as the degree to which our conception of the sanctity of life includes notions of quality of life as well. (italics added)

Two important questions may be asked of this passage. Firstly, what is the sense of *any* ? It is crucial to know whether the word was being used in an inclusive (all-embracing) or restrictive sense. Sue Rodriguez was not seeking assistance in *any* (inclusive/all-embracing) circumstances but in the setting of a terminal illness. The striking down of s. 241(b) would allow assistance in suicide in *any* (inclusive/all-embracing) circumstances but restrictive remedies were proposed by the Chief

Justices of British Columbia and British Columbia (579). Secondly, Dworkin actually used his conceptualisation of the sanctity of life to argue in favour of assistance in dying — in paraphrase: we all agree that life is sacred but how we express that sacredness varies according to personal beliefs and world view (Dworkin, 1993, 241):

> If people retain the self-conciousness and self-respect that is the greatest achievement of our species, they will let neither science nor nature simply take its course, but will struggle to express, in the laws they make as citizens and the choices they make as people, the best understanding they can reach of why human life is sacred, *and the proper place of freedom in its dominion.* (italics added)

Dworkin argues that an individual who chooses assistance in suicide or voluntary active euthanasia may be seen to be making an ultimate expression of autonomy, integrity and dignity, consistent with the way the person has led their life — rather than to be opting for a necessarily negative, desperate or hopeless last act (199):

> Death had dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying — the emphasis we put on dying with "dignity" — shows how important it is that life ends *appropriately*, that death keeps faith with the way we want to have lived.

It now seems clear that rigid interpretations of what has become known as the principle of the sanctity of life are susceptible to widespread intellectual and public opinion challenges (Singer, 1994).[11] For instance, in *Bland* [1993] 1 All ER 821, Hoffman L.J. clearly shows that judges in other courts, like the minority in *Rodriguez*, have started to question an "absolutist" interpretation when this position is seen to obstruct autonomous and clinically appropriate decision-making at the end of life. Hoffman L.J. talks of the sanctity of life as (851):

> only one of a cluster of ethical principles which we apply to decisions about how we should live. Another is respect for the individual human being and in particular for his right to choose how he should live his own life.

Palliative Care

From the perspective of palliative care, the most striking and challenging aspect of the story was Sue Rodriguez' reportedly negative view of

palliative care. She had seen such care as an option which would lead to a dying process of indeterminate time length with an unacceptable level of sedation and lack of control:

> During this summer, a grief counselor with the Victoria Hospice Society, Eve Joseph, visited Sue on a regular basis, as did Dr Debbie Braithwaite, who was in charge of Sue's pain management. Dr Braithwaite and Sue talked about palliative care for Sue's final days but Sue's heart was not in it. She simply didn't want to spend that time in a narcotic coma even though the Hospice Society was willing to come into her home with 24-hour care so that she could die there without ever going into a hospital. (Hobbs Birnie and Rodriguez, 1994, 130)

There are interesting reflections on the absence of relationship which subsequently existed with the Hospice Society (132):

> Sue felt well cared for by Debbie Braithwaite, but despite the doctor's expertise and her warm and engaging manner, no real relationship ever developed between her and Sue. Dr Braithwaite was a believer in palliative care to the end. Sue had a way of cutting out people whose ideas were not in line with her own. A subtle wall dropped. Sue would accept palliative care, but only to the extent that she could control it. Beyond that, she wanted nothing of it.

It was not so much that she feared a painful and distressing death, which is so often expressed by patients who have cancer, but that the alternative state which might result from optimal palliative care was unacceptable to her and that this resulting phase of her life in its dying process had no meaning or value to her. In fact it would be an irreconcilable burden to her and constituted her main identified and articulated concern in advance of her death, which was ultimately to drive her all the way to the Supreme Court of Canada in her quest for the reassurance that a medical practitioner could, at some future time to be determined by her, assist in the ending of her life. This is a confronting message for palliative care practitioners, particularly those who believe that they should deploy their professional skills in the societal debate against those who support euthanasia. No matter how good palliative care access and quality are, for a growing number of people who might benefit from such services, the best care that can be offered does not necessarily impute meaning into the dying process or relieve the suffering.

Expressions of a desire for death occurs in a small number of patients in palliative care programmes, although some people may elect not to be

referred to such services because they fear that their wishes will not be granted. At Daw House, a 15 bed palliative care unit in Adelaide, 6% of patients made a request for assistance to die at the time of the question, which is similar to the reported incidence of acts of euthanasia reported to the Remmelink Commission in The Netherlands (Hunt *et al.*, 1995).

Harvey Chochinov, a psychiatrist at the University of Manitoba, has pointed out that there is a significant relationship between requests to die and treatable depression; also, that such requests fluctuate with time (Chochinov *et al.*, 1995). But the Rodriguez case shows that such requests can be rational, reasonable, consistent and uninfluenced by the presence or absence of optimal palliative care support. We should therefore be wary of over-medicalising the issue by suggesting that *all* such requests can be rendered unnecessary as result of medical care, inclusive of optimal palliative care and treatment of depression. It is also clear that there is more to life than absence of pain, suffering and depression; that the quality and value of a person's life (as assessed by that person) should not then be reduced by doctors, lawyers or others, to an objective standard framed in the negative.

It is important for hospice and palliative care services to feel comfortable in working with people who make consistent rational requests for assistance to die. This need not mean that there is agreement on the issue of euthanasia — both parties can respect each other's viewpoint but still be clear about what is and what is not on offer. Whilst the palliative care service will not institute treatment with the intention of causing death it is important to emphasise that pain and symptom control will not be compromised and no potentially life-prolonging measures will be continued or initiated against the person's will. Just as the hospice and palliative care movement has asked the rest of medicine to recognise its limitations, so too it should be ready to recognise its own.

It is clear that there is evidence that Sue Rodriguez may have kept her emotional distance from the Victoria Hospice Service but she also received many of the elements of palliative care, including opioid pain relief. It is a matter for speculation as to whether more could have been done for her if she had more wholeheartedly embraced the service, although she probably related to them in a way which was consistent with her personality and appropriate for her own perceptions of her needs.

There is an assumption in both *Rodriguez* and *Bland* that pain relief may contribute to the cause of death but this is not deemed to be a culpable act. This assumption has been challenged, as there is now more than twenty years of experience in modern hospice and palliative care

practice to demonstrate that pain and symptom control can be achieved for most patients with a terminal illness safely, without causing their deaths (Ashby, 1995). There is certainly no generalisable threshold morphine dose above which death is likely to be caused. Safe initial doses and dose escalation steps titrated against the patient's pain reporting are now a well described part of standard medical practice. It has been argued, however, that sometimes in difficult situations where symptoms appear to be uncontrollable by other means, heavy sedation may be used, with the patient and family's consent. This is sometimes termed "pharmacological oblivion" or, by Canada's Senate Special Committee (1995), "total sedation". This report is clear to state that the intention is not to end life, but Hunt (1994) has argued that on occasions this is a foreseeable and even the intended outcome, though strictly within the context of the person's actual dying process. It is a measure of the public policy commitment (in several countries) to achieving good pain and symptom relief that this assumption of contribution to the cause of death is made but allowed on the basis of intention (see Law Reform Commission of Canada, 1982, House of Lords, 1994). This approach is also reflected in relevant Australian legislation, such as the *Consent to Medical Treatment and Palliative Care Act* 1995 (SA).[12]

Personal History and Control

The issue of control in modern society is worthy of reflection. It is clear that patient autonomy is the over-arching principle for all modern health care decision-making and there would be few detractors from it. However, none of us lives in an autonomous vacuum at any stage of our lives, least of all when we are sick and dying. Palliative care services have long recognised a person's social context (family and friends) as the unit of care, with the patient as the central and principal (but not the only) decision maker and care recipient. In her analysis of *Rodriguez*, Somerville (1994) has asked major questions about the consequences for modern secular societies of attempting to legalise euthanasia. In particular she asks (602):

> Is euthanasia liberalism in the form of intense individualism gone mad, or is it a rational response of caring individuals and a caring community?
>
> Is the euthanasia debate a reflection of the fact that we are a death-denying but also a death-obsessed society that has lost its main forum — namely organised religion — for "death talk"?

> Is legalising euthanasia an expression that allows us to feel that we have both individual and societal death under control — tamed and civilised?

Both Somerville (1994) and Mullen (1995) have asked similar questions about the meaning of death in modern societies and the element of mystery which appears to be replaced by an attempt at mastery of the process manifest in the euthanasia debate. The Canadian historian Michael Ignatieff (1993, 68) has written about the slow death of his own mother from Alzheimer's disease:

> The real problem, of course, is what we are to think of death. People like us who live by the values of self-mastery are not especially good at dying, at submitting to biological destiny. The modern problem is not death without religious consolation, without afterlife. The problem is that death makes the modern secular religion of self-development and self-improvement appear senseless. We are addicted to a vision of life as narrative, which we compose as we go along. In fact, we didn't have anything to do with the beginning of the story; we are merely allowed to dabble with the middle; and the end is mostly not up to us at all, but to genetics, biological fate and chance.

In fact, Sue Rodriguez seemed to be very good at facing the inevitability of death and did state that she believed in an after-life, although she adhered to no specific religion. However, her personal life, as described in *Uncommon Will*, was very much of her time and many aspects of it were painful to read. Like so many others of her generation she had difficult relationships with her family and two broken marriages. There is clear evidence that this pain shaped her destiny and had an all-pervasive influence on her life. The break up of her second marriage and the return of her husband (Henry) after separation to care for her were very distressing:

> Increasingly Sue blamed her disease for the fact that Henry did not seem to love her. Her earlier understanding that he had returned for financial and supportive reasons had shifted. She now saw his return to the home after seven months of separation as essentially an attempt at reconciliation. Yet he had little to say to her and seemed to avoid her. (Hobbs Birnie and Rodriguez, 1994, 41)

Henry relates that the relationship was quite over, which she clearly had great difficulty in accepting (6, 26):

> She would remain bitter toward her husband, distant from many of her family. Unable or unwilling to use her newfound strengths to change attitudes and habits that had marked her character since childhood, she would destroy many of her own dreams and create for herself profound psychological pain. To the end, her belief in the correctedness of her own standards would remain inflexible, her need to control, profound. Yet the grace and strength that she would project, the calm dignity that would make the sweet face of Sue Rodriguez instantly and nationally recognisable, would not be an illusion or a staged image. Her serenity would mirror other positive facets of a personality whose very complexity was the fulcrum of all her strengths. ...
>
> This complex family and social environment was to leave Sue a legacy of unresolved relational problems. It also endowed her with attitudes and skills that were rare, valuable but virtually unused in her daily life. Ironically, the disease that was killing her would also be the thing that created her.

On balance, it seems unfair to ascribe her wish for assistance to die to these unhappy aspects of her personal life. Whilst they may have spurred her on to pursue her public legal path in a way that many would not have felt able to do, all the evidence from Sue herself points to the fact that she wished to avoid the last part of her dying process irrespective of the state of her personal relationships.

Conclusion

This remarkable human story played out in the legal system with intense media coverage had a profound impact on Canadian society. There is no doubt that Sue Rodriguez' tragic personal history, which touched everyone, underpinned her remarkably tenacious legal pursuit of the only control she felt was left to her, namely to determine the manner and timing of her own death. As Somerville has observed (1994, 609), the dissenting judgement of Lamer C.J. might be argued to have been primarily motivated by compassion, the resultant holding being fashioned in order to grant her wish. Sue Rodriguez appears to have experienced a considerable amount of emotional pain in her personal life, and particularly in family relationships — a fact which she very courageously allowed to be revealed in her authorised biography. This together with her clearly expressed need for control leaves some dangling questions over modern world views which concentrate on overriding individualism and the true nature of "control" in our modern lives — and deaths. Would she have been so keen to have assistance to die if her personal life had been happier? Was it an attempt to tame death

and somehow make it bearable by "controlling" it? Many amongst the millions of Canadians who witnessed the case and the very public dying process of Sue Rodriguez on prime-time television must have had their doubts whether she should have been so exposed. But it is clear that she undertook the legal battle in her own interests and of her own free will and that the level of debate and deep consideration of the issues by Canadian society, including the Senate enquiry, must be judged as healthy for any liberal democratic society.

As did so many in Canada at the time, this writer felt her pain and disappointments, but concludes that the evidence shows that her desire to avoid the final part of her dying process was rational and consistent with the world view of the majority of her generation. If this apparent generational shift in attitudes on euthanasia continues it is likely that future legislative initiatives may succeed in other jurisdictions, as it appears that Sue Rodriguez and the dissenting judges could be more reflective of prevailing views than the majority.

Notes

1 Lisa Hobbs Birnie is an Australian writer resident in Canada.

2 I would like to acknowledge the assistance I have received from the excellent summarising article by Bernard Dickens (1994) — "When Terminally Ill Patients Request Death: Assisted Suicide Before Canadian Courts". The director (Professor Margaret Somerville) and staff of the McGill Centre for Medicine, Ethics and Law in Montreal also offered invaluable assistance during my visit to Canada. I am indebted to Professor Somerville for showing me her article, "Death Talk in Canada: the Rodriguez Case", prior to publication (see Somerville, 1994). This article is contained in a special issue of the *McGill Law Journal* (Vol. 39, No. 3) devoted to analysis of the case.

3 Motor neurone disease (MND) is also known as amyotrophic lateral sclerosis (ALS), and in North America, as Lou Gehrig's disease, after a famous baseball player who died of the disease. It consists of a progressive loss of motor power, often predominantly and initially affecting the bulbar muscles which control speech and swallowing but eventually all muscles are involved. It runs a variable time course from months to many years. The most famous public figure with long term MND is Professor Stephen Hawking, author of *A Brief History of Time* (1988).

4 For example, see the title of the Report of the Inquiry by the Select Committee on Euthanasia, Legislative Assembly of the Northern Territory of Australia: *The Right of the Individual or the Common Good* (Northern Territory, 1995).

5 Section 241 of the Criminal Code states that:

> Every one who

(a) counsels a person to commit suicide, or
(b) aids or abets a person to commit suicide,
whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years.

6 The relevant sections of the *Charter* are:

> 1. The Canadian Charter of Rights and Freedoms guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.
> 7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.
> 12. Everyone has the right not to be subjected to any cruel and unusual treatment or punishment.
> 15. (1) Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

7 The guidelines were based on those proposed by McEachern C.J. in the British Columbia Court of Appeal ([1993] 79 C.C.C. (3d) 1). Lamer C.J. stated ((1993) 3 SCR 519 at 579):

> (1) the constitutional exemption may only be sought by way of application to a superior court;
> (2) the applicant must be certified by a treating physician and independent psychiatrist, in the manner and at the time suggested by McEachern C.J., to be competent to make the decision to end her own life, and the physicians must certify that the applicant's decision has been made freely and voluntarily, and at least one of the physicians must be present with the applicant at the time the applicant commmits assisted suicide;
> (3) the physicians must also certify:
> (i) that the applicant is or will become physically incapable of committing suicide unassisted, and (ii) that they have informed him or her, and that he or she understands, that he or she has a continuing right to change his or her mind about terminating his or her life;
> (4) notice and access must be given to the Regional Coroner at the time and the manner described by McEachern C.J.;
> (5) the applicant must be examined daily by one of the certifying physicians at the time and in the manner outlined by McEachern C.J.;
> (6) the constitional exemption will expire according to the time limits set by McEachern C.J.; and
> (7) the act causing the death of the applicant must be that of the applicant him- or her-self, and not of anyone else.

8 Tribe (1988, 1370–71) states:

> The right of a patient to accelerate death as such — rather than merely to have medical procedures held in abeyance so that disease processes can work their natural course — depends on a broader conception of individual rights than any contained in common law principles. A right to determine when and how to die would have to rest on constitutional

principles of privacy and personhood or on broad, perhaps paradoxical, conceptions of self-determination.

Although these notions have not taken hold in the courts, the judiciary's silence regarding such constitutional principles probably reflects a concern that, once recognized, rights to die might be uncontainable and might prove susceptible to grave abuse, more than it suggests that courts cannot be persuaded that self-determination and personhood may include a right to dictate the circumstances under which life is to be ended. In any event, whatever the reason for the absence in the courts of expansive notions about self-determination, the resulting deference to legislatures may prove wise in light of the complex character of the rights at stake and the significant potential that, without careful statutory guidelines and gradually evolved procedural controls, legalizing euthanasia, rather than respecting people, may endanger personhood.

9 See, for example, the House of Lords Select Committee on Medical Ethics (1994, Paper 21-II, 271–72) citing evidence of a large increase in the number of people who (when well) approve of medical assistance to die. This trend is most striking in Australia and Canada, but is also evident in the UK and USA.

10 In *Airedale NHS Trust v Bland* [1993] 1 All ER 821 see the deliberations of Lord Browne-Wilkinson (880) and Lord Mustill (886–87).

11 See particularly, Chapter 4: "Tony Bland and the Sanctity of Human Life".

12 The relevant part of the *Consent to Medical Treatment and Palliative Care Act* 1995 (SA) provides:

DIVISION 2 — THE CARE OF PEOPLE WHO ARE DYING

The care of people who are dying

17.1(1) A medical practitioner responsible for the treatment and care in the terminal phase of a terminal illness, or a person participating in the treatment and care of the patient under the medical practitioner's supervision, incurs no civil or criminal liability by administering medical treatment with the intention of relieving pain or distress —

(a) with the consent of the patient or of patient's representative; and

(b) in good faith and without negligence; and

(c) in accordance with proper professional standards of palliative care,

even though an incidental effect of the treatment is to hasten the death of the patient.

(2) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, is, in the absence of an express direction by the patient or the patient's representative to the contrary, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state.

(3) For the purposes of the law of the State —

(a) the administration of medical treatment for the relief of pain or distress in accordance with subsection (1) does not constitute cause[1] of death; and

(b) the non-application or discontinuance of life sustaining measures in accordance with subsection (2) does not constitute a cause[1] of death.

Saving provision

18. (1) This Act does not authorise the administration of medical treatment for the purpose of causing the death of the person to whom the treatment is administered.

(2) This Act does not authorise a person to assist the suicide of another.

[1] A *novus actus interveniens* ie a cause that breaks a pre-existing chain of causation.

See also *Medical Treatment Act* (ACT) 1994, s. 23; and *Criminal Code* 1995 (Qld), s. 82.

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EDITORIALS

gress.[13] Perhaps the time has come when colonoscopy should be recommended for average-risk individuals at 50 years of age. We now have options to enable screening to be tailored for each individual, which should increase compliance. As compliance is the key to success of any screening program, individual case-finding, rather than population screening, should be the first step.

Bell and colleagues remind us how common colorectal cancer is in Australia. We now have techniques to prevent it, and programs involving these should be offered to the community. We need a public education program about diet, as well as a commitment to early diagnosis and prevention and accurate Australian data about the cost–benefit ratio of different screening strategies. If there is little cost–benefit difference between strategies, doctors can at least help patients choose the program that suits them best. The next decade will determine whether or not such measures make a real difference, but only if we decide to implement them.

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The fallacies of death causation in palliative care

While the debate about euthanasia continues, society should focus more on palliative care which is clinically safe and ethically sound

In studies which generated the first data on the incidence of euthanasia in the Netherlands,[1-3] the practice was categorised as a type of "medical decision at the end of life", defined as: "all decisions by physicians concerning courses of action aimed at hastening the end of life of the patient or courses of action for which the physician takes into account the probability that the end of life of the patient is hastened." Two other categories which van der Maas and colleagues created were the administration of "high" doses of opiates that "almost certainly would shorten the life of the patient" and decisions in which "life-prolonging" treatment was withheld or withdrawn.[4] In this issue of the Journal (*page 191*), Kuhse et al. report the results of their Australian study based on the approach taken by these studies.

One line of argument advanced by those in favour of legalising euthanasia is to suggest that if doctors already cause (or hasten) death by stopping "active" treatment or by palliative interventions, such as the use of escalating morphine doses for pain control, they should not object to the administration of a lethal injection or the supply of the means to commit suicide at the explicit request of a terminally ill patient. By demonstrating a high incidence of so-called "medical decisions at the end of life" which are argued to cause death (approximately 65% of deaths in the study by Kuhse et al.), advocates of the legalisation of voluntary active euthanasia presumably hope to show that existing medical practice is inconsistent in both its principles and processes.

There are two major false premises which need to be challenged. Firstly, it is a common belief, and the basis of a considerable body of legal and legislative opinion, that the dose of morphine (or other opioid) *per se* is the main determinant of whether the drug causes or hastens death.[5] In fact, there is no such determinative dose. What matters is the relationship of a dose to the previous dose. In pain management gradual dose escalation by 50%–100% of the previous dose is usual practice, although substantially higher increases can usually be well tolerated by patients who are not new to the drug. It is therefore the size of the initial dose, and the rate of subsequent increases, which are important.

Unlike most other forms of drug treatment, there are no predetermined dose ranges of morphine for achieving satisfactory control of cancer pain. Therefore, treatment has to be skilfully adjusted on an individual basis. For most adults a daily dose in the range 30–200 mg, orally, will achieve initial pain control. The accepted practice, used safely for at least 20 years, is to adjust the regular dose (usually) upwards according to the requirements to keep the pain under control, balanced against the occurrence of side effects. Many

doctors still believe that they are causing or hastening the death of patients by this process, despite an extensive and sustained international campaign by the World Health Organization and a lack of any evidence to support this view. Like any drug, morphine is dangerous if used without clinical skill. Appropriate opioid use is surrounded by myths and fears among both the general public and health care professionals, appearing to be largely attributable to the history and non-medical use of this class of drugs.[6]

Secondly, surely nobody benefits from lines of argument which equate the cessation of treatment or decisions not to treat when a person is dying (even if treatment is *potentially* life-prolonging) with giving a lethal injection to end a life. "Moral-equivalence" arguments based on outcome cannot ignore the assessment of clinical proportionality and appropriateness. Although Keyserlingk has argued against overemphasis on "but-for" causality in this debate,[7] the death is surely caused only if the treatment can be demonstrated to be clinically effective in the circumstances, and the underlying condition is potentially reversible (i.e., there is a disruption of a pre-existing chain of causation).[8] For a competent patient who expresses a wish to reject any medical treatment whatsoever, this has been clearly accepted as morally and legally permissible, and the issue is not controversial.

While van der Maas et al.[9] and Kuhse et al. are right to draw attention to situations in which patients were not consulted about medical decisions, treatment abatement cannot be negotiated with incompetent dying people. Unfortunately, incompetence due to organic brain dysfunction is fairly common during the dying process and medical decisions do have to be taken.[10] Although the Australian doctors in the report by Kuhse and colleagues may be reflecting a degree of honest pragmatism, this finding clearly needs more exploration — with particular emphasis on the transparency of process, negotiation and consultation.

Kuhse et al. state that death was the "partly or explicitly" intended outcome of a medical decision to end life in 36.5% of all Australian deaths. While they attempted to ascertain intention, neither their study nor the Dutch studies validate the doctors' responses by examining clinical data and prescription records. In the absence of formal training in palliative care — a relatively recent advent in most medical schools — doctors' attitudes and clinical behaviour are complex and variable. They range from abrupt cessation of treatment, minimalist palliative care and treatment directed at bringing about a rapid dying process, to excessive caution about being seen to be instrumental in causing the death, particularly with regard to providing pain and symptom relief, withdrawal or non-initiation of artificial hydration and alimentation, and cardiopulmonary resuscitation.[11]

While academic study in this area is essential and welcome, neither reliance on empirical research[12] (despite its attractiveness to doctors and policymakers) nor the generation of increasingly ingenious ethical or legal arguments will resolve the issue of euthanasia. The debate has become stagnant, circular and divisive and it distracts our society from the on-going task of improving care and decision-making at the end of life. The most important thing is promoting the comfort, dignity and autonomy of people who are dying.

Divergence about whether third-party assistance (medical or non-medical) to die is permissible reveals a deep and complex fault line in modern Western democracies, as they chart their courses based more on individual conceptions of liberty and autonomy than those of organised religion and deontological codes.[13] This process is ongoing and resolution will not come easily. Society's energy should be more focused on palliative care, about which we can nearly all agree, and where modest investments have yielded excellent results for patients and families by improving care and decision-making at the end of life. There is much still to do.

Euthanasia should be narrowly defined as "the deliberate action to terminate life by someone other than, and at the request of, the patient concerned",[14] which is the matter at stake in the on-going societal debate. The Australian public need to have complete confidence that there is a safe and morally sound body of modern palliative care practice which is clearly and unambiguously distinguished from euthanasia. Palliative care practitioners are confident to give this reassurance.

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BOOK REVIEWS

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BOOK REVIEWS

***Palliative Care Ethics. A good companion* by Fiona Randall and R.S. Downie. Oxford: Oxford University Press, 1996 xix, 202pp AUD $59.95.**

This book on palliative care ethics is the latest in a series of publications by Oxford University Press in the field of palliative care, which started with the release of the world's first authoritative textbook in 1993 (*Oxford Textbook of Palliative Medicine*, edited by Doyle, Hanks and Macdonald). The great strength of the hospice and palliative care movement has been that it has made a primarily practical rather than intellectual response to the needs of dying people. Despite considerable publicity and education, its substantial achievements have occurred against a background of variable, but usually limited social and professional awareness of what can realistically be achieved for dying people and those close to them. Fear of being responsible for the cause of a person's death still often seems to hinder good palliative care referral practices, decision-making and care planning. For instance, it has already taken nearly thirty years to establish the safe use of opioid analgesia in cancer pain and there is still work to do. There is clearly a continuing need to address the attitudinal dimension: the ethical and legal perceptions that surround death in the modern world.

Randall and Downie are a writing partnership of an experienced palliative care specialist and a philosopher, a combination which immediately seems appealing for the first serious separate work of this type on palliative care. The writing is clear and the language should be accessible to a wide readership, and certainly to most health care workers, although those who have had no prior introduction to health care ethics may need to have a basic text such as *Principles of Biomedical Ethics* by Beauchamp and Childress to hand for reference and expanded explanation of the fundamental concepts of the discipline. The chapters are clearly laid out and the main points are summarised at the end of each chapter.

The authors invoke the four classical principles of health care ethics (non-maleficence, beneficence, respect for autonomy, justice) and

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add a fifth — utility (p. 13). But the main philosophical basis of the book is Aristotelian. Palliative care should aim to promote the 'total good' of the patient. It therefore needs to have both intrinsic and extrinsic aims (chapter 1). The intrinsic aims promote what the authors term the 'medical good' of the person 'related to physical or mental illness' (p. 24). The extrinsic aims are defined in terms of experienced practitioners offering advice and discussion 'based on practical wisdom generated by interaction between their own personality, and their experience of health care and life in general' (p. 24). One of the central tenets of the hospice movement is that the care is centred on the 'whole person' or is said to be 'holistic'. Randall and Downie argue that such holistic care addresses the patient's 'total good', which can only be defined by the patient, and that incursions into this domain require their informed consent. 'Whole person' care is a combination of the addressing of the intrinsic and extrinsic aims of palliative care.

It is not clear why this reliance on Aristotle is seen as such a promising or safe philosophical basis for discussion and action in palliative care. Aristotle himself did not reach a sharp conclusion about the nature of good. Human flourishing is variously articulated as the attainment of theoretical excellence in the *Nichomachean Ethics* and as a more mixed table of civic and theoretical virtues in the *Eudemian Ethics*. No one could possibly disagree with the notion that it is worthwhile, indeed indispensable to good care, palliative or not, that practitioners should have life experience, sensitivity and good communication skills. Nor is it disputed that these desirable characteristics (read virtues) may be summarised by the Aristotelian concept of 'phronesis', translated as 'practical wisdom'. But how are the parameters and content of 'phronesis' defined, and by whom? Instead of relying on the Aristotelian account, it might be worth exploring a utilitarian approach of evaluating potential outcome for the patient and family, a sort of 'extrinsic' or non-medical therapeutic ratio determination.

The authors do one of their best services in this book by calling to mind the fine line between appropriate and acceptable holistic care on the one hand and unwanted or unrequested intrusion and breach of privacy on the other. They certainly made this writer review the whole way we effortlessly slip into very personal aspects of a patient or family's intimate space on ward rounds or in palliative care team meetings. These transgressions are usually made with the best of intentions and often generate real good, but they usually occur without the explicit consent of patients and families who may feel under covert pressure by the palliative care team to confront or disclose issues which they would really rather not. The warning

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about the danger of allowing the needs and wishes of relatives too much influence, that 'the squeaky wheel gets the grease' is also a timely reminder. Relatives and friends may attempt to speak for the patient without due regard for what the patient really wants, or may amplify pain or problems as a result of their own sense of grief and loss.

The book's most adventurous aspects are contained in the sections which question the teaching of communication skills as a formula and the limitations of the counselling model. It is a very significant advance in medical education that most medical schools are addressing the area of communication skills. However, it is important for students and young doctors to realise that there is no substitute for continuous improvement. Formula approaches which fail to emphasise individuality, spontaneity, real human interaction, and self monitoring are very limiting. The problem with the counselling model in health care is that it is often conceptualised as a separate task, when it really ought to be an interwoven part of the approach, particularly in palliative care. The authors also question the need for special expertise and argue that there is an inherent contradiction between the statements that those who seek counselling are in search of 'real people' but that professional training is necessary to provide that service, that is that you require training in counselling or psychotherapy to be a 'genuine' and 'real' person to a dying person (p. 166). This will probably ruffle a few feathers. Certainly most experienced palliative care practitioners acquire substantial skills in this area, but we also need the insights of our colleagues in social work, pastoral care, psychiatry and psychology.

The United Kingdom focus is irritating for an international audience, which the publishers presumably intend for the book. Examples include mention of the Patient Charter (p. 29), the Community Care Act (1990) (UK) (pp. 144–6) and a very limited but wordy discussion on advance directives from a UK perspective (p. 136). The chapter on resource allocation seems to be included for the sake of completeness and really does not add much to the overall work.

Perhaps the book's most significant overall deficit is the lack of references (twenty six for the whole book), an absence of footnotes and obviously no attempt to locate the reader in the ethics of palliative care. This also highlights a lack of argumentation. The reader is often left saying 'we know what you think, but not why you think it'. Nowhere is this more glaringly apparent than the total avoidance of any discussion of euthanasia. The book starts by stating that euthanasia is not part of palliative care and is therefore not considered further. On the one hand, it is a relief to be able to

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consider the ethics of palliative care without the (seemingly obligatory) inclusion of euthanasia which has so dominated and obscured discussions in the field in recent years. On the other, the differentiation between good palliative care practice and euthanasia is a big issue in many countries. Palliative care opposition to euthanasia has often adopted a propagandist tone, relying on varying combinations of consequentialist hypotheses, and the doctrine of double effect. An intellectually sound exposition, from the palliative care perspective, of why the legalisation of euthanasia may not achieve the aims which its proponents seek is long overdue. To avoid this territory altogether is surprising and is in itself a highly significant political statement.

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***The Concept of Moral Consensus: The Case of Technological Interventions into Human Reproduction* edited by Kurt Bayertz. Dordrecht: Kluwer Academic Publishers, 1994. vii + 249 pp. £72.**

This book is a compilation of papers presented at a conference in Bielefeld, Germany in 1990. The editor, presented in one of the two editorial errors of this book as professor of philosophy in Munich as well as in Münster, has a long-standing record in publishing in the area of medical ethics in Germany. His expertise is mostly in the area of ethical issues in the 'new genetics'.

Bayertz managed to get scholars of high international reputation to the sleepy town of Bielefeld. Among them Helga Kuhse (one of the editors of this journal), the Americans H. Tristam Engelhardt, James F. Childress, Larry Tancredi, Jonathan D. Moreno and a number of European and German contributors. This makes *Concept of Moral Consensus* very useful to anyone interested in a transatlantic dialogue on consensus in bioethics. An interesting paper by Simone Novaes offers some insight into the working of an ethics committee of the French Federation of CECOS semen banks. Some of the authors agree that it should be possible to find a consensus about specific policies and perhaps even some principles, while it seems to be illusory to attempt finding a consensus about moral theories. This opinion was defended most notably by Jonathan Moreno in his paper on consensus by committee. On a practical level there might be some truth to this claim for debates in liberal societies (as opposed to cross-cultural ethical debates).

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LEGISLATION

NATURAL DEATH ACT, 1983

No. 121 of 1983

SUMMARY OF PROVISIONS

Section

1. Short title
2. Commencement
3. Interpretation
4. Power to make direction
5. Act not to affect other rights
6. Certain aspects of causation of death
7. Saving clause

ANNO TRICESIMO SECUNDO

ELIZABETHAE II REGINAE

A.D. 1983

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No. 121 of 1983

An Act to provide for, and give legal effect to, directions against artificial prolongation of the dying process.

[*Assented to 22 December 1983*]

BE IT ENACTED by the Governor of the State of South Australia, with the advice and consent of the Parliament thereof, as follows:

Short title.

1. This Act may be cited as the "Natural Death Act, 1983".

Commencement.

2. This Act shall come into operation on a day to be fixed by proclamation.

Interpretation.

3. In this Act—

"extraordinary measures" means medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation:

"recovery", in relation to a terminal illness, includes a remission of symptoms or effects of the illness:

"terminal illness" means any illness, injury or degeneration of mental or physical faculties—

(a) such that death would, if extraordinary measures were not undertaken, be imminent;

and

(b) from which there is no reasonable prospect of a temporary or permanent recovery, even if extraordinary measures were undertaken.

Power to make direction.

4. (1) A person of sound mind, and of or above the age of eighteen years, who desires not to be subjected to extraordinary measures in the event of his suffering from a terminal illness, may make a direction in the prescribed form.

(2) The direction must be witnessed by two witnesses.

(3) Where a person who is suffering from a terminal illness has made a direction under this section and the medical practitioner responsible for his treatment has notice of that direction, it shall be the duty of that medical practitioner to act in accordance with the direction unless there is reasonable ground to believe—

(a) that the patient has revoked, or intended to revoke, the direction;

or

(b) that the patient was not, at the time of giving the direction, capable of understanding the nature and consequences of the direction.

(4) This section does not derogate from any duty of a medical practitioner to inform a patient who is conscious and capable of exercising a rational judgment of all the various forms of treatment that may be available in his particular case so that the patient may make an informed judgment as to whether a particular form of treatment should, or should not, be undertaken.

(5) The Governor may, by regulation, prescribe a form for the purposes of subsection (1).

Act not to affect other rights.

5. (1) This Act does not affect the right of any person to refuse medical or surgical treatment.

(2) This Act (other than section 6) does not affect the legal consequences (if any) of—

(a) taking, or refraining from taking, therapeutic measures (not being extraordinary measures) in the case of a patient who is suffering from a terminal illness (whether or not he has made a direction under this Act);

or

(b) taking, or refraining from taking, extraordinary measures in the case of a patient who has not made a direction under this Act.

(3) A medical practitioner incurs no liability for a decision made by him in good faith and without negligence as to whether—

(a) a patient is, or is not, suffering from a terminal illness;

(b) a patient revoked, or intended to revoke, a direction under this Act;

or

(c) a patient was, or was not, at the time of giving a direction under this Act, capable of understanding the nature and consequences of the direction.

Certain aspects of causation of death.

6. (1) For the purposes of the law of this State, the non-application of extraordinary measures to, or the withdrawal of extraordinary measures from, a person suffering from a terminal illness does not constitute a cause of death.

(2) This section does not relieve a medical practitioner from the consequences of a negligent decision as to whether or not a patient is suffering from a terminal illness.

Saving clause

7. (1) Nothing in this Act prevents the artificial maintenance of the circulation or respiration of a dead person—

(a) for the purpose of maintaining bodily organs in a condition suitable for transplantation;

or

(b) where the dead person was a pregnant woman—for the purpose of preserving the life of the foetus.

(2) Nothing in this Act authorizes an act that causes or accelerates death as distinct from an act that permits the dying process to take its natural course.

In the name and on behalf of Her Majesty, I hereby assent to this Bill.

D. B. DUNSTAN, Governor

BY AUTHORITY: D. J. WOOLMAN, Government Printer, South Australia

NOTICE OF DIRECTION PURSUANT TO NATURAL DEATH ACT, 198

To: The Medical Practitioner responsible for my treatment
at such time when I am suffering from a terminal illness*

I, ...declare that I am of sound mind
(name of person making direction)
and a person of or above the age of eighteen years AND in the event that I may suffer from a terminal illness* within the meaning of the Natural Death Act, 1983 AND having the desire not to be subjected to extraordinary measures, namely medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation DO HEREBY make the direction that I not be subjected to such extraordinary measures.

Dated:.....19.....

Signature of person making direction:.....

WITNESSED in the presence of two witnesses:

1 .....2 .....

.....

.....

(Name, address, occupation) (Name, address, occupation)

*Terminal illness means any illness, injury or degeneration of mental or physical faculties:

(a) such that death would, if extraordinary measures were not undertaken, be imminent;
and

(b) from which there is no reasonable prospect of a temporary or permanent recovery, even if extraordinary measures were undertaken.

Victoria

No. 41 of 1988

Medical Treatment Act 1988

[Assented to 24 May 1988]

[As amended by the Medical Treatment (Enduring Power of Attorney) Act 1990 [Assented to 10 pril 1990] (No.7 of 1990) and the Medical Treatment (Agents) Act 1992 [Assented to 16 June 1992] (No.26 of 1992).]

Preamble.

The Parliament recognises that it is desirable—

(*a*) to give protection to the patient's right to refuse unwanted medical treatment;

(*b*) to give protection to medical practitioners who act in good faith in accordance with a patient's express wishes;

(*c*) to recognise the difficult circumstances that face medical practitioners in advising patients and providing guidance in relation to treatment options;

(*d*) to state clearly the way in which a patient can signify his or her wishes in regard to medical care;

(*e*) to encourage community and professional understanding of the changing focus of treatment from cure to pain relief for terminally-ill patients;

(*f*) to ensure that dying patients receive maximum relief from pain and suffering.

The Parliament of Victoria therefore enacts as follows:

PART 1—PRELIMINARY

Purpose.

1. The purposes of this Act are—

(*a*) to clarify the law relating to the right of patients to refuse medical treatment;

(*b*) to establish a procedure for clearly indicating a decision to refuse medical treatment;

(*c*) to enable an agent to make decisions about medical treatment on behalf of an incompetent person. .

[From Medical Treatment (Enduring Power of Attorney) Act 1990]

Purposes [10 April 1990]

1. The purposes of this Act are—

(*a*) to define the power of an agent appointed under an enduring power of attorney (medical treatment);

(*b*) to provide for safeguards over the exercise of an enduring power of attorney (medical treatment);

(*c*) to amend the *Instruments Act* 1958 to make it clear that the powers of an agent under an enduring power of attorney under that Act do not include a power to make decisions about medical treatment;

(*d*) to provide that sections 6B (2) and 463 (B) of the *Crimes Act* 1958 continue to have effect and that inciting, aiding or abetting suicide, or homicide, continue to be offences.

[From Medical Treatment (Agents) Act 1992]

1. *Purpose* [16 June 1992]

The purpose of this Act is to enable a person to appoint an alternate agent to make decisions about the medical treatment of the person if the person becomes incompetent and the agent is unable or unavailable to act.

Commencement.

2. This Act comes into operation on a day to be proclaimed.

[The Medical Treatment (Agents) Act 1992 came into operation on 16 June 1992, the day on which it received the Royal Assent.]

Definitions.

3. In this Act—

"agent" means an agent appointed under an enduring power of attorney (medical treatment) and, except in sections 5A, 5AA, 5C, 5D and 7 and Schedule 2, includes an alternate agent appointed under an enduring power of attorney (medical treatment); .

"Medical practitioner" means a legally qualified medical practitioner.

"Medical treatment" means the carrying out of—

(*a*) an operation; or

(*b*) the administration of a drug or other like substance; or

(*c*) any other medical procedure—

but does not include palliative care.

"Palliative care" includes—

(*a*) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or

(*b*) the reasonable provision of food and water.

"Refusal of treatment certificate" means a certificate in the form of Schedule 1 and, if that certificate is modified, includes that certificate as modified and in force for the time being.

Other legal rights not affected.

4. (1) This Act does not affect any right of a person under any other law to refuse medical treatment.

(2) This Act does not apply to palliative care and does not affect any right, power or duty which a medical practitioner or any other person has in relation to palliative care.

(3) This Act does not—

(*a*) affect the operation of section 6B (2) or 463B of the *Crimes Act* 1958; or

(*b*) limit the operation of any other law.

(4) A refusal of medical treatment under this Act does not limit any duty of a medical practitioner or other person—

(*a*) to advise and inform the patient or the patient's agent or guardian; or

(*b*) to provide medical treatment, other than medical treatment that has been refused. .

PART 2—REFUSAL OF TREATMENT

Refusal of treatment certificate.

5. (1) If a medical practitioner and another person are each satisfied—

(*a*) that a patient has clearly expressed or indicated a decision—

(i) to refuse medical treatment generally; or

(ii) to refuse medical treatment of a particular kind—

for a current condition; and

(*b*) that the patient's decision is made voluntarily and without inducement or compulsion; and

(*c*) that the patient has been informed about the nature of his or her condition to an extent which is reasonably sufficient to enable the patient to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case requires) for that condition and that the patient has appeared to understand that information; and

(*d*) that the patient is of sound mind and has attained the age of 18 years—

the medical practitioner and the other person may together witness a refusal of treatment certificate.

(2) A refusal of treatment certificate must be in the form of Schedule 1.

(3) For the purposes of sub-section (1) (*a*), the patient may clearly express or indicate a decision in writing, orally or in any other way in which the person can communicate.

Agents and guardians

5A. (1) A decision about medical treatment of a person may be made in accordance with this Act—

(*a*) if the person has appointed an agent in accordance with this section, by that agent; or

(*aa*) if the person has appointed an alternate agent in accordance with this section, and section 5AA is complied with, by the alternate agent; or

(*b*) if the person is a represented person and an appropriate order has been made under the *Guardianship and Administration Board Act* 1986 providing for decisions about medical treatment, by the person's guardian.

(2) An appointment of an agent— or alternate agent

(*a*) shall be by way of an enduring power of attorney (medical treatment) in the form of Schedule 2 and must be witnessed by two persons, one of whom shall be a person authorised by law to take and receive statutory declarations and neither of whom shall be the agent or alternate agent to be appointed; and

(*b*) takes effect if and only if the person giving the power becomes incompetent.

and

(*c*) in the case of an appointment of an alternate agent, takes effect if and only if section 5AA is complied with .

(3) If a person gives an enduring power of attorney (medical treatment), any earlier power of attorney (medical treatment) given by that person is revoked.

(4) Despite any rule of law to the contrary, an enduring power of attorney (medical treatment) is not revoked—

(*a*) by the subsequent incapacity of the donor of the power; or

(*b*) upon the donor of the power becoming—

(i) a protected person within the meaning of the *Public Trustee Act* 1958; or

(ii) a represented person within the meaning of the *Guardianship and Administration Board Act* 1986—

but is revoked in any other way in which a general power of attorney is revoked."

(5) An enduring power of attorney (medical treatment) given to an agent (but not an alternate agent) must be taken to be in the form in Schedule 2 as amended by the **Medical Treatment (Agents) Act 1992** if it is in the form in that Schedule as in force immediately before the commencement of that Act. .

5AA. ***When can an alternate agent act?***

(1) An enduring power of attorney (medical treatment) given to an alternate agent authorises the alternate agent to make a decision about medical treatment of the person giving the power if and only if, not more than 7 days before making the decision, the alternate agent completes and, before making that decision, produces to each person required to be satisfied of a matter mentioned in section 5B (1) (*a*) and (*b*) a statutory declaration—

(*a*) giving details of the enquiries or information which forms the basis for the statement of belief in paragraph (*b*);

(*b*) stating that, as a result of those enquiries or that information, the alternate agent believes that the agent is dead, incompetent or cannot be contacted or that the agent's whereabouts are unknown.

(2) A person who, under section 5B (1) (*a*) and (*b*), needs to be satisfied of a matter before an alternate agent can make a decision about medical treatment must decline to be so satisfied if—

(*a*) a statutory declaration completed by the alternate agent is not produced; or

(*b*) he or she reasonably believes that—

(i) the enquiries or information mentioned in the statutory declaration do not form a reasonable basis for the statement of belief set out in that declaration; or

(ii) the person's agent can be contacted and is not incompetent.

Refusal of treatment certificate by agent or guardian

5B. (1) If a medical practitioner and another person are each satisfied—

(*a*) that the patient's agent or guardian has been informed about the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if he or she were competent, to make a decision about whether or not to refuse medical treatment generally or of a particular kind for that condition; and

(*b*) that the agent or guardian understands that information—

the agent or guardian, on behalf of the patient—

(*c*) may refuse medical treatment generally; or

(*d*) may refuse medical treatment of a particular kind—

for that condition.

(2) An agent or guardian may only refuse medical treatment on behalf of a patient if—

(*a*) the medical treatment would cause unreasonable distress to the patient; or

(*b*) there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted.

(3) Where a refusal is made by an agent or a guardian, a refusal of treatment certificate must be completed in the form of Schedule 3.

Guardianship and Administration Board may suspend or revoke authority

5C. (1) On an application under this section, the Guardianship and Administration Board—

(*a*) may in accordance with sub-section (3), (4), (4A) or (4B) suspend or revoke an enduring power of attorney (medical treatment);

(*b*) may in accordance with sub-section (4A) determine whether an enduring power of attorney (medical treatment) given to an alternate agent does or does not authorise the making of a particular decision by the alternate agent;

(*c*) may in accordance with sub-section (4B) determine any question arising out of a conflict between a decision made about a person's medical treatment by the person's agent and alternate agent, including a determination that any or all of those decisions are ineffective.

(2) An application may be made by—

(*a*) the Public Advocate; or

(*b*) a person who, in the opinion of the Board, has a special interest in the affairs of the donor of the power; or

(*c*) the agent or alternate agent appointed under the power.

(3) If the Board is satisfied that refusal of medical treatment, either generally or of a particular kind, at a particular time or in particular circumstances is not in the best interests of the donor, the Board may suspend the power for a specified period.

(4) If the Board is satisfied that it is not in the best interests of the donor of a power for the power to continue, or for the power to continue to be exerciseable by the agent or alternate agent, the Board may revoke the power.

(4A) If the Board is satisfied that—

(*a*) an alternate agent—

(i) has completed a false statutory declaration under section 5AA; or

(ii) has set out in a statutory declaration enquiries or information that do not form a reasonable basis for the statement of belief, set out in the declaration, that a person's agent is dead, incompetent or cannot be contacted or the agent's whereabouts are unknown; or

(iii) is not authorised by an enduring power of attorney (medical treatment) to make a particular decision because of a failure to comply with section 5AA; and

(*b*) it is in the best interests of the person giving the power to do so—

the Board may, to the extent that the power is given to the alternate agent, revoke it, suspend it for a specified period or declare that it does not authorise the making of a particular decision.

(4B) If the Board is satisfied that—

(*a*) a person's agent and alternate agent have made conflicting decisions about the medical treatment of the person; and

(*b*) it is in the best interests of the person to do so—

the Board may do any of the following—

(*c*) revoke the enduring power of attorney (medical treatment);

(*d*) suspend for a specified period the enduring power of attorney (medical treatment);

(*e*) determine that decisions of the agent or alternate agent or both are ineffective;

(*f*) make any other determination about the validity or effect of any of the conflicting decisions that it considers necessary to resolve the conflict.

(4C) A determination of the Board under sub-section (4A) or (4B) revoking or suspending an enduring power of attorney (medical treatment) does not affect the previous operation of—

(*a*) an enduring power of attorney (medical treatment); or

(*b*) any decision made under that power; or

(*c*) any refusal of treatment certificate completed under that power.

(5) Where—

(*a*) the donor of a power is a patient in a public hospital, denominational hospital, private hospital or nursing home; and

(*b*) the Board revokes or suspends the power—

the Board must give written notice of the revocation or suspension to the chief executive officer (by whatever name called) of the hospital or home and the chief executive officer must ensure that a copy of the notice is placed with the patient's record kept by the hospital or home.

Revocation or suspension of refusal of treatment certificate

5D. (1) If—

(*a*) an enduring power of attorney (medical treatment) is revoked; or

(*b*) the order appointing a guardian under the *Guardianship and Administration Board Act* 1986 is revoked—

any refusal of treatment certificate completed by the agent or alternate agent or guardian is also revoked.

(2) If the Guardianship and Administration Board suspends an enduring power of attorney (medical treatment), any refusal of treatment certificate completed by the agent or alternate agent before the suspension ceases to have effect during the period of the suspension.

(3) If the Guardianship and Administration Board declares that—

(*a*) a decision of an agent or alternate agent resulting in the completion of a refusal of treatment certificate is ineffective; or

(*b*) a decision of an alternate agent resulting in the completion of a refusal of treatment certificate is not authorised by the enduring power of attorney (medical treatment)—

that refusal of treatment certificate is revoked when the declaration is made.

Copies of refusal of treatment certificate

5E. (1) The Board of a public hospital or denominational hospital and the proprietor of a private hospital or nursing home must take reasonable steps to ensure that a copy of any refusal of treatment certificate applying to a person who is a patient in the hospital or home and of any notification of the cancellation of such a certificate—

(*a*) is placed with the patient's record kept by the hospital or home; and

(*b*) is given to the chief executive officer (by whatever name called) of the hospital or home;

(*c*) is given to the Guardianship and Administration Board within 7 days after the certificate is completed.

(2) A medical practitioner who signs the verification in a refusal of treatment certificate for a person who is not a patient in a public hospital, denominational hospital, private hospital or nursing home must take reasonable steps to ensure that a copy of the refusal of treatment certificate is given to the Guardianship and Administration Board within 7 days after it is made.

Penalty for obtaining certificate by fraud etc.

5F. (1) A person who—

(*a*) is a beneficiary under the will of another person; or

(*b*) has an interest under any instrument under which another person is the donor, settlor or grantor; or

(*c*) would be entitled to an interest in the estate of another person on the death intestate of that person—

and who, by any deception, fraud, mis-statement or undue influence, procures or obtains, whether directly or indirectly, the execution by that other person of a certificate under this Act, forfeits any interest under the will, instrument or intestacy, as the case requires.

(2) This section is in addition to any other penalty in respect of the deception, fraud, mis-statement or undue influence under any other Act or law.

Offence of medical trespass.

6. A medical practitioner must not, knowing that a refusal of treatment certificate applies to a person, undertake or continue to undertake any medical treatment ~~which the person has refused~~, being treatment for the condition in relation to which the certificate was given.
to which the certificate applies

Penalty: 5 penalty units.

Cancellation, modification or cessation of certificate.

7. (1) A refusal of treatment certificate may be cancelled ~~or modified by the patient to whom the certificate applies~~ clearly expressing or indicating to a medical practitioner or another person a decision to cancel ~~or modify~~ the certificate.
by the person who gave the certificate or on whose behalf it was given

(1A) A refusal of treatment certificate given by a person's agent may be cancelled in accordance with sub-section (1) by the person's alternate agent, as if the alternate agent gave the certificate.

(1B) A refusal of treatment certificate given by a person's alternate agent may be cancelled in accordance with sub-section (1) by the person's agent, as if the agent gave the certificate.

(2) For the purposes of sub-section (1), a person may clearly express or indicate a decision in writing, orally or in any other way in which the person can communicate.

(3) A refusal of treatment certificate ceases to apply to a person if the medical condition of the person has changed to such an extent that the condition in relation to which the certificate was given is no longer current.

Effect of certificate or notice issued under this Part.

8. (1) This section applies to a refusal of treatment certificate and to a written notice of a cancellation ~~or modification~~ of a refusal of treatment certificate.

(2) In any civil or criminal proceeding, production of either of the instruments mentioned in sub-section (1) is—

(*a*) evidence; and

(*b*) in the absence of evidence to the contrary, proof—

that the patient has refused medical treatment or has cancelled ~~or modified~~ a refusal of treatment certificate.

(3) This section does not affect other methods of proving a decision to refuse medical treatment.

PART 3—PROTECTION OF MEDICAL PRACTITIONERS

Protection of medical practitioners.

9. (1) A medical practitioner or a person acting under the direction of a medical practitioner who, in good faith and in reliance on a refusal of treatment certificate, refuses to perform or continue ~~the medical treatment which he or she believes on reasonable grounds has been refused~~ medical treatment in accordance with this Act ~~treatment which the person has refused~~ is not—

(*a*) guilty of misconduct or infamous misconduct in a professional respect; or

(*b*) guilty of an offence; or

(*c*) liable in any civil proceedings—

because of the failure to perform or continue that treatment.

(2) For the purposes of this section ~~sub-section (1)~~ a person who acts in good faith in reliance on a refusal of treatment certificate but who is not aware that the certificate has been cancelled ~~or modified~~, is to be treated as having acted in good faith in reliance on a refusal of treatment certificate.

SCHEDULE 1

Sections 3, 5 (2)

REFUSAL OF TREATMENT CERTIFICATE: COMPETENT PERSON

We certify that we are satisfied—

(*a*) that ..... (name of patient) has clearly expressed or indicated a decision, in relation to a current condition, to refuse—

* medical treatment generally;

or

* medical treatment, being .....
(specify particular kind of medical treatment);

(*b*) that the patient's decision is made voluntarily and without inducement or compulsion;

(*c*) that the patient has been informed about the nature of his/her current condition to an extent which is reasonably sufficient to enable him/her to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case requires) and that he/she has appeared to understand that information; and

(*d*) that the patient is of sound mind and has attained the age of 18 years.

Dated:

Signed.....(Medical Practitioner)

Signed.....(Another person)

Patient's current condition

The patient's current condition is ..... (describe condition)

Dated:

Signed: .....

(To be signed by the same medical practitioner) .

Verification to be completed by patient, if physically able to do so.

In relation to my current condition, I refuse—

* medical treatment generally.

or

* medical treatment, being .....
(specify particular kind of medical treatment).

I give the following instructions as to palliative care:

Dated:

Signed.....(Patient)

NOTICE OF CANCELLATION (*for completion where patient cancels the certificate under section 7 of the Medical Treatment Act 1988*)

I cancel this certificate

Dated:

Signed: (Patient)

or

The patient clearly expressed or indicated a decision to cancel this certificate on (Date).

Signed .....(Person witnessing patient's decision) .

* Delete whichever is not applicable

NOTE: "Medical treatment" means the carrying out of—

(*a*) an operation: or

(*b*) the administration of a drug or other like substance: or

(*c*) any other medical procedure—

but does not include palliative care.

"Palliative care" includes—

(*a*) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or

(*b*) the reasonable provision of food and water.

The refusal of palliative care is not covered by the *Medical Treatment Act* 1988.

SCHEDULE 2

Section 5A (2)

ENDURING POWER OF ATTORNEY (MEDICAL TREATMENT)

THIS ENDURING POWER OF ATTORNEY is given on the day of 19 , by A.B. of under section 5A of the *Medical Treatment Act* 1988.

1. I APPOINT

* C. D. of to be my agent.

* C. D. of to be my agent and E. F. of to be my alternate agent.

(* delete whichever is inapplicable) ;

2. I AUTHORISE my agent to make decisions about medical treatment on my behalf. or, if applicable, my alternate agent,

3. I REVOKE all other enduring powers of attorney (medical treatment) previously given by me.

SIGNED SEALED AND DELIVERED by:

We .....(names of witnesses) each believe that A.B. in making this Enduring Power of Attorney (Medical Treatment) is of sound mind and understands the import of this document.

WITNESSED by:

(Signature of Witness) (Signature of Witness)

(Name of Witness) (Name of Witness)

(Address of Witness) (Address of Witness)

NOTE: Section 5A (2) (*a*) requires at least one of the witnesses to this instrument to be a person authorised by law to take and receive statutory declarations.

SCHEDULE 3

Sections 3, 5B

REFUSAL OF TREATMENT CERTIFICATE
AGENT OR GUARDIAN OF INCOMPETENT PERSON

I ..... [name] ..... [address] certify that I am empowered to act in relation to decisions about medical treatment of.....[name of patient] ("the patient").

I have been appointed to act by—

* an enduring power of attorney (medical treatment) issued under the *Medical Treatment Act* 1988.
* an order of the Guardianship and Administration Board under the *Guardianship and Administration Board Act* 1986.

I certify that—

(*a*) the patient has attained the age of 18 years;

(*b*) I have been informed about and understand the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if he/she were competent, to make a decision about whether or not to refuse medical treatment generally or of a particular kind for that condition. I believe that the patient would request that no medical treatment, or no medical treatment of the particular kind mentioned below, be administered to him/her.

On behalf of the patient, in relation to his/her current condition, I refuse—

* medical treatment generally.
* medical treatment, being ..... (specify particular kind of medical treatment).

Dated:

Signed: .....(Agent/Guardian for .....[Name of patient])

*Delete whichever is not applicable

Verification

We each certify as follows:

(*a*) I am satisfied that ..... [name of agent or guardian] has been informed about the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if he/she were competent, to make a decision about whether or not to refuse medical treatment generally or of a particular kind for that condition and that the agent/guardian understands that information;

(*b*) I was not a witness to the enduring power of attorney (medical treatment) under which ..... (name of agent) was appointed.

Dated:

Signed: ..... Signed: .....

(Medical Practitioner) (Another Person)

Patient's current condition

The patient's current condition is .....(describe condition)

The patient is incompetent.

Dated:

Signed:

(To be signed by the same medical practitioner)

patient

NOTICE OF CANCELLATION (*For completion where agent or guardian cancels the certificate under section 7 of the Medical Treatment Act 1988*)

I cancel this certificate

Dated:

Signed: Patient, (Agent or guardian)

patient, *or*

The agent or guardian clearly expressed or indicated a decision to cancel this certificate

on (Date)

Signed 1. (Person witnessing patient's agent or guardian's decision)

NOTES "Medical treatment" means the carrying out of—

(*a*) an operation; or

(*b*) the administration of a drug or other like substance; or

(*c*) any other medical procedure—

but does not include palliative care.

"Palliative care" includes—

(*a*) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or

(*b*) the reasonable provision of food and water.

The refusal of palliative care is not covered by the *Medical Treatment Act* 1988.

2. An alternate agent can only make a decision about a patient's medical treatment if the alternate agent first produces to each medical practitioner who is to verify this certificate a statutory declaration that meets the requirements of section 5AA (1) of the Medical Treatment Act 1988.

3. If this certificate is to be completed by an alternate agent, a medical practitioner must refuse to verify this certificate if the alternate agent does not produce to him or her a statutory declaration that meets the requirements of section 5AA (1) of the Medical Treatment Act 1988 or if the medical practitioner reasonably believes that the original agent can be contacted and is not incompetent.

4. A medical practitioner who has doubts about the circumstances of the issue of this certificate, whether the medical practitioner must refuse to verify it, the competency of the patient or the competency, good faith or motives of the agent or guardian in giving a direction about medical treatment under this certificate is advised to request the Guardianship and Administration Board to review the case.

NOTES

1. *Minister's second reading speech—*

   Legislative Council: 23 March 1988

   Legislative Assembly: 6 May 1988

2. The long title for the Bill for this Act was "A Bill to create an offence of medical trespass, to make other provision concerning the refusal of medical treatment and for other purposes.".

APPENDIX 28

South Australia

CONSENT TO MEDICAL TREATMENT AND PALLIATIVE CARE ACT 1995

No. 26 of 1995

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SCHEDULE 3
Repeal and Transitional Provisions and Consequential Amendments

ANNO QUADRAGESIMO QUARTO

ELIZABETHAE II REGINAE

A.D. 1995

****

No. 26 of 1995

An Act to deal with consent to medical treatment; to regulate medical practice so far as it affects the care of people who are dying; to repeal the Natural Death Act 1983 and the Consent to Medical and Dental Treatment Act 1985; to amend the Guardianship and Administration Act 1993 and the Mental Health Act 1993; and for other purposes.

[*Assented to 27 April 1995*]

The Parliament of South Australia enacts as follows:

PART 1
PRELIMINARY

Short title

1. This Act may be cited as the *Consent to Medical Treatment and Palliative Care Act 1995*.

Commencement

2. (1) This Act will come into operation on a day to be fixed by proclamation.

(2) All provisions of this Act, other than section 14, must be brought into operation simultaneously.

(3) Section 14 may be brought into operation after the other provisions of this Act except that if it has not been brought into operation sooner, it will, by force of this provision, come into operation six months after the commencement of this Act.

Objects

3. The objects of this Act are—

(a) to make certain reforms to the law relating to consent to medical treatment—

(i) to allow persons of or over the age of 16 years to decide freely for themselves on an informed basis whether or not to undergo medical treatment; and

(ii) to allow persons of or over the age of 18 years to make anticipatory decisions about medical treatment; and

(iii) to provide for the administration of emergency medical treatment in certain circumstances without consent; and

(b) to provide for medical powers of attorney under which those who desire to do so may appoint agents to make decisions about their medical treatment when they are unable to make such decisions for themselves; and

(c) to allow for the provision of palliative care, in accordance with proper standards, to people who are dying and to protect them from medical treatment that is intrusive, burdensome and futile.

Interpretation

4. In this Act, unless the contrary intention appears—

"**administration**" of medical treatment includes the prescription or supply of drugs;

"**anticipatory direction**"—*See section 7*;

"**authorised witness**" means—

(a) a justice of the peace;[1] or

(b) a commissioner for taking affidavits in the Supreme Court; or

(c) a member of the clergy; or

(d) a registered pharmacist;

"**available**"—*For availability of medical agent to act under medical power of attorney, see section 9(2)*;

"**child**" means a person under 16 years of age;

"**dentist**" means a person who is registered on the general register or specialist register under the *Dentists Act 1984;*

"**guardian**" means a person acting or appointed under any Act or law as the guardian of another;

"**life sustaining measures**" means medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation, and includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation;

"**medical agent**" means a person empowered to consent or refuse consent to medical treatment under a medical power of attorney;

"**medical practitioner**" means a person who is registered on the general register under the *Medical Practitioners Act 1983* and includes a dentist;

"**medical treatment**" means treatment or procedures administered or carried out by a medical practitioner in the course of medical or surgical practice or by a dentist in the course of dental practice and includes the prescription or supply of drugs;

"**palliative care**" means measures directed at maintaining or improving the comfort of a patient who is, or would otherwise be, in pain or distress;

"**parent**" includes a person *in loco parentis*;

"**representative**" means a person who is empowered by medical power of attorney or some other lawful authority to make decisions about the medical treatment of another when the other is incapable of making decisions for her/himself;

"**terminal illness**" means an illness or condition that is likely to result in death;

"**terminal phase**" of a terminal illness means the phase of the illness reached when there is no real prospect of recovery or remission of symptoms (on either a permanent or temporary basis).

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[1] Section 34 of the *Oaths Act 1936* provides that where provision is made by an Act for the attestation of an instrument by a justice, the provision is complied with if the witness is a justice, a proclaimed postmaster, a proclaimed bank manager, or a proclaimed member of the police force.

Application of Act

5. This Act does not apply to medical procedures conducted for the purposes of research rather than for the purpose of treating, or determining the appropriate treatment for, the patient subjected to those procedures.

PART 2
CONSENT TO MEDICAL TREATMENT

DIVISION 1—CONSENT GENERALLY

Legal competence to consent to medical treatment

6. A person of or over 16 years of age may make decisions about his or her own medical treatment as validly and effectively as an adult.

DIVISION 2—ANTICIPATORY GRANT OR REFUSAL OF CONSENT

Anticipatory grant or refusal of consent to medical treatment

7. (1) A person of or over 18 years of age may, while of sound mind, give a direction under this section about the medical treatment that the person wants, or does not want, if he or she is at some future time—

(a) in the terminal phase of a terminal illness, or in a persistent vegetative state; and

(b) incapable of making decisions about medical treatment when the question of administering the treatment arises.

(2) A direction under this section—

(a) must be in the form prescribed by Schedule 2 or in a form prescribed by regulation; and

(b) must be witnessed by an authorised witness who completes a certificate in the form prescribed by Schedule 2 or in a form prescribed by regulation.

(3) If—

(a) a person by whom a direction has been given under this section—

(i) is in the terminal phase of a terminal illness or in a persistent vegetative state; and

(ii) is incapable of making decisions about his or her medical treatment; and

(b) there is no reason to suppose that the person has revoked, or intended to revoke, the direction,

the person is to be taken to have consented to medical treatment that is in accordance with the wishes of the person as expressed in the direction and to have refused medical treatment that is contrary to those expressed wishes.

DIVISION 3—MEDICAL POWERS OF ATTORNEY

Appointment of agent to consent to medical treatment

8. (1) A person of or over 18 years of age may, while of sound mind, by medical power of attorney, appoint an agent with power to make decisions on his or her behalf about medical treatment.

(2) A medical power of attorney—

(a) must be in the form prescribed by Schedule 1 or in a form to similar effect; and

(b) must be witnessed by an authorised witness who completes a certificate in the form or to the effect of the certificate in Schedule 1.

(3) A person is not eligible to be appointed an agent under a medical power of attorney unless over 18 years of age.

(4) The fact that a person has an interest under the will, or in the estate, of the grantor of a medical power of attorney does not invalidate the appointment of that person as a medical agent, or the exercise of any power by that person under a medical power of attorney.

(5) A person is not eligible to be appointed an agent under a medical power of attorney if that person is, in a professional or administrative capacity, directly or indirectly responsible for or involved in the medical care or treatment of the person by whom the medical power of attorney is to be given and, if a person who is validly appointed as a medical agent becomes so responsible or involved, the person is disqualified from acting as a medical agent under the medical power of attorney.

(6) If a medical power of attorney appoints two or more agents, it must indicate the order of appointment and, in that case, if the person designated first in order of appointment is unavailable, the power is to be exercised by the person designated second in order of appointment, if the first and second are not available, by the person designated third in order of appointment, and so on, but a medical power of attorney may not provide for the joint exercise of the power.

(7) A medical power of attorney—

(a) authorises the agent, subject to any conditions and directions contained in the power of attorney, to make decisions about the medical treatment of the person who granted the power if that person is incapable of making decisions on his or her own behalf; but

(b) does not authorise the agent to refuse—

(i) the natural provision or natural administration of food and water; or

(ii) the administration of drugs to relieve pain or distress; or

(iii) medical treatment that would result in the grantor regaining the capacity to make decisions about his or her own medical treatment unless the grantor is in the terminal phase of a terminal illness.

(8) The powers conferred by a medical power of attorney must be exercised—

(a) in accordance with any lawful conditions and directions contained in the medical power of attorney; and

(b) if the grantor of the power has also given an anticipatory direction—consistently with the direction,

and subject to those requirements, in what the agent genuinely believes to be the best interests of the grantor.

(9) The grantor of a medical power of attorney may, by any form of representation that indicates an intention to withdraw or terminate the power, revoke the power of attorney.

(10) The grantor of a medical power of attorney may, on regaining capacity to make decisions about his or her medical treatment, vary or revoke any decision taken by the medical agent during the period of incapacity.

Exercise of powers under medical power of attorney

9. (1) A medical agent is only entitled to act under a medical power of attorney if—

(a) the agent produces a copy of the medical power of attorney for inspection by the medical practitioner responsible for the treatment of the grantor of the power; and

(b) the medical agent is not disqualified from acting under the medical power of attorney[1]; and

(c) the medical agent is of full legal capacity.

(2) A medical agent will only be regarded as available to act under a medical power of attorney if—

(a) the medical practitioner responsible for the treatment of the grantor of the medical power of attorney is aware of the appointment; and

(b) the medical agent is entitled to act under the medical power of attorney; and

(c) it is reasonably practicable in the circumstances for the medical practitioner responsible for the grantor's treatment to obtain a decision from the medical agent.

[1] See section 8(5) which disqualifies certain medical agents from acting.

Review of medical agent's decision

10. (1) The Supreme Court may, on the application of—

(a) the medical practitioner responsible for the treatment of the grantor of a medical power of attorney; or

(b) any person who has in the opinion of the Court a proper interest in the exercise of powers conferred by a medical power of attorney,

review the decision of a medical agent.

(2) The Court may not review a decision by a medical agent to discontinue treatment if—

(a) the grantor is in the terminal phase of a terminal illness; and

(b) the effect of the treatment would be merely to prolong life in a moribund state without any real prospect of recovery.

(3) The purpose of the review is—

(a) to ensure that the medical agent's decision is in accordance with lawful conditions and directions contained in the medical power of attorney and, if the grantor of the power has also given an anticipatory direction, is consistent with that direction; and

(b) to ensure as far as possible that the medical agent's decision is in accordance with what the grantor would have wished if the grantor had been able to express his or her wishes.

(4) A decision of a medical agent that is not contrary to lawful conditions and directions given by the grantor will, in the absence of proof to the contrary, be presumed to be in accordance with what the grantor would have wished if the grantor had been able to express his or her wishes but this presumption does not apply if—

(a) the grantor is not in the terminal phase of a terminal illness; and

(b) the effect of the medical agent's decision would be to expose the grantor to risk of death or exacerbate the risk of death.

(5) The Court may—

(a) confirm, cancel, vary or reverse the decision of the medical agent; and

(b) give advice and directions that may be necessary or desirable in the circumstances of the case.

(6) The Court must conduct a review under this section as expeditiously as possible.

(7) A person must not publish by newspaper, radio or television a statement or representation—

(a) by which the identity of a person who is, or has been, the subject of proceedings under this section (the "**patient**") is revealed; or

(b) from which the identity of a person who is, or has been, the subject of proceedings under this section (the "**patient**") might be inferred.

Penalty: $10 000.

(8) Subsection (7)—

(a) ceases to apply if or when the patient recovers and then gives his or her consent to the publication of the information; or

(b) ceases to apply after the death of the patient.

(9) In subsection (7)—

"**newspaper**" includes any journal, magazine or other publication that is published daily or at periodic intervals.

Penalty for fraud, undue influence, etc.

11. (1) A person who, by dishonesty or undue influence, induces another to execute a medical power of attorney is guilty of an offence.

Penalty: Imprisonment for 10 years.

(2) A person who purports to act as a medical agent under a medical power of attorney knowing that the power of attorney has been revoked is guilty of an offence.

Penalty: Imprisonment for 10 years.

(3) A person convicted or found guilty of an offence against this section forfeits any interest that that person might otherwise have had in the estate of the grantor of the power of attorney.

DIVISION 4—MEDICAL TREATMENT OF CHILDREN

Administration of medical treatment to a child

12. A medical practitioner may administer medical treatment to a child if—

(a) the parent or guardian consents; or

(b) the child consents and—

(i) the medical practitioner who is to administer the treatment is of the opinion that the child is capable of understanding the nature, consequences and risks of the treatment and that the treatment is in the best interest of the child's health and well-being; and

(ii) that opinion is supported by the written opinion of at least one other medical practitioner who personally examines the child before the treatment is commenced.

DIVISION 5—EMERGENCY MEDICAL TREATMENT

Emergency medical treatment

13. (1) Subject to subsection (3), a medical practitioner may lawfully administer medical treatment to a person (the "**patient**") if—

(a) the patient is incapable of consenting; and

(b) the medical practitioner who administers the treatment is of the opinion that the treatment is necessary to meet an imminent risk to life or health and that opinion is supported by the written opinion of another medical practitioner who has personally examined the patient; and

(c) the patient (if of or over 16 years of age) has not, to the best of the medical practitioner's knowledge, refused to consent to the treatment.

(2) A supporting opinion is not necessary under subsection (1) if in the circumstances of the case it is not practicable to obtain such an opinion.

(3) If—

(a) the patient has appointed a medical agent; and

(b) the medical practitioner proposing to administer the treatment is aware of the appointment and of the conditions and directions contained in the medical power of attorney; and

(c) the medical agent is available to decide whether the medical treatment should be administered,

the medical treatment may not be administered without the agent's consent.

(4) If no such medical agent is available and a guardian of the patient is available, the medical treatment may not be administered without the guardian's consent.

(5) If the patient is a child, and a parent or guardian of the child is available to decide whether the medical treatment should be administered, the parent's or guardian's consent to the treatment must be sought but the child's health and well-being are paramount and if the parent or guardian refuses consent, the treatment may be administered despite the refusal if it is in the best interests of the child's health and well-being.

DIVISION 6—REGISTER

Register

14. (1) The Minister must establish a register of—

(a) directions under section 7 of this Act ("**treatment directions**"); and

(b) medical powers of attorney.

(2) The Minister must appoint a suitable person (referred to below as the "**Registrar**") to administer the register.

(3) A person who has given a treatment direction, or granted a medical power of attorney, may, on application to the Registrar, have the direction or power of attorney registered in the register.

(4) An application under subsection (3) must be accompanied by—

(a) a copy of the direction or power of attorney (to be held by the Registrar for the purposes of this section); and

(b) a fee prescribed by regulation.

(5) The Registrar must, at the request of a medical practitioner responsible for the treatment of a person by whom a registered direction or power of attorney was given, or any other person with a proper interest in a registered direction or power of attorney, produce the direction or power of attorney for inspection by that medical practitioner or other person.

(6) The Registrar must, on application by a person who gave a registered treatment direction or granted a registered power of attorney, register the revocation of the direction or power of attorney and remove it from the register.

PART 3
PROVISIONS GOVERNING MEDICAL PRACTICE

DIVISION 1—MEDICAL PRACTICE GENERALLY

Medical practitioner's duty to explain

15. A medical practitioner has a duty to explain to a patient (or the patient's representative), so far as may be practicable and reasonable in the circumstances—

(a) the nature, consequences and risks of proposed medical treatment; and

(b) the likely consequences of not undertaking the treatment; and

(c) any alternative treatment or courses of action that might be reasonably considered in the circumstances of the particular case.

Protection for medical practitioners, etc.

16. A medical practitioner responsible for the treatment or care of a patient, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, incurs no civil or criminal liability for an act or omission done or made—

(a) with the consent of the patient or the patient's representative or without consent but in accordance with an authority conferred by this Act or any other Act; and

(b) in good faith and without negligence; and

(c) in accordance with proper professional standards of medical practice; and

(d) in order to preserve or improve the quality of life.

DIVISION 2—THE CARE OF PEOPLE WHO ARE DYING

The care of people who are dying

17. (1) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, incurs no civil or criminal liability by administering medical treatment with the intention of relieving pain or distress—

(a) with the consent of the patient or the patient's representative; and

(b) in good faith and without negligence; and

(c) in accordance with proper professional standards of palliative care,

even though an incidental effect of the treatment is to hasten the death of the patient.

(2) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, is, in the absence of an express direction by the patient or the patient's representative to the contrary, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state.

(3) For the purposes of the law of the State—

(a) the administration of medical treatment for the relief of pain or distress in accordance with subsection (1) does not constitute an intervening cause[1] of death; and

(b) the non-application or discontinuance of life sustaining measures in accordance with subsection (2) does not constitute an intervening cause[1] of death.

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[1] A *novus actus interveniens* i.e. a cause that breaks a pre-existing chain of causation.

Saving provision

18. (1) This Act does not authorise the administration of medical treatment for the purpose of causing the death of the person to whom the treatment is administered.

(2) This Act does not authorise a person to assist the suicide of another.

PART 4
REGULATIONS

Regulations

19. The Governor may, by regulation, prescribe forms for the purposes of this Act.

SCHEDULE 1

Medical Power of Attorney

1. I, *[here insert name, address and occupation]*, appoint the following person(s) to be my medical agent(s):

[Here set out name, address and occupation of the agent. If two or more agents are appointed, the order of appointment must be indicated by placing the numbers 1, 2, 3... beside each name. This indicates that, if the first is not available, the second is to be consulted, if the first and second are not available, the third is to be consulted and so on. It should be noted that a medical power of attorney cannot provide for the joint exercise of the power. (See section 8(6) of the Consent to Medical Treatment and Palliative Care Act 1995.)]

2. I authorise my medical agent to make decisions about my medical treatment if I should become unable to do so for myself.

3. I require my agent to observe the following conditions and directions in exercising, or in relation to the exercise of, the powers conferred by this power of attorney:

[Here set out any conditions to which the power is subject and any directions to the agent.]

4. This is an enduring power of attorney made under the *Consent to Medical Treatment and Palliative Care Act 1995*.

.....
[signature]

Dated the day of 19 .

Acceptance of Power of Attorney

I, *[here set out name, address and occupation of medical agent]*, accept appointment as a medical agent under this medical power of attorney and undertake to exercise the powers conferred honestly, in accordance with the conditions and directions set out above, and, subject to that, in what I genuinely believe to be my principal's best interests.

.....
[signature]

Dated the day of 19 .

Witness's certificate

I, *[here set out name and address of the witness and the qualification by virtue of which the witness is an authorised witness under the Consent to Medical Treatment and Palliative Care Act 1995]*, certify:

(a) that the grantor and grantee of this power of attorney signed it freely and voluntarily in my presence; and

(b) both appeared to understand the effect of the power.

.....
[signature]

Dated the day of 19 .

SCHEDULE 2

Direction under section 7 of the Consent to Medical Treatment and Palliative Care Act 1995

1. I, *[here insert name, address and occupation]*, direct that if, at some future time, I am—

(a) in the terminal phase of a terminal illness, or in a persistent vegetative state; and

(b) incapable of making decisions about my own medical treatment,

effect is to be given to the following expression of my wishes:

[The person by whom the direction is given must include here a statement of his or her wishes. The statement should clearly set out the kinds of medical treatment that the person wants, or the kinds of medical treatment that the person does not want, or both. If the consent, or refusal of consent, is to operate only in certain circumstances, or on certain conditions, the statement should define those circumstances or conditions.]

2. I make this direction under section 7 of the *Consent to Medical Treatment and Palliative Care Act 1995*.

.....
[signature]

Dated the day of 19

Witness's certificate

I, *[here set out name and address of the witness and the qualification by virtue of which the witness is an authorised witness under the Consent to Medical Treatment and Palliative Care Act 1995]* certify that the person whose signature appears above:

(a) signed this direction in my presence; and

(b) appeared to understand the nature and effect of the direction.

.....
[signature]

Dated the day of 19

SCHEDULE 3

Repeal and Transitional Provisions and Consequential Amendments

Repeal

1. The following Acts are repealed:

(a) the *Natural Death Act 1983*;

(b) the *Consent to Medical and Dental Treatment Act 1985*.

Transitional provisions

2. (1) Despite the repeal of the *Natural Death Act 1983*, a direction made under that Act remains effective, subject to revocation or amendment by the person who made it, as a statement of that person's desire not to be subjected to extraordinary measures as defined in that Act to prolong life if suffering from a terminal illness.

(2) If before the commencement of this Act a person granted an enduring power of attorney and purported to confer on the agent power to decide questions about the medical treatment of the grantor of the power in the event of the grantor's incapacity to do so, that power of attorney is as valid and effective as if it had been made under this Act.

Amendment of Guardianship and Administration Act 1993

3. The *Guardianship and Administration Act 1993* is amended—

(a) by inserting in section 3(1) after the definition of "**the Health Commission**" the following definition:

"**medical agent**" means a person appointed under a medical power of attorney under the *Consent to Medical Treatment and Palliative Care Act 1995* to be the medical agent of another;;

(b) by striking out section 58 and substituting the following section:

Application of this Part

58. This Part applies in relation to a person—

(a) who, by reason of his or her mental incapacity, is incapable of giving effective consent, whether or not he or she is a protected person; and

(b) who does not have a medical agent who is reasonably available and willing to make a decision as to the giving of consent to the medical or dental treatment of the person.;

(c) by striking out from section 61(1) "prescribed circumstances exist for the purposes of section 62" and substituting "circumstances exist for the giving of emergency medical treatment under the *Consent to Medical Treatment and Palliative Care Act 1995*, but otherwise notwithstanding that Act";

(d) by striking out section 62.

Amendment of Mental Health Act 1993

4. The *Mental Health Act 1993* is amended—

(a) by inserting in section 3 after the definition of "**director**" the following definition:

"**medical agent**" means a person appointed under a medical power of attorney under the *Consent to Medical Treatment and Palliative Care Act 1995* to be the medical agent of another;;

(b) by inserting in section 13(4)*(e)* "or medical agent" after "a guardian";

(c) by striking out from section 20(2) "or relative" and substituting ", relative or medical agent";

(d) by striking out from section 21(2)*(d)* "relative or guardian" and substituting "guardian, relative or medical agent";

(e) by striking out subsubparagraph (C) from section 22(1)*(b)*(ii) and substituting the following subsubparagraph:

(C) where the patient is incapable of giving effective consent and is of or over 16 years of age—

- if the patient (being of or over 18 years of age) has a medical agent who is reasonably available and is willing to make a decision as to consent—of the medical agent;

- in any other case—of the Board,;

(f) by inserting in section 26(1) after paragraph *(b)* the following paragraph:

(ba) a guardian, relative or medical agent of the patient;;

(g) by striking out clause 5 from Division 2 of the Schedule.

In the name and on behalf of Her Majesty, I hereby assent to this Bill.

ROMA MITCHELL Governor

BY AUTHORITY: A. J. SECKER, Government Printer, South Australia

MISCELLANEOUS

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On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?

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Author's abstract

This paper explores ethical issues relating to the management of patients who are terminally ill and unable to maintain their own nutrition and hydration. A policy of sedation without hydration or nutrition is used in palliative medicine under certain circumstances. The author argues that this policy is dangerous, medically, ethically and legally, and can be disturbing for relatives. The role of the family in management is discussed.

This issue requires wide debate by the public and the profession.

Introduction

From time to time in the professional life of a doctor incidents occur which cause one to stop and think hard. There are times when two doctors, each with the best interests of the patient at heart, would treat in diametrically opposite ways. There are widely divergent opinions on what is correct and morally acceptable when it comes to the management of patients who are, or appear to be, terminally ill and unable to maintain their own nutrition and hydration. This inability to eat and drink may be a consequence of the illness or of the treatment, for example heavy sedation. Differences in opinion about management may be voiced by relatives, by nurses and by doctors who may or may not be directly or professionally involved in the care of the patient. Particularly difficult management problems may arise if the dissenting relative is a nurse, doctor or paramedic, and great care must be taken to ensure that his or her views are taken into account and discussed openly, and that the management adopted is acceptable to all parties, if this is humanly and legally possible.

Ethical dilemmas in the field of hydration and nutrition cover a wide spectrum, from dehydration due to dysphagia of various aetiologies, through terminal cancer with intestinal obstruction, to the persistent vegetative state, terminal Alzheimer's disease patients who are unable to eat, and patients with anorexia nervosa or elderly depressives who deliberately refuse nourishment to the point of self-annihilation. The main issue highlighted by this paper is the use of sedation without hydration or nourishment in the terminally ill. This raises ethical issues which require debate by the profession and the public.

Key words

Nutrition; hydration; sedation; terminally ill; ethics; euthanasia.

The need for an open mind about intravenous hydration in terminal care

Palliative medicine is a relatively new and growing specialty and the hospice movement is held in high esteem by the public. Some doctors, however, have reservations. There are dangers in grouping patients labelled 'terminal' in institutions, because diagnoses can be wrong (1). There is a risk that if all the staff in an institution are orientated towards death and dying and non-intervention, treatable illness may be overlooked. Not everyone who is referred for terminal care proves to be terminally ill, and no physician should accept such a diagnosis without reviewing the evidence personally.

Certain policies that are practised in palliative medicine would be dangerous if applied without due care and thought. In particular the view that in the terminal phase of disease 'no form of artificial hydration or alimentation is undertaken, all measures not required for comfort are withdrawn, and no treatment-related toxicity is acceptable' (2). It is not uncommon for the elderly to be admitted to hospital in a seriously dehydrated condition, looking terminally ill. A treatment-orientated physician will rehydrate these patients energetically, often with dramatic results, in order to buy time in which to assess the situation carefully. A therapeutically inactive doctor would lose many patients for the sake of avoiding a drip. Two examples from my personal experience will illustrate this point.

Case 1

An elderly man was sent to hospital for terminal care with a diagnosis of carcinoma of the pancreas. He

had indeed had a stent inserted at another hospital to relieve bilary obstruction due to tumour. However, his 'terminal' illness was due to a small stroke and uncontrolled diabetes mellitus. He recovered with insulin and intravenous rehydration and lived happily for several weeks more.

Case 2

An elderly man was admitted for terminal care but the geriatrician felt the diagnosis of cancer was not well established. The main problem was severe dehydration with ischaemic feet and severe pressure sores on the heels. With intravenous rehydration and intensive nursing he recovered and went home for 18 months.

It is important for the public to realise that most patients with terminal illness can continue to eat and drink as and when they wish. Only in the last days may they be too weak or tired to bother, in which case the lack of food and drink will not contribute to death. If dehydration develops under these circumstances it is a natural consequence of irreversible disease, and artificial hydration would not be appropriate.

The use of sedation

There are times in the care of the dying 'when it is necessary to use benzodiazepines, phenothiazines and barbiturates to sedate a patient in order to relieve intolerable distress where dying is complicated by an agitated delirium or tracheal obstruction' (3). In skilled hands no person should die in pain, whatever the cause of the illness. As a last resort some people advocate use of high-dose analgesia and induction of sleep with continuous intravenous midazolam (4). Whatever the underlying pathology 'the cardinal ethical principle remains that the treatment goal must be achieved with the least risk to the patient's life' (3). I would add – and in a manner that is acceptable to the patient's closest relatives.

Having decided that sedation is needed, the doctor must try to find a drug regime that relieves distress but does not prevent the patient from taking fluid and nourishment, does not prevent verbal communication with friends and relatives, and does not lead to toxic side-effects, or expedite death. Unfortunately currently available therapeutic options are not ideal in all these respects. Even light sedation can cause drowsiness that may prevent a person from taking enough fluid to maintain hydration. Heavy sedation may render an alert person incapable of swallowing within minutes, depending on the drug regime used.

If death is imminent few people would feel it essential to put up a drip but ethical problems arise if sedation is continued for more than one or two days, without hydration, as the patient will become dehydrated. Dehydration can result in circulatory collapse, renal failure, anuria and death. I do not think it is morally acceptable to leave a sedated patient for long without hydration. Others would dissent from this view using words such as 'meddlesome' and 'unethical' if intravenous fluids are suggested under such circumstances. However, in my opinion, if it is not possible to reduce sedation to a level that enables the patient to drink, the question of hydration must be addressed to everyone's satisfaction.

Particular problems may arise if the patient has a primary mental disorder such as chronic schizophrenia or depression. In such people the stress of the physical illness may make the mental state worse. Great skill may be needed to distinguish a potentially treatable psychotic reaction from an untreatable, terminal agitated delirium. In cases of difficulty expert psychiatric help should be obtained as the distinction may be vital. If the diagnosis is a psychotic reaction, hydration must be maintained and the patient observed in the hope that sedation can be reduced. If the diagnosis is a terminal agitated delirium, those with experience advise against reducing sedation, and argue against giving intravenous fluids as this would prolong dying.

To take a decision to sedate a person, without hydration, until he/she dies is a very dangerous policy medically, ethically and legally. No doctor's judgement is infallible when it comes to predicting how close a patient is to death. To say that it is a matter of days, and to treat by this method, is to make the prediction self-fulfilling. I know of a patient who died after at least seven days of sedation without hydration – how much longer would he have survived with hydration? Diagnostic errors can also occur. A reversible psychosis or confusional state can be mistaken for terminal delirium, aspiration pneumonia for tracheal obstruction, obstruction due to faecal impaction for something more sinister, and so on. The only way to ensure that life will not be shortened is to maintain hydration during sedation in all cases where inability to eat and drink is a direct consequence of sedation, unless the relatives request no further intervention, or the patient has made his/her wishes known to this effect. If naturally or artificially administered hydration and nutrition is withheld, the responsible medical staff must face the fact that prolonged sedation without hydration or nutrition will end in death, whatever the underlying pathology. Even a fit Bedu tribesman riding in the desert in cool weather, can only survive for seven days without food or water (5).

The legal question

The Institute of Medical Ethics working party on the ethics of prolonging life and assisting death has argued the case for withdrawing food and water from patients in a persistent vegetative state (6). Such

patients are unaware of their surroundings as a result of severe brain damage. Recent reports indicate that 'persistent' does not necessarily mean 'permanent' (7) and it is essential to ensure that the prognosis is hopeless before considering withdrawing treatment (8).

A key issue in English law in such patients has been 'whether artificial feeding counts as medical treatment – which can lawfully be discontinued if the patient is receiving no benefit – or is simply the means of sustaining life, which if withdrawn could lay a doctor open to a charge of murder' (8). This argument is largely semantic since in patients with a persistent vegetative state this treatment sustains life. The key issue surely is whether it benefits the patient to be alive rather than dead. Those who advocate withdrawing food and water from these patients have been warned by medical defence organisations that such a policy may result in a charge of manslaughter by neglect (9). This risk has been reduced but not eliminated by the Bland case ruling (10) which has clarified the legal position in England and Wales. The legal position in Scotland remains unclear but is being actively reviewed by the Lord Advocate following the judgement in the Bland case.

The case of Airedale NHS Trust v Bland

In the final judgement or declaratory statement made in the House of Lords in February 1993, it was ruled that the responsible attending physicians could lawfully discontinue all life-sustaining treatment and medical supportive measures designed to keep the patient (Mr Bland) alive in his persistent vegetative state, including the termination of ventilation, nutrition and hydration by artificial means (10). In coming to this judgement, the Law Lords accepted as responsible medical opinion, a paper prepared by the British Medical Association (BMA) medical ethics committee (11). Referring to this the judges highlighted four safeguards which should be observed before discontinuing life support in a patient with a persistent vegetative state – namely, 1. Every effort should be made at rehabilitation for at least six months after injury; 2. The diagnosis of irreversible persistent vegetative state should not be considered confirmed until at least 12 months after injury; 3. The diagnosis should be agreed by at least two other independent doctors, and 4. Generally the wishes of the patient's immediate family should be given great weight.

Lord Goff pointed out that to discontinue artificial feeding might be categorised as an omission, which if deemed to constitute a breach of duty to the patient is unlawful (10). However, in the case of Mr Bland, he argued that the patient was incapable of swallowing and therefore of eating and drinking in the normal sense of these words. Artificial feeding via a nasogastric tube was therefore a form of life support, and could be discontinued if treatment was futile and no longer in the best interests of the patient.

It must be emphasised that the case of Airedale NHS Trust v Bland does not give doctors freedom to withdraw treatment from all patients in a persistent vegetative state. For the foreseeable future doctors in England and Wales must apply to the family division of the High Court for a declaration in each case as to the legality of any proposed discontinuance of life support, where there is no valid consent on the part of the patient. There has not been a rush of applications to date. Moreover a civil court ruling is no guarantee against subsequent prosecution in a criminal court, since a declaration as to the lawfulness or otherwise of future conduct is 'no bar to a criminal prosecution, no matter the authority of the court which grants it' (12).

The judgement regarding hydration and nutrition in the Bland case was clearly swayed by the patient's irreversible brain damage, although the law as to killing is unaffected by the victim's mental state (13). It would be extremely dangerous to extrapolate the legal decision made in this case to other clinical situations. The legality or otherwise of withholding hydration and nutrition from the dying has not been tested in the courts in the United Kingdom (13).

Despite the differences in mental state, pathology and life expectation between a terminally ill sedated patient and one with a persistent vegetative state, the key issues are similar. Are you, by withholding fluid and nourishment, withholding the means of sustaining life? In short are you killing the patient? The answer I fear in some cases could be YES. In some terminally ill patients, especially those who are rendered unable to swallow by heavy sedation, failure to hydrate and nourish artificially could be judged an unlawful omission. The question of intent is important and the principle of double effect, and other medico-legal issues are relevant (13). However, doctors who deliberately speed death could face the prospect of life imprisonment (13). Clearly the legality of prolonged sedation without hydration is highly debatable yet this treatment is regarded as ethical and compassionate by senior and respected specialists in palliative medicine. If a dying patient is treated in this way there may be reasonable grounds for doubt as to whether the patient died of the treatment or the disease. It is our duty and our privilege as doctors to sustain life, not to shorten it. Euthanasia must remain illegal, and practices that seem tantamount to euthanasia must be exposed.

The risk of inappropriate sedation

Clearly a policy of sedation without hydration or nutrition in terminal care is a drastic solution to a difficult problem. Those who take such action no doubt do so thinking that they have the patient's best

interests at heart. They may also be influenced by subconscious fears. As Main said: 'Perhaps many of the desperate treatments in medicine can be justified by expediency, but history has an awkward habit of judging some as fashions, more helpful to the therapist than the patient. Patients tend to be sedated when the carers have reached the limit of their resources, and are no longer able to stand the patient's problems without anxiety, impatience, guilt, anger or despair. A sedative will alter the situation and produce a patient who if not dead, is at least quiet' (14). The case of the Winchester rheumatologist who was convicted of attempted murder demonstrates what can happen when doctor and patient reach the end of their tether (15,16).

The importance of comfort

The guiding principle in the care of the dying is that 'everything in the terminal phase of an irreversible illness should be clearly decided on the basis of whether it will make the patient more comfortable and whether it will honour his/her wishes' (17). 'Comfort' is a state of conscious physical and mental well-being. It is debatable therefore whether the word can be applied to a heavily sedated, dehydrated patient. However, most would agree that it is preferable to be comfortable and conscious or semi-conscious without pain, than uncomfortable, distraught and fully awake.

The therapeutic ideal would be to have a patient who is calm, clear-headed and pain-free. Unfortunately there are times when this cannot be achieved with the drugs at our disposal.

The consensus in the hospice movement seems to be that rehydration and intravenous fluids are inappropriate in terminal care (2,18,19). Dehydration is even considered to be beneficial in patients with incontinence (18)! This is a weak argument to justify withholding intravenous fluids. Therapeutic anuria may be the ultimate cure for incontinence but the side-effect is death. Those who have coped with incontinence without a catheter in the past can be nursed without a catheter to the end, if that is their wish. Rehydration should not influence this aspect of care. Hospice staff also argue that a drip makes it more difficult to turn a dying patient in bed, yet they are happy to give analgesics by subcutaneous infusion when necessary, and occasionally use a drip in patients with hypercalcaemia. To those of us who use drips frequently on acute medical, surgical and geriatric wards, these arguments do not carry much weight. Setting up a drip or a subcutaneous infusion is a simple and straightforward procedure that rarely causes the patient discomfort or distress. Many dehydrated patients look and feel a lot better when they are rehydrated. If the staff in hospices used drips more, they would not have to find so many reasons for avoiding them.

The question of thirst

If hydration and nutrition are withheld, the attendant staff must be sensitive to the effect this may have on the family and friends (17). Some say that a patient should be comatose, so as not to experience thirst, before it is morally acceptable to withhold or withdraw intravenous fluids (20). It is widely assumed that a terminally ill patient is not troubled by hunger or thirst but this is difficult to substantiate as few people return from the grave to complain. Thirst may or may not bother the patient. Concern about thirst undoubtedly bothers relatives. They will long to give their loved one a drink. They may sit by the bed furtively drinking cups of tea, taking care to make no sound lest the clink of china is torture to the patient. Anyone who has starved for hours before an anaesthetic will sympathise with dying patients who seem to thirst and starve for days. Nurses are taught that moistening the patient's mouth with a damp sponge is all that is necessary to prevent thirst. Relatives may not be convinced. It may well be that sedation relieves the sensation of hunger and thirst. If there is evidence to this effect it would be helpful for the relatives of dying patients to be told about it.

The role of the family

It has been said that the family must request no further medical procedures before treatment can be withheld and that the previously expressed wishes of the patient or current family must predominate over those of staff (20). Staff who believe strongly that intravenous fluids are inappropriate should not impose their views on knowledgeable or distressed relatives who request that a dying patient be given intravenous fluids to prevent dehydration or thirst. To overrule such a request is, in my view, ethically wrong. The only proviso would be if the patient had, when *compos mentis*, specifically said that he/she did not want a drip under any circumstances.

No relatives should be forced to watch a loved one die while medical staff insist on withholding hydration. This has happened to my knowledge. Such an experience is deeply disturbing and could haunt a person forever. Is all this agony worth it for the sake of avoiding a drip? I think not.

The converse also applies. There will be occasions when the medical staff who are professionally involved would like to use a drip, but a knowledgeable relative requests no intervention. In this situation, the medical team will need to make a carefully balanced judgement as to whether intervention is essential or not. If the scales are not heavily weighted in favour of intervention the wise doctor will compromise and stand back in the interests of the peace of mind of the relative.

A doctor cannot be obliged to act contrary to his or her own conscience but equally doctors should bear in mind that relatives also have consciences, and

should not be forced to accept for their loved ones treatment that they consider to be unethical. It is inevitable that terminally ill patients will die and that their relatives will be sad. Care must be taken to ensure that the burden of bereavement is not loaded heavily by distress about patient management in the terminal phase. In the care of the dying, both patients and their relatives must be treated with compassion.

Final comments

The question of hydration and nutrition in terminal care is one that generates strong views. It is probably inevitable that sooner or later those working in the field of palliative medicine will meet colleagues working in different fields of medicine who are used to adopting a more active approach to management. Those who don't believe in using intravenous fluids will encounter those who do. Faced with this situation it is essential that both parties sit down together to discuss the issues. They must reach a compromise that takes into account the expressed or probable wishes of the patient concerned and the views of the closest relatives. No one individual has right entirely on his/her side. The ethically correct solution may prove to be somewhere in the middle, and it must be found.

Where opinions differ on the management of an individual case, further discussion may throw light on the situation, firmly held opinions may prove to be wrong, diagnoses may need to be revised and factors that had not been considered before may soften entrenched attitudes. If the issue is the futility or otherwise of intervention, or doubt about the patient's views or best interest, there may be room for manoeuvre in any given situation. The underlying reasons for sedation and the cause of the patient's inability to eat and drink are obviously of critical importance. What is essential in the final analysis is that all parties should feel comfortable with the clinical management strategy adopted. If this is not the case the strategy is probably not ethically sound. Somewhere between the poles of opposing opinion there must be some morally acceptable common ground. If after further discussion a mutually acceptable management policy cannot be agreed, it is no solution to the dilemma for a hospice team to tell the relatives to take the dying patient elsewhere. Where for example can you take a dying man, in the middle of winter, in an ambulance strike? However strong your ethical position, it is unacceptable to seek to silence dissent in this way. Where time permits, a second consultant opinion should be sought, or help from some other appropriate independent source.

As Rabbi Lionel Blue said recently of theology: 'Even more important than your views is the kindness with which you hold them, and the courtesy with which you treat those who oppose you'. The same could be said of the issues explored in this paper. People who hold strong views in this difficult and emotive area of palliative medicine should hold them kindly and with sensitivity. At the end of the day there should not be the slightest grounds for suspicion that death was due to anything but the disease. Unless this can be guaranteed, the public's faith in doctors in general, and in the hospice movement in particular, will be ill founded.

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On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues

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Abstract

The author reviews and continues the debate initiated by her recent paper in this journal.[1] The paper was critical of certain aspects of palliative medicine, and caused Ashby and Stoffell to modify the framework they proposed in 1991.[2] It now takes account of the need for artificial hydration to satisfy thirst, or other symptoms due to lack of fluid intake in the terminally ill.[7] There is also a more positive attitude to the emotional needs and ethical views of the patient's family and care-givers. However, clinical concerns about the general reluctance to use artificial hydration in terminal care remain, and doubts persist about the ethical and legal arguments used by some palliative medicine specialists and others, to justify their approach. Published contributions to the debate to date, in professional journals, are reviewed. Key statements relating to the care of sedated terminally ill patients are discussed, and where necessary criticised.

Introduction

I welcome the discussion that has been generated by my paper in this journal, on the subject of withholding nutrition and hydration in the terminally ill.[1] I criticised a framework for palliative care advocated by Ashby and Stoffell.[2] My central theme was the issue of the need for artificial hydration when a patient is rendered incapable of swallowing by sedation. I argued that to withhold hydration is dangerous medically, ethically and legally, and can be disturbing for relatives.

At the time of writing I am aware of six papers and two letters that have been published in reply in this journal[3–8] and two papers elsewhere.[9 10] Gillon touched on legal aspects and raised the question of the need for formal mediation procedures.[3] Wilkes, in a gentle and broadly-based commentary, shared some of my anxieties,[4] Ashby and Stoffell continued the debate in a wide-ranging response[7] and others focused on clinical aspects.[8 10] The issues raised have been considered by the ethics committee of the Association for Palliative Medicine in the United Kingdom, by the board of the Cancer Relief Macmillan Fund, and by senior people in many walks of life. This paper summarises and extends the debate as it has developed in professional journals.

The subject under discussion straddles the boundaries of medicine, ethics and law, and strays into other academic areas too. The debate could easily get out of hand. In replying to papers that have appeared to date, I will not engage in detailed discussion of concepts such as care, needs, proportionality of medical interventions and processes of communication, although the discussion that follows touches on these issues in several places. To shift the focus of the argument into these areas, as proposed by Ashby and Stoffell,[7] could be detrimental to progress. There are matters arising which need to be clarified before the agenda moves on. It is important to continue the debate on a level that will be of practical assistance to medical practitioners and possibly lawyers, who may be embroiled in the management of these difficult cases.

Key words

Hydration; nutrition; sedation; euthanasia; terminal care; law.

Clinical aspects

NEED FOR ARTIFICAL HYDRATION IN SOME CIRCUMSTANCES IS ACKNOWLEDGED

I am glad to say that Ashby and Stoffell have amended their framework for palliative care to take account of some of my criticisms. They now say, with some preamble, that "artificial hydration may be required in the terminal phase to satisfy thirst, or other symptoms due to lack of fluid intake", and admit that "the emotional needs and ethical views of the patient's family and care-givers must be acknowledged and considered". They add that "if artificial hydration and nutrition are identified as necessary for comfort by attending staff or family members, and may be effective in achieving the stated aims, then they should not be refused".[7]

Dunlop *et al* agree that there are rare occasions when it is justifiable to give subcutaneous fluids for the sake of the family, but do not recommend the routine use of intravenous or subcutaneous fluids. They distinguish between sedation used in terminal delirium, and sedation used in patients who are not

actually dying. They imply that in the latter situation problems with hydration rarely occur and so their discussion stops short of the ethical dilemma at issue.[8]

Dunphy *et al* in a brave and balanced discussion of the whole issue of rehydration in palliative or terminal care, stress the need to make "genuine and unprejudged assessments of the relevance of dehydration to each individual's clinical presentation, and above all to be responsive to the wishes of the family."[10]

RISKS OF ARTIFICAL HYDRATION ARE EXAGGERATED

Ashby and Stoffell exaggerate the risks of artificial hydration quite considerably.[7] Dunlop *et al* comment that no studies to their knowledge have demonstrated any adverse effects from fluid therapy, but advise caution if the serum albumin is low.[8] Artificial hydration could be harmful in patients with cerebral oedema,[5] cardiac failure, or any condition where symptoms are related to fluid overload. There will also be situations where fluid restriction is helpful, for example in patients with inappropriate secretion of anti-diuretic hormone – a condition that is found in some patients with cancer. All medical intervention must be used with clinical discretion. Some patients may benefit initially from a reduction in fluid intake, or cessation of artificial hydration and alimentation (AHA), but no one can survive indefinitely without sustenance.

RISK OF MISDIAGNOSIS AND UNDERTREATMENT

Ashby and Stoffell fail to understand the basis for my general concern. They take a comment about the need to buy time for assessment by energetic rehydration as a cue to launch into a tirade about technological brinkmanship. Yet they admit that when accepting patients for palliative care they have to "insist on fuller clinical information than some referring doctors think is really necessary for palliative care". The inference to be drawn is that patients are being labelled as terminal on inadequate grounds – which, to coin a phrase used by Ashby and Stoffell, is my point entirely. The case reports I gave to illustrate this point were dismissed as "hard cases which can be mobilised to undermine any approach". Actually they were hard cases that could represent the tip of an iceberg. Who knows how many patients die at home, or in hospital labelled as terminal, misdiagnosed and undertreated? As Wilkes observed, dehydration occurs far too frequently, far removed from the territory of palliative care.[4]

ARTIFICAL NUTRITION

Dunlop *et al* rightly consider hydration and nutrition as separate issues.[8] My main concerns relate to hydration, as the need for long term nutritional support with all its potential difficulties will rarely arise in terminal care. Although the administration of conventional dextrose solutions via a peripheral vein does not constitute full nutritional support,[8] it does provide some useful calories in the short term, and is often given on medical and surgical wards for one or two weeks, to tide over patients who cannot eat. Dextrose solutions should not be given subcutaneously.

THE QUESTION OF THIRST

Ashby and Stoffell claim that I allege that sedation is used to mask the effects of dehydration or starvation.[7] I did not say this, although it may well be so in some cases. On the question of thirst in general there is a hint of irritation and dismissal in their response to my comments, and they fail to appreciate that it is the relatives' concern about suffering that I describe. It is no good brusquely referring people to the literature. Jo Blogs is not aware of the literature, all he sees is someone apparently dying of thirst or starving to death. That is the public perception of the situation, and in some cases they could be right. Moreover the literature is not uniformly reassuring on this point.

McCann and co-workers found thirst and/or a dry mouth to be a major symptom in 66% of 32 patients initially, with hunger being less of a problem, despite severe protein-calorie malnutrition.[11] Thirst tended to decrease as death approached, despite probable dehydration. Anorexia may have been due to fasting, underlying disease or narcotic administration.[11] Dunlop *et al* comment that most terminally ill cancer patients reach a point during their general decline when they first stop eating, and subsequently stop drinking.[8] They make the interesting suggestion that the normal homeostatic mechanisms controlling fluid intake and fluid balance may be altered in the dying process. All the evidence in support of this suggestion needs to be carefully and impartially reviewed, but the letter by Waller to which they refer is open to criticism.[6]

Much remains to be discovered about the pathophysiological sequence of events, as some changes may prove to be reversible. Does severe dehydration, for example, suppress thirst in cancer patients, as it does in the healthy elderly? If so the result would be an escalating spiral of decline. Is it not time that someone studied the beneficial effects of rehydration in terminal care?

Clearly if patients have stopped drinking because of an irreversible decline it is one thing, but if they are suddenly rendered incapable of eating or drinking by sedation it is another. It is the latter situation that creates ethical problems.

THE NEED TO KEEP INTERVENTION SIMPLE

I am not advocating artificial hydration and nutrition in all dying patients irrespective of the circumstances, nor did I propose, as Ashby and Stoffell try to imply, "that provision of alimentation and hydration is a truly ordinary measure, with the means of delivery being irrelevant ... even when a person is dying."[7] I

argued that a drip or subcutaneous infusion is a simple, ordinary and effective procedure, that rarely causes the patient discomfort or distress, and should be used more readily in a hospice setting.[1] I agree that to advocate measures such as gastrostomy or total parenteral nutrition when death is imminent and unavoidable, would be inappropriate. However, as others comment: "It may be that the issue we need to address is our assessment of likely benefit, rather than attempting to quantify medical intrusion."[10]

Ashby and Stoffell complain that excessive reliance on technology can have unfortunate consequences for medical practice. One consequence is the introduction of advance directives, or living wills, by those who wish to protect themselves from the worst excesses of technology, or who, conversely, wish to be treated. Difficulties in medicine may now arise, not only for doctors who wish to discontinue treatment in the dying,[7] but also for those who wish to treat their patients and return them from imminent death to life. Not all of us share the view of the fictional doctor who said "I have every confidence that the law is not such an ass that it will force me to watch a patient of mine die unnecessarily."[12] None of these problems would have arisen, had doctors proved better at walking the tight-rope between over-treatment and under-treatment. Excessive swings in either direction need to be curbed, and a balanced approach achieved.

The legal question

Legal matters are covered in some detail by Ashby and Stoffell, assisted by Professor M Somerville and the staff of the Centre for Medicine, Ethics and Law of McGill University, and by a bioethicist from Queensland.[7] In wide-ranging discussion, scattered throughout their response they refer to papers on the distinction between natural and artificial provision of fluid and nourishment and conclude that the latter constitutes medical treatment. This remains somewhat contentious. On the subject of the limits to a medical practitioner's duty to care, they quote recommendations made by the Canadian Law Commission in 1982. Reference to the established law as it applies in the United Kingdom would have been more relevant. They quote the comments of a judge in New Zealand to illustrate what might be termed "useless" with regard to medical care, but, with respect, the situation of a man rendered incompetent and paralysed by an extreme form of Guillain-Barré syndrome does not equate with the clinical situation under discussion. All in all, this international sledge-hammer approach does not crack the kernel of the problem, which is whether sedation without hydration or nutrition in terminal care is legal in the UK. Indeed it makes focused debate rather more difficult. I have, however, selected some key issues for discussion. Others would no doubt choose a different path through the legal and ethical maze.

1. THE FUTILITY ARGUMENT

It is often said that a doctor has no duty to continue a treatment that is useless and of no benefit to the patient – but as others have observed, futility is not always the ethical trump card that some would like it to be.[13] Ashby and Stoffell argue that "It is possibly true that sedation may hasten the actual time at which relatively imminent death will occur. But it is not deemed necessary to hydrate sedated patients during the dying process when they are unable to maintain oral intake, as it makes no sense to attempt to treat a transiently reversible component of their overall dying process".

This is not a terribly satisfactory response to the dilemma presented. From a legal standpoint the provision of hydration may be crucial, particularly since Ashby and Stoffell stress elsewhere in their paper that "from a legal point of view ... the cause of death is the underlying condition which has led to the absence of oral intake" ... (ie in some cases sedation) ... and that "non-provision of artificial hydration can shorten life."[7]

We need to consider the case of a patient who is not dying, or in whom death is not relatively imminent. Such a patient may need sedation, perhaps for intractable pain, and could become fatally dehydrated as a consequence. Clearly some people would consider hydration of such a patient futile, and so it may be if the end point sought is restoration of the patient to health. Or consider the case of a stroke patient, confused and perhaps aphasic, whose prospects of recovery are judged to be poor, and who may have swallowing difficulties in addition. Many such patients get dehydrated even without sedation, and some physicians take an inactive approach to management.

Is there any good reason why treatment decisions made about such patients should be any less rigorous than those required for incompetent patients? In the latter case "as long as the patient is alive, the legal justification for providing treatment is the principle of necessity."[14] Treatment is "necessary" provided that it is in the "best interests" of patients, and this occurs "if, but only if, it is carried out either to save their lives, or to ensure improvement, or prevent deterioration in their physical or mental health."[15]

Sometimes in the case of terminally ill or physically disabled patients, it is tacitly assumed that it is in their best interests that they should die. Yet in cases of doubt, especially where survival outcome or prognosis is uncertain, the balance should be weighted in favour of prolonging life.

Even when death is inevitable, the simple and safe measure of a subcutaneous infusion may not be futile. It may be of some help to the patient, and may comfort the relatives, calm their fears, and reduce the incidence of pathological grief and post-traumatic stress reactions. It may also reassure all concerned that the patient died of his or her disease, rather than

the treatment. Thus it could avert the need for lengthy, costly and distressing inquiries after death.

2. CASE STUDIES IN ENGLISH, IRISH AND SCOTTISH LAW

There is still no case law on the issue of abatement of artificial hydration and alimentation in the dying, and the most relevant legal deliberations relate to the case of Airedale Trust v Bland in England,[16] the Irish Supreme Court case in the Republic of Ireland,[17 18] and the case of Mrs Johnstone of Lanarkshire, which has clarified the law regarding patients with a persistent vegetative state (PVS) in Scotland.[19]

The Bland case ruling applied strictly, and only, to the situation in that case[16 20] and should not be extrapolated to other clinical situations.[1] However, Ashby and Stoffell have done just that, saying ... "if AHA was not required for Bland, who unlike the dying person was not actually or actively dying of a progressive fatal condition at the time of the judgment, there is even less basis for saying that it is required for all dying persons."[7] This is a very rash statement. Firstly no one is saying that AHA is required for all dying persons. Secondly some patients who require sedation in palliative care are not actually dying, nor are they necessarily unconscious. Thirdly the statement demonstrates an alarming lack of appreciation of the exceedingly careful ethical and legal deliberations that led to the decision in the Bland case. If society takes a decision about one patient with PVS so seriously, surely equally serious thought should be given to matters of hydration and nutrition in sedated patients with incurable disease. The shorter time scale in the dying does not eliminate the legal and ethical dilemmas. Fourthly the statement overlooks the major differences in mental state and underlying pathology between a terminally ill patient who is sedated, and a patient with PVS.

The Irish Supreme Court case

This concerned a 45-year-old woman in a near PVS, who retained some ability to recognise people, but could not move or communicate, following brain damage sustained in a minor operation 23 years earlier. The court ruled in May 1995 that she could be allowed to die by withdrawal of nourishment. The chief justice took the view that the true cause of the woman's death would be the injuries she sustained in 1973, and not withdrawal of nourishment.[17] Mr Justice Lynch said that what he had to decide was not the morality of the course that the family sought to follow, but the lawfulness of it.[18]

The Irish Medical Council, in a statement issued in August 1995,[21] saw no need to alter its ethical guidelines, so leaving any doctor who assisted in withdrawing AHA open to disciplinary action. The council emphasised certain paragraphs which are of relevance to the present discussion.

- Doctors must do their best to preserve life and promote the health of the sick person.
- Medical care must not be used as a tool of the state to be granted or withheld or altered in character under political pressure.
- Where death is imminent, it is the doctor's responsibility to take care that a patient dies with dignity and with as little suffering as possible. Euthanasia, which involves deliberately causing the death of a patient, is professional misconduct and is illegal in Ireland.

They also quoted articles two and four of Principles of Medical Ethics in Europe[21]:

- Article 2: In the course of his medical practice a doctor undertakes to give priority to the medical interests of the patient. The doctor may use his professional knowledge only to improve or maintain the health of those who place their trust in him; in no circumstances may he act to their detriment.
- Article 4: ... The doctor must not substitute his own definition of the quality of life for that of his patient.

Finally the Irish Medical Council added their view that "access to nutrition and hydration is one of the basic needs of human beings. This remains so even when, from time to time, this need can only be fulfilled by means of long-established methods such as naso-gastric and gastrostomy tube feeding."[21]

The Scottish Court of Session case. Law Hospital Trust v Johnstone

The final judgment in the case of Mrs Janet Johnstone, who has had PVS for four years following a drug overdose, was given recently. According to reports in *The Guardian*,[19] Lord Cameron of Lochbroom, after hearing evidence, passed the case on to the Inner House of the Court of Session for legal guidance. Five senior judges headed by Lord President Hope, declared that Lord Cameron would, if he chose, be entitled to grant requests that artificial feeding be abandoned. However, they warned that they had had no right to grant Mrs Johnstone's doctors immunity from prosecution for murder. Scotland's senior law officer, the Lord Advocate, Lord Mackay of Drumadoon later stated that he would not "authorise the prosecution of a qualified medical practitioner (or any person acting on the instructions of such a practitioner) who, acting in good faith and with the authority of the Court of Session, withdraws or otherwise causes to be discontinued life-sustaining treatment or other medical treatment from a patient in a persistent, or permanent vegetative state, with the result that the patient dies". Permission to cease AHA was finally granted by Lord Cameron.[19] Immunity from prosecution cannot automatically be extended to treatment-limiting decisions in the dying, or the disabled. Society is now, rather painfully, through the courts, deciding where the line should be drawn.

It cannot be said that there is universal agreement that AHA can be regarded as medical treatment that can be stopped if deemed to be futile. Grave doubts

remain, as evidenced by the Irish Medical Council's statement, Lord Mustill's unease concerning the Bland case,[16] the views of the House of Lord's Select Committee on Medical Ethics,[22] and comments made by the Hon Mr Justice Ognall when discussing the hypothetical case of a patient whose severe pain could only be controlled by general anaesthesia.[23] He drew attention to subtleties of distinction between switching off a life support system, as in the Bland case, and the withdrawal of nutrition and hydration in the latter situation.[23] The House of Lords Select Committee were unable to reach a decision about whether nutrition and hydration, even when given by invasive methods, may ever be regarded as treatment, which in certain circumstances it may be inappropriate to initiate or continue.[22]

3. THE PRINCIPLE OF DOUBLE EFFECT

The medical profession, supported by the legal profession, tend to shelter behind the principle of double effect. Ashby and Stoffell are no exception, arguing that "the influence on timing of death should be of secondary consideration to the comfort and dignity of the dying person".[7]

The principle of double effect was used by the judge in the case of R v Adams in 1957. It was alleged that Dr Adams had killed a patient affected by a stroke, by giving large doses of heroin and morphine. He was acquitted, the judge saying: "If the first purpose of medicine, the restoration of health can no longer be achieved, there is still much for the doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life."[24] Forty years on standards of medicine have changed. If all that is proper and necessary is done, there should rarely be any need for life to be shortened.

Anglican and Catholic Bishops have recently reaffirmed their support for the principle of double effect, noting that "There is a proper and fundamental ethical distinction ... between that which is intended and that which is foreseen but unintended."[25]

I have argued elsewhere that the principle of double effect is open to abuse, and could be quoted in the defence of medical practitioners whose standards of care and intentions are open to question. Where the side-effects of a treatment, such as sedation, are predictable, potentially lethal, and easily overcome by simple measures, failure to use such measures could be regarded as negligent.[9] Some witnesses to the House of Lords Select Committee also expressed concern and suggested that the double effect of some therapeutic drugs, when given in large doses, was being used as a cloak for euthanasia. The committee, however, expressed confidence in the medical profession, and in the ability of a jury to evaluate a doctor's intention.[26] The profession must prove worthy of such public trust.

4. THE EUTHANASIA QUESTION

Notwithstanding the objections raised by Ashby and Stoffell who say "there is no place for emotive language about killing patients in this context,"[7] a consideration of this matter is not out of place in this debate. I posed the questions: "Are you, by withholding fluid and nourishment, withholding the means of sustaining life? In short are you killing the patient?"[1]

Gillon refers to moral distinctions between killing, and letting die.[3] The Hon Mr Justice Ognall points out that "the distinction between deliberate acts intended to kill ... and letting die ... is not free from difficulties. Is a doctor who allows a terminally ill patient to die guilty of murder? Our law says no, but, providing his intention in omitting to act is to hasten the patient's death, what is the distinction in that circumstance between an act on the one hand, and an omission on the other?"[23]

The current legal position regarding euthanasia in Scotland, England and Wales involves two elements: "a) a guilty act and b) the necessary intent. In general an omission to prevent death is not a guilty act, and cannot give rise to a conviction for murder. But where the accused was under a duty to the deceased, for example as his parent, nurse or doctor, to carry out the act which he omitted to do, such omission could be sufficient for the crime of either murder or culpable homicide, depending on the intention of the accused."[27]

Thus the question of whether the practice of sedation without hydration or nourishment in terminal care is legal, can only be decided by careful consideration of all the facts in an individual case.

Other matters

WHO SHOULD DECIDE?

Ashby and Stoffell end a rather tortuous paragraph on decision-making at the end of life, with the objection that "It is not the duty of any moral, legal or medical commentator to decide *a priori*, which treatment may or may not be chosen by a person or his/her substitute health care decision-maker or agent."[7]

This sweeping statement takes us into the minefield of patient autonomy, and to a consideration of the adverse effects that this can have on a physician's authority, and on the whole equilibrium of the health care team. The tensions created account for many of the difficulties that dissenting relatives or attendant staff may experience. Such tension will be greatest where life and death decisions are involved. It can also be sensed when a dissenting colleague questions "received wisdom" in the journals! For a philosophical overview on autonomy, see Norden.[12] The nurse/physician authority relationship is explored by May.[28]

From a purely practical point of view there may be no problem if the patient is able to make his or her

views about treatment known. Substitute health-care decision-makers, however, have no legal standing in the UK at present. Problems arise when treatment-limiting decisions must be made for an incompetent patient. The House of Lords Select Committee on Medical Ethics advised that in this situation "decisions should be made by all those involved in his or her care, including the whole health care team, and the family or other people closest to the patient. Their guiding principle should be that a treatment may be judged inappropriate if it will add nothing to the patient's well being as a person."[22] The principle of necessity referred to above is also pertinent.

I drew attention to the problems that can arise when relatives or members of the health care team request intervention such as hydration, in terminally ill patients.[1] Ashby and Stoffell believe that the sensitivities and consultative processes required to handle such a situation are already embodied in contemporary palliative care practice. I would say that there is much room for improvement and no cause for complacency. Their penultimate paragraph hints at persuasion of the family to accept treatment abatement.[7] One cannot help feeling that anyone who requested active intervention, for any reason, would need to be exceedingly persuasive, determined and articulate to achieve it. The more gentle, flexible and unqualified approach to the family adopted by Dunlop *et al* is preferable.[8]

THE NEED FOR FORMAL MEDIATION PROCEDURES

Gillon drew attention to the need for some formal mediation procedure in British hospitals and hospices,[3] but little progress has been made on this point. However, there are encouraging signs, in the form of a thoughtful paper on the subject of clinical ethics committees, from the Institute of Epidemiology and Health Services Research in Leeds.[29]

SOME THOUGHTS ON CARE AND COMPASSION

A physician can work for a lifetime with care and compassion without pausing to analyse these sentiments, or read books on the subject. There is an approach to ethics based on care, which some view as hopelessly vague.[30] Some Buddhist and Christian views have been discussed in this journal recently, and are relevant to this debate.[25] The word care itself, is in danger of being devalued, since those who campaign for the right to die in Oregon, USA, see their action as a campaign for compassionate care. No doubt they are motivated by sadness and pity in response to pain and disability, but compassion need not kill. "It is unsafe to encourage or even to allow compassion to see death as its only or prime instrument."[31]

There is correct compassion and correct care. Anglican and Catholic Bishops refer to the ... "Special care and protection" ... that the vulnerable deserve ... "which provides a fundamental test as to what constitutes a civilised society."[25] "Good medicine involves compassion, but it must be correct compassion leading to constructive action."[32] Doctors should care for the patient supportively and wisely, care for the relatives sensitively, and care for the carers.

Finally there is the legal view of a doctor's duty to care, some aspects of which have been mentioned already.[1 7 27] As the Irish Supreme Court case showed, legal and medical opinions in this area do not always agree. There is clearly a need for doctors, lawyers and ethicists to find more common ground, but standards must not be compromised for political or economic reasons. In the context of the care of the dying it is essential that the law of double effect is honoured, and not abused.[9]

SOME THOUGHTS ON NEEDS

This debate has highlighted the needs of the terminally ill patient for comfort and supportive care, the needs of the relatives, and the need for formal mediation procedures. Doctors and nurses also need to recognise that their own values, attitudes to disability, training and experience will influence their decision-making. Some may consider that there are fates worse than death, but as the Leicester hospice team report, "even a terminally ill patient with incurable malignancy may find life worthwhile and precious."[33] There is a need for research into the value of maintaining hydration, so that treatment can be evidence-based. At present, as Dunphy *et al* point out, it may be that a patient's place of care, whether hospital, hospice or home, is the main factor that determines whether he or she is rehydrated or not.[10]

The view that access to nutrition and hydration is a basic human need, irrespective of the means by which it is delivered[21] is profoundly important. Access to nutrition and hydration determines whether a person lives or dies, whether on a hospital ward, or during famine or war. Decisions about AHA give society, through doctors, considerable power over life and death. Such power must be used with the utmost responsibility.

Summary

This debate has proved valuable. On clinical aspects the responses to date have shown a refreshing willingness by palliative medicine specialists to examine and question their clinical practice.[10] Some have modified certain aspects of their practice but have defended others vigorously.[7] There is some measure of agreement that careful assessment of individual patients is essential, and that some will benefit from rehydration.[10 6] Hydration can be maintained quite simply using the subcutaneous route in the patient's home if need be.[34]

Legal and ethical discussion has highlighted areas of great difficulty. Consideration of cases such as the Bland case, though necessary, has tended to

deflect attention away from the central issue of the use of sedation without hydration in terminal care. However, discussion has been greatly helped by the deliberations of the House of Lord's Select Committee on Medical Ethics.[22] They made it clear that it should be unnecessary to consider the withdrawal of nutrition or hydration except in circumstances where its administration is in itself a burden to the patient. Careful consideration of the benefit/burden equation in individual patients is of central importance to patient management.

We all want the dying to depart in peace, in comfort and with dignity. We should all try to ensure that their relatives have peace of mind too. Of course we are not required to "treat the dying as if they were curable"[35] – but we are required to support life wisely, until it comes to a natural end. That is the whole purpose of this debate.

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On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A commentary

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One has to share some of Dr Craig's anxieties. We must strive for an accurate diagnosis for those who have not long to live or we cannot provide all possible help for them. But we know that hospice physicians create more routine investigations and a balance between over-investigation and neglect in the care of the dying is not easily achieved. I remember Dame Albertine Winner saying that a cup of tea is of much more use than a blood count in such cases.

Accurate diagnosis in hospice patients is usually straightforward. Admission should be preceded by careful clinical assessment and a full medical report. A hospice is no place for solving diagnostic problems, but so long as over ninety-five per cent of admissions are to do with disseminated and inoperable malignant disease, this presents few difficulties.

Even so, during my 15 years as medical director of a busy hospice occasionally humiliating lessons had to be learned; but these were more often cases of unexpected survival – the breast cancer patient whose skeletal abnormalities turned out to be due to Paget's Disease, for example – rather than errors associated with mismanagement and a premature death. I remember only one case of leukaemia, many years ago, that seemed to have had inadequate therapy. Our referral to a different specialist unit led to further treatment and the pleasure of seeing the patient's case demonstrated at a grand round several years later as 'a cure referred by the hospice'. That must be very rare.

Indeed hospice colleagues tell me that they still see more of enthusiastic over-treatment than of neglect. There are implications here for hospital training that sooner or later will need to be addressed and for hospice training too, as palliative care moves towards mainstream medicine. The fact that old age is the time for multiple pathologies as well as for dying means that the training of the hospice physician must have a generalist approach.

Key words

Nutrition; hydration; sedation; terminally ill; euthanasia; ethics.

If we take even half seriously the aspirations of the recent Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee paper, *Principles and Provision of Palliative Care* (1), the expertise in the symptom control of advanced cancer will not be enough. Some geriatric and rehabilitation skills will also be required, the management of advanced AIDS and Motor Neurone Disease, of secondary diagnoses such as renal failure or uncontrolled diabetes, all must be part of our stock in trade.

Palliative care is essentially a multi-disciplinary effort, and although the diffusion of hospice responsibilities will occur only slowly and with difficulty, analogous problems await our nursing colleagues for which they are not yet prepared.

If their patient has only a short time to live the problem of excessive dependence is irrelevant: but a disabled sufferer from, say, multiple sclerosis must be helped to cope with years of survival and patients encouraged to dress themselves even if it is exhausting and takes a long time. That would be cruel and unacceptable for the breathless lung cancer patient. It is difficult to combine these two different cultural attitudes on the same ward.

There are two tendencies to be observed in the present background to palliative care. First, the crudities of the 'contract culture' may threaten the survival of the costly hospice units. Second, if staffing levels are lowered and our responsibilities widened to take in the whole spectrum of incurable illness, the new specialty of palliative medicine will have its expertise dangerously diluted.

It may well be therefore that Dr Craig's points are not to be taken too seriously – yet: but they point the way to problems that will be with us for a long time to come and will not easily be resolved.

Dying is a social act. Usually even in the presence of grief, there should be little in the way of anger or resentment directed at the carers by those about to be bereaved so long as they are informed and involved as fully as possible in the management of the case. The health professionals need to be aware that every casual phrase, any inevitable difficulties, the minutest details, are likely to be recalled by the family to the end of their days – influencing attitudes and giving

comfort or distress for many years. This makes information and effective communication essential. Generally the process is both easy and rewarding.

But there are always exceptions and we need to be tactfully resistant to sacrificing the interests of our patient to the emotional distress of the relatives. An old man, transferred to a hospice after a hospital transfusion, was going gently downhill, but this caused sufficient distress to the son for him to demand: 'Can't you do more for my father? He's only ninety two'.

Such poor adjustment to dying can be found in all walks of life, although those who have a tough life in the city or on the farm quite often cope better than the doctor or the priest when they have to face the death of someone close. But everyone can feel excluded and ignored if all the measures that might prolong the process of dying are not deployed.

Sometimes patients come to a hospice seeking sanctuary from modern medicine, such as a respite from their chemotherapy. Others may be desperate to continue their chemotherapy for all that in their case it may be little more than a toxic or costly placebo. All doctors will therefore have to walk the tight-rope between over-treatment and neglect. The comfort of the patient must come first. Two common threats to the comfort of the dying are chest infections and dehydration, so perhaps they merit special mention.

Pneumonia was called, significantly enough in the last century, the old man's friend, for so often it put an end to suffering. Today in modern palliative care the chest infection in the incurably ill may be an intercurrent infection causing fever, cough, breathlessness so as to merit treatment under the heading of symptom-control. Alternatively it can be the beginning of the process of dying and not therefore to be officiously prolonged. Usually the difference is readily obvious, especially if colleagues and carers are involved in the assessment. The previously expressed opinions and wishes of the patient can be both helpful and relevant.

But rarely there will be doubt and here a delay of a day in the initiation of antibiotic treatment can either make the desirability of energetic treatment clear or it can see the patient moving speedily towards death. Where there is still doubt, the patient should have the benefit of it.

Near the beginning of my career as a hospice physician, when patients' symptoms were well controlled and they were resting peacefully, as they moved nearer to death I would tend to reduce the dosage. This too often was associated with a restlessness as patients surfaced close to a reality with which they could no longer cope. The regime necessary to control distress was therefore maintained to the end. A comatose patient was much the lesser evil, yet despite encouraging nurses and carers to keep giving small frequent sips of water, dehydration could occur. Indeed, it sadly occurs far too frequently on medical and surgical wards far removed from the territory of palliative care.

In a hospice one is properly anxious to avoid either intravenous or subcutaneous infusions unless the needs are clear, for these can medicalise the process of dying, inhibit the limited mobility of the patient, and impede the involvement of the relatives. But in a sedated patient such infusions may be necessary to control discomfort or prevent infection. This is not often necessary and can be made even rarer by the overnight insertion of a slow drip of rectal tapwater when it has proved difficult to maintain adequate oral intake of fluids. This homely remedy still has a place, especially as dehydration can distress the more aware relatives and sour their relationships with the carer to what may seem a disproportionate degree.

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On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A reply

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Abstract

Patients who are dying of cancer usually give up eating and then stop drinking. This raises ethical dilemmas about providing nutritional support and fluid replacement. The decision-making process should be based on a knowledge of the risks and benefits of giving or withholding treatments. There is no clear evidence that increased nutritional support or fluid therapy alters comfort, mental status or survival of patients who are dying. Rarely, subcutaneous fluid administration in the dying patient may be justified if the family remain distressed despite due consideration of the lack of medical benefit versus the risks. Some cancer patients who are not imminently dying become dehydrated from reversible conditions such as hypercalcaemia. This may mimic the effects of advanced cancer. These conditions should be sought and fluid replacement therapy should be given along with the specific treatments for the condition.

The issues surrounding the management of fluid and nutritional status in the terminally ill were brought sharply into focus by Dr Craig (1). She rightly pointed out the dangers of automatically withholding fluid replacement therapy. Palliative care never has been, and never should be, an excuse for bad medicine. The need for careful clinical assessment and diagnosis of every problem is a central premise of palliative care. Reversible conditions such as hypercalcaemia may cause dehydration in cancer patients who are not imminently dying. If rehydration is not carried out, the patient will deteriorate rapidly. The gaunt appearance and altered state will mimic the effects of advanced cancer.

It is important to distinguish those patients for whom fluid replacement is medically indicated. A distinction can often be made on clinical grounds. Dying patients have a longer history (weeks or months) of gradual deterioration with increasing weakness, fatigue, weight loss and drowsiness. Dehydration will cause a more rapid deterioration, usually over days, in the setting of a precipitating cause suggested by the history (for example, polyuria, polydipsia with hypercalcaemia, or vomiting from bowel obstruction), clinical examination and appropriate laboratory findings. The acute change will cause considerable distress both to the patient and the family. Such distress should be used as a further prompt to search for a reversible problem. It should be borne in mind that some people deny the previous history of gradual decline and then 'suddenly' become distressed when the patient finally stops swallowing. When there is doubt, a therapeutic trial of fluids and other appropriate treatments may well be warranted so long as the wishes of the patient are not contravened.

On the other hand, most terminally ill cancer patients reach a point during their gradual physical decline when they first stop eating and then subsequently stop drinking. This occurs even in patients who are not taking medications and as Dr Craig pointed out, this situation arouses considerable distress for the relatives. Dr Gillon discussed the principles which should be followed when conflict arises between patient proxies and staff (2). However, conflict may be prevented by anticipatory dialogue based on the evidence for the risks and benefits of giving versus withholding treatment.

Nutritional support should be considered as a separate issue from hydration. The administration of conventional dextrose solutions via peripheral veins does not constitute nutritional support. This can only be achieved by enteral feeding (nasogastric tube or gastrostomy) or by parenteral administration into a central vein. Although patients with advanced cancer appear to be malnourished, the metabolic abnormalities are quite different from starvation in an otherwise healthy person. There is no evidence that in patients with advanced cancer, aggressive nutritional support, either enteral or parenteral, prolongs life or even significantly alters the metabolic abnormalities (3). Indeed there is evidence that cancer growth may be accelerated, thereby increasing local symptoms from the cancer (4). Nutritional support may be helpful for the small number of patients who have local disease causing swallowing difficulties but who are not

Key words

Nutrition; hydration; palliative medicine; terminally ill.

yet dying from widely disseminated endstage cancer, for example, those with head and neck cancers.

Dehydration results from an intake of water below the minimum required to maintain homeostasis. In someone who is otherwise healthy, the symptoms are thirst, dry mouth, headache, fatigue, then cognitive impairment followed by the sequelae described by Dr Craig: circulatory collapse, renal failure, anuria and death. The first clue suggesting that the situation in cancer patients is not equivalent to acute dehydration came from clinical observations in dying patients who were not taking any medications and who did not have correctable causes for their deterioration. In such patients systemic symptoms such as fatigue and drowsiness usually precede the cessation of fluid intake by several days or weeks. Even though these patients may be very drowsy at the time they stop drinking, they can rouse and respond to questions from family for example.

Analysis of blood and urine chemistry in terminally ill patients has failed to disclose evidence of the expected changes from dehydration (5,6). In a recent prospective study of dying cancer patients (median time to death, two days) the symptoms of dry mouth and thirst were not correlated with the level of hydration (6). These findings support the work of Burge who investigated dehydration symptoms in 51 cancer patients with an estimated prognosis of less than 6 weeks. He found no significant association between biochemical markers of dehydration (serum osmolality, urea and sodium) and the symptom of thirst (7). Therefore giving additional fluid to dying patients in order to alleviate the symptoms of dry mouth and thirst may well be futile.

In the same way that hunger is not a feature of the anorexia-cachexia syndrome, thirst is not associated with decreasing fluid intake in those close to death. It is possible that the normal homeostatic mechanisms controlling fluid intake and fluid balance are altered in the dying process. Further evidence for this hypothesis derives from studies of patients given fluids intravenously. Waller *et al* compared 55 patients treated with oral fluids with 13 patients who received IV fluids (8). They found no difference in the biochemical parameters and state of consciousness between the two groups.

It seems reasonable to conclude from these observations that nutritional or fluid supplementation cannot be automatically justified on medical grounds for patients dying of advanced cancer. Is fluid therapy harmful? To our knowledge, no studies have demonstrated any adverse effects from fluid therapy. Intravenous cannulae can pose a problem to patient comfort if the arm needs splinting. This can be overcome by using the subcutaneous route. Terminally ill patients have lower albumin levels (6) which may cause problems when crystalloid solutions are administered. Albumin is the plasma protein which is largely responsible for maintaining colloid osmotic pressure. This pressure counteracts the forces which tend to move fluid out of the blood vessels. The authors have seen patients develop pulmonary oedema, rapidly increasing ascites, and unsightly peripheral oedema involving conjunctivae and the hands when given intravenous fluids in acute hospital wards, particularly if the serum albumin is below 26 g/l.

Dr Craig drew attention to the use of sedation in terminal care. Once again, a careful history and examination is necessary to distinguish terminal agitation from a reversible problem in someone who is not actually dying. Terminal agitation must be treated aggressively, otherwise the distress of the patient will become extreme. Even when incremental doses of sedatives are given, it is rarely possible to achieve a balance between relief of agitation and alertness. All palliative care practitioners would echo the experience of Dr Wilkes who described the problems of trying to reduce the dose of sedatives when the patient is settled (9).

When sedation is required in a patient who is not actually dying, we rarely find that it is necessary to render the patient unconscious. Nursing staff can still feed the patient and maintain hydration. The dose of tranquillisers is always reduced to the lowest dose necessary to control the symptoms. We would seek the advice of a consultant psychiatrist in treating such cases.

Given that there is no clear evidence of symptomatic benefit from nutritional or fluid therapy in cancer patients who are dying and that there is potential for harm if there is severe hypoalbuminaemia, we do not recommend the routine use of intravenous or subcutaneous fluids. When discussing these issues with a family, it is important not to argue from some philosophical standpoint, but it is important to present the facts carefully. On most occasions, families will be reassured and their sense of helplessness can be assuaged by encouraging them to perform mouthcare. Some families (particularly from some cultural and religious backgrounds) may not be satisfied. In these circumstances, so long as no contrary opinion has been expressed by the patient, we give subcutaneous fluids for the sake of the family. This situation only arises two to three times per 1,000 admissions per year at St Christopher's Hospice. The volume is kept to no more than one litre per 24 hours to avoid overload. The use of a local anaesthetic cream will prevent pain from the cannula insertion. The infusion is usually given overnight; the subcutaneous line is capped and left in-site during the day so that the patient is not subjected to multiple needle pricks. By giving the infusion intermittently, it is easier for the family to make the decision to discontinue therapy.

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News and notes

Euthanasia: Towards a European consensus?

A conference entitled Euthanasia: Towards a European Consensus? will be held in Brussels, Belgium from the 24–26 November this year.

Participants will include Judge Christian Byk, former bioethics adviser to the Secretary-General of the Council of Europe, Professor Paul Schotsmans, The Catholic University of Leuven, and Patrick Verspieren SJ, Centre Sevres, Paris.

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