Life or Death
a
Donor Parent's Dilemma

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Statement

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

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Dedications

To Greg and James: My loves, my light, my life.

Acknowledgments

Writing a thesis, although at times a solitary pursuit is, in the end, a product of considerable effort and support from the many people who surround you. Hence, to remember and acknowledge each and every person who has helped along the way would result in this acknowledgment being as equal in length as the thesis. I therefore say thankyou to everyone and have faith that those who counselled and supported me along the way realise the deepest sincerity I imbue these words with and will never forget their efforts made.

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Abstract

Death of a child is one of the most, if not the most, emotionally challenging experiences that a parent can endure. A firm conviction in the capacity of medical science to limit such deaths from occuring is the rational *totem* of many parents. Consequently, when this death happens suddenly and is surrounded by an ambiguous diagnosis of death called *Brain Death* the parents' experience becomes dominated by uncertainty. Still able to feel the warmth of their child's skin, and see the beat of their heart, parents become confused by the surrounding talk of death and subsequent request for consent to organ donation.

Eventually, despite this confusion, the parents are called upon to make a decision about this life and death, but where do they begin? Standing, waiting at the bedside the parents struggle to gather any fragments of meaning from their cultural heritage that may help them to accommodate this ambiguity and so become firm in their decision making. Only in the fanciful realms of fiction, science fiction, does there appear to be any similarities with their child's overtly living body (as evidenced by the life-support monitors that surround them) and dead brain. However, the parents are not living a fiction. This paradox of life and death revolves around their child who lays before them literally pulsing with life.

Only a life time of coming to appreciate what this ambiguity means could help parents to truly accept what is taking place. Time to understand however, is the one thing they have little of. Understanding is for later. Donor parents leave the hospital filled with hope that the months and weeks to come will be replete with opportunities to further understand what has taken place. A life time of trying to understand and accept what has happened to their child and family is, however, all that is possible for many donor parents.

Here, through a methodological blend of hermeneutics, phenomenology and social constructionism the experiences of donor parents Phedra, Andrew & Joyce, Thomas &

Abstract

Emma, Ellen, Pip & Daniel are presented for you to understand. Using a process of dialogical interpretion the themes of Unprepared, Uncertainty, Watching, Waiting and Aloneness have been developed to further deepen and expand our understanding(s) of donor parents experiences. These interpretation of mine, when coupled with my cultural critique of death, conclude in a polemic called a *Crisis of Limitations.*

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Prologue

A soft kiss on her cheek, a tight squeeze around her neck and the voice—"I'll see you later mum, have a good day." How could Sarah know that these words would be David's last? And his smile; why would she want to entertain the thought that this would be the last time she would see her David smile? David so loved being with his friends. He went riding with them every afternoon through the bush, totally lost in the excitement of the moment. "So full of life, so full of love" she states, "He was such a beautiful boy, and everyone loved him". How could Sarah begin to anticipate that her comfortable world could end so suddenly, so unexpectedly. What parent would want to entertain such thoughts?

After the kiss David rushes through the front gate with Bronte the family dog close at heel. Following these casual goodbyes Sarah attends to James, her youngest son, getting him ready as they were going into town to do some shopping. It was a clear crisp morning, bright with sunshine. The kind of day where the beauty of it all just makes Sarah happy to be alive. She breathes in deeply as if attempting somehow to hold onto its magic. This morning's shopping however, cannot be leisurely as Sarah needs to be home by 3.00 p.m. Sarah and her husband (Robert) are entertaining friends for a barbecue.

The morning passes quickly with Sarah and James arriving home at 3.00 p.m. surprised not to see David's bike nor Bronte waiting in the driveway. They agree that David must be at Declan's house, probably 'shooting some baskets'. David loved basketball and both David and Declan were in the 'A grade' team at school and often played late into the afternoon, practicing for the next game in the competition.

Sarah unpacks the car and carries the groceries into the house. As she opens the door she spots a piece of white paper: a note on the floor. He's left me a note to tell me where he is, she thinks to herself as she continues to carry the groceries into the kitchen. David would always either leave a message on the phone or a note, "Just to keep you happy

mum" he would say, "you're such a worry wart." Sarah wasn't concerned. As she carries the groceries through the house to the kitchen she notices, out of the corner of her eye, the answering machine flashing madly. "How can that be so full?" she questions herself. "I mustn't have emptied that tape properly this morning before leaving the house?" Yet again Sarah fails to anticipate that anything is wrong. Why would she, everything she is experiencing has a possible reason. Nothing seems out of the ordinary. Everything that is happening now has happened on previous 'lazy-day' Saturdays. Maybe David has rung and tried to leave a message telling her where he is? Or maybe Robert has given their home number to his new clients? These are just some of the explanations she entertains for the answering machine being so full as she continues unpacking the groceries. Thus, Sarah doesn't rush to listen to the messages, and she forgets quickly about the note on the floor. How could Sarah have known that this absence of concern would become her greatest burden and unceasing regret in just a moment's time?

Before Sarah can finish unpacking the groceries the phone rings. She walks across the room to answer it, unknowing that the life for which she gave thanks this morning is about to change. Her life will no longer be filled with gratitude but will instead be engulfed by a sorrowful hush. Although Sarah and Robert, like most parents recognise all too readily the loss of a child as incomprehensible and fearful, such imaginings were pushed aside and ignored in favour of an impassioned wish for them to remain in the realms of imagination rather than a reality.

As Sarah lifts the receiver she anticipates David's voice. Instead, the voice enquires if she is Mrs Stevens, and procedes in a very calm and controlled manner to tell her that her boy, her first born, has been in an accident and that she is needed at the hospital as soon as possible.

Being the mother of an active sixteen year old boy, Sarah's immediate reaction is, "Oh what has he done? Don't tell me he has fallen of his bike and broken a limb or something?" But the voice at the other end of the phone won't give her any details. Instead, the voice evades all her questions, repeating instead a request for her to come to

the hospital as soon as possible. As Sarah replaces the receiver she hears the front door screen open. Fearful that James is wandering outside alone she turns to find him opening the screen door to a man and woman in police uniform—seeking information as to the whereabouts of his mummy and daddy.

Sarah's heart begins to quicken in pace. All of a sudden the seeming normality of the day and the ease of reasons for events thus far start to fade as Sarah begins to slowly understand why the police are standing at her front door. Sarah walks to the door and once again crosses over the note laying on the floor—a note that the policewoman would later refer to in their conversation as evidence of her previous visit to try and inform Sarah of her son's accident.

"Thankyou, um, Yes I know" is Sarah's reply in a voice that is barely audible as it struggles with the rest of her thoughts to gain passage through her mouth. "Is he hurt badly?" she inquires with hesitation. The police officers hesitate to give her any more information than the voice on the phone. This lack of any detail about David's condition adds to Sarah's mounting anxiety which echoes in the sound of her heart beating deep within her ears. She can feel her blood pulsing through her head, competing for space with the thousands of questions that have no exit, no answers. Sarah feels her motherhood being threatened. Is it more than just a fractured arm? she questions herself in silence. Maybe my boy is unconscious and they have to take him to surgery. Maybe they are waiting for me to get there before they can help him, and I was late getting home. A well of regret starts to fill deep within her soul. How could I not know that my son is hurt? This last question is the one that runs relentlessly through her mind. How much time; how long has David been laying in hospital waiting for me? and all I was doing was shopping. But still nobody can appease this flood of questions, not even herself. Sarah would never be able to answer such questions for herself, despite their insistence throughout the coming years.

The policewoman's voice breaks through the torrent of questions crowding Sarah's mind. "Would you like us to drive you and James to the hospital? Do you have a partner that you need to contact? Can we help in getting you to the hospital?" "Ah, no

um, no thankyou" replies Sarah as she turns into the house scanning the room for what she might need; hoping that 'it' would choose itself rather than make her choose. Her mind, already overrun with questions about David, seems to have no room for trivial questions such as these.

Sarah struggles to answer. "No, I think I will be fine". How will I tell Robert she thinks to herself. Years later Sarah finds it hard to recall how she managed to take James to his grandmothers, phone her husband and pick him up from his office on the way to the hospital. But time is not moving fast enough for Sarah. Sarah needs to be with David now; and the reuniting seems to be stretching further and further away from her the harder she tries.

Sarah and Robert arrive at the hospital and suddenly realise that they do not know where David is—another question that seems to have no ready answer. The lights are bright and the sounds are harsh as they stand anxiously queuing up, like everybody else, waiting to be helped. But the waiting is unbearable and Robert races to the triage nurse and asks if she can help him find his son. She asks for David's full name punching briskly the letters into the computer. "Your son has been taken to intensive care", she says casually, "which is on the sixth floor in East Wing. You are now in North Wing, here" as she points to a map of the hospital. "You need to take your first right and follow the corridor all the way to the end and then it takes a dog's leg turn to the right again and then opens into a waiting area for the lifts. You need to take the yellow lift to the sixth floor and then follow the signs to intensive care from there, okay?" The directions and words match the maze of unfamiliar, cold corridors that Sarah and Robert wander through aimlessly until a stranger takes them to the doors of the intensive care unit. Such kindness and direction is comforting for Sarah and Robert and they value it greatly.

Arriving at the intensive care unit a large bold red lettered sign - DO NOT ENTER. STAFF ONLY PAST THIS POINT halts them in their passage. An arrow points to a button with directions PUSH AND WAIT FOR REPLY. Sarah is becoming frustrated with all the points of delay that seem to waste her time. All she wants to do is see her

son. She begins to question, with no audience but herself, as to why she cannot see him. The waiting continues to threaten Sarah's motherhood. By this time Sarah is imagining the worst. Has David lost a limb, or is he paralysed from breaking his neck? Robert and Sarah just want to see their son but the voice over the intercom asks who they are and instructs them to wait in the waiting room until someone comes out to find them.

They turn to see a series of chairs lining the wall of a very grey small room. There is a low set table in the middle with some old magazines spread across its surface, and a styrefoam cup half filled with cold milk coffee precariously perched on an open page of a well thumbed *Women's Weekly*. All four chairs that stand on either side of the entrance to the waiting room are already taken by people waiting. Like Sarah and Robert they too want to be as close as possible to their loved one, even while waiting.

Sarah and Robert sit amongst the low pitched conversations of other families and watch the doors of the intensive care unit open and close. They begin to envy the people who have freedom of access and who seem to enter and exit these doors with ease. Each time the doors open they hope that the person exiting is an escort for their entrance, but they wait. Finally, a woman exits the door and sits in the chair next to Robert. She introduces herself as the Senior Registrar caring for David and proceeds to tell Sarah and Robert in a low, calm voice that he has been hit by a car and is in a critical condition. What does she mean by critical? is Robert's silent question. He is almost too scared to ask. He fears the answer. The Doctor continues to tell Sarah and Robert that David is in need of having an operation that will relieve the pressure mounting in his brain and that other than this intervention there is really no other option but to wait. She ends her conversation by conceeding that she unfortunately does not hold much hope for David's survival.

What does she mean by not much hope? Of course he has hope, he is only sixteen. He is young. Sarah cannot understand what the Doctor is trying to say. It all seems too much to comprehend. What can she possibly mean by not much hope? are the words that keep running through Sarah's mind. Sarah stops listening, for fear of being crushed by the pressure of the words and instead asks when will they be able to see their son. The doctor again proceeds to instruct in a calm soft voice that she will take them to see him

but that they should be prepared for what they will see. Her words however have lost their meaning. Sarah watches the doctor's lips move but does not hear the sounds, for she is more eager to be escorted through the doors to her son. This talking is doing nothing more than maintaining a distance from her son which Sarah can no longer bear. She needs to see for herself if what the doctor is saying is true.

The doors swing open into the unit as Robert and Sarah gingerly follow the doctor. The room is filled with the hush of low pitched voices, punctuated by the various alarms of machines. Everywhere Robert looks there are occupied beds, surrounded by equipment and machines. He searches each face hoping to find David's until eventually David's sleeping body lay in front of him. Sarah scans the perimeter of her child's frame. He is surrounded with tubes and drips and his head is bandaged. He is covered in a clean white sheet and his eyes are closed. He looks peaceful. He looks asleep. Robert and Sarah feel swamped with confusion, overwhelmed with anxiety. They search each other's face for an answer to their questions. What do they mean critical, no hope? when his face does not have a scratch on it! The nurse caring for David gives them a welcome smile as they stand motionless at the bedside and watch her every move. They watch as she cleans David's eyes and plot lines and numbers on a large piece of graph paper resting on a table at the end of the bed.

Sarah can feel the nurses watching her as she struggles to try and get closer to her son. She needs David to know that she is finally by his side and will not leave. Sarah stands looking at David, feeling helpless in her want to touch him; to hold his hand; to cuddle him and tell him that she is by his side. But where or how will she start? The plastic tubing of the intravenous infusions, light and transparent, stand like bars of steel between Sarah and her child. She is fearful of disturbing anything that is helping him. Watching Robert and Sarah, the nurse encourages them to hold David's hand and to talk to him. She brings a chair and places it next to the bed. Sarah reaches for David's hand but can only feel the warmth of his fingers as the rest of his hand is wrapped in a bandage holding the intravenous needle in place.

After what only seems a moment to Sarah the nurse asks both she and David to wait outside as she needs some privacy with David. Sarah resents the lack of control that she now perceives she has over obtaining her own privacy with her son. She becomes distressed with this request as she fears that David may wake up and see that she is not there—as she has only just told him that she will not leave his side. Reluctantly, Robert and Sarah give the nurses some privacy while eagerly waiting to return.

On their return to the bedside Robert starts to question the nurse about the different equipment that surrounds David, asking what each number and wave on the monitor means. The nurse informs Robert and Sarah that David is very unwell and that only time will tell his outcome. She adds that she has seen people walk out of the unit who were in a worse condition than David. Robert and Sarah's anxiety is momentarily appeased by this conversation as they hold tight to this hope for David's recovery and commit themselves to the waiting, however long it will take. They believe that a miracle will happen, as it must.

Sarah spends her time talking to David, telling him what she and James did that day. She tells him that James is with his grandmother and will be in to see him in the morning. As Sarah is talking to David, Robert can hear in the background the doctors telling the nurses that the surgery is ready and that the family will need to leave, to return to waiting outside in the waiting room. The nurse approaches Sarah and Robert with the directive and proceeds to lead them to the waiting room, where time seems to be warped and stretched out of proportion to their needs. They wait what seems like an eternity to hear what is happening. While waiting they talk and agree that David does not look as bad as what the doctors are saying. "He feels warm" says Sarah. "And all the monitors show that his heart is working", states Robert, "And that his blood pressure is okay". They wait together in silence yet surrounded by other families also waiting and debating their hopes.

Suddenly the midnight silence of the corridor is filled with the sound of a trolley being pushed towards the unit and through the doors that keep the waiting families at bay. What seems like hours later a nurse gives Robert and Sarah permission to once again sit

by David's side. The doctors are unable to answer any of Sarah's questions about recovery except with what seems to have become the rhetoric of their experience encompassed in the nebulous phrase, "Only time will tell." The waiting becomes unbearable for Robert as he feels he has no control over his son's destiny. All he can do is watch the nurse care for David while mesmerised by the monitors and their every alarm. Robert, like Sarah, continues to struggle with this intolerable lack of anything definite but waiting, particularly when David looks so peaceful with barely a mark on his body. A struggle that is endorsed by the nurse's answers to his questions, "His condition's unchanged, your son is stable at the moment".

The hours fall into each other as Robert and Sarah sit and talk to David, caressing his hands, unwilling to leave his side unless requested by the nurses. The nurse tries to encourage them to go and have something to eat or have some time away from David. But such considerations of their own time are insignificant when compared to their need to be by their son's side. Everything appears stable and unchanging. In their waiting, Robert and Sarah learn from the nurse the scale of 'normal' for the pressures in David's body and therefore begin to anticipate what numbers on the monitor indicate problems. They are grateful that nothing seems to be changing for the worse, and that everything appears stable, until a doctor approaches and asks if he could speak to them in his office. He walks Robert and Sarah into an small room and asks them to sit comfortably. A short while later the nurse who has been caring for David enters the room. Sarah becomes anxious as she wonders who is with David. The nurse sits next to the doctor; she remains silent. The doctor is holding David's chart in his hands. He struggles to look at Robert and Sarah as he starts to tell them that he believes from all that he has seen and tested to date that their son, David, is brain dead. The word *dead* showers pain throughout their parental souls. What does he mean dead! screams Sarah inwardly. David's alive, he's unconscious but he is alive. I can see it on the monitors and I can feel his warmth in my hands. How can he be saying that David is dead? Robert becomes weak as he feels his soul being torn in half. Every word that the doctor says thereafter stings Sarah and Robert's senses and seares their memory.

The doctor continues to tell them that he will need to conduct more tests to prove his diagnosis. He tries however to assure them of his certainty by claiming that he does not attempt such test without first being quite certain of his diagnosis. He urges Sarah and Robert to start accepting that there is no more hope for their son's recovery, that David is dead.

Before leaving, the doctor warns Sarah and Robert that they eventually face having to make a difficult choice. He states that after the tests are completed Robert and Sarah will have to choose either to withdraw therapy—switch the machines off that are helping their son breathe—or consider helping someone else who is in need and therefore consent to organ donation. He asks the grief striken pair, "Have they ever considered organ donation?" This conversation however seems absurd to Sarah. She feels as if she has been placed into another world; a world that is full of cruel jokes. She struggles to escape this space of pain. She is consumed by her need to be next to David. As far as she is concerned David is alive and in need of her being at his side. She cannot understand how they can be saying such things. But Sarah is unable to leave this space of pain and envies the ease with which the doctor and nurse seem to negotiate these spaces. The doctor and nurse move out of the space leaving Robert and Sarah ensnared with a decision: a decision that has no other outcome but a recognition of their son's death. "How can they be asking us to do this" cries Sarah to Robert, "When they know that we can see that he is alive? I don't understand what's happening. What do they mean, dead?"

Chapter One

Introduction

> *This existence of ours is as transient as autumm clouds. To watch the birth and death of beings is like looking at the movements of a dance. A lifetime is like a flash of lightning in the sky rushing by, like a torrent down a steep mountain.*
>
> (Sogyal Rinpoche 1992)

Comforting the dying and preparing the dead are important rituals for many nurses in their daily practice. As a nurse working in intensive care I have ventured to understand the needs of the dying patient and their family and have valued my conversations with them as significant in attempting such understandings. I have stood by the bedside of dying patients as the families' tears have fallen. I have listened to families speak—tell stories—of the life that has been and the future plans and dreams now lost. I have gained entrance to their sadness through these stories and with this entrance had the opportunity to share my regret and sense of futility when confronted with death's dominion.

Nursing has a rich history of caring for the sick and the dying (Maeve 1998). Nursing is regarded by many in society as among the professions who *understand* death and how it *should* be managed[1]. There tends to exist a societal expectation of nurses to support patients and family in their attempts to understand and manage death when it suddenly enters their lives (Chapman 1998). In an effort to address this demand nurses have drawn upon the cultural norms, rituals and expectations of death and dying and tried to fashion them in ways to suit the peculiar demands of the institutional setting.

Nurses try to support family and friends in the acceptance of their loved one's death by many poignant, simple gestures. Cleansing the dead, surrounding the body with soothing

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[1] 'managed' is the guiding term here as throughout the 20th Century we have, in theory, capitulated to the institutionalisation of death through medicine's gradual sanitisation and medicalisation of its process.

fragrances and calming colours are just some of the ways nurses endeavour to present death to the grieving family. Sometimes a flash of colour, in the form of a flower, taken from the bedside vase, will be placed on the chest or in the patient's hands as a symbol of respect for the patient and their family, as well as a statement of hope for peace in their journey to come. Simple rituals such as these, though complex in meaning, can often help nurses with their efforts to provide the family (and themselves) with a peaceful environment where they can spend time coming to terms with death's immediate presence, and inevitability for all.

There is however a *new* death challenging the way some nurses[2] care for the dying and their family. Continuous advances in biomedical technology have brought with them a necessary reinterpretation and subsequent re-defining of death. Within intensive care units death is no longer just presented as the stillness of heart beat and breath. The medical application of a new definition of death has resulted in death at times being diagnosed inspite of these signs of life. This study confronts, questions and endeavours to understand this new death and its ambiguous connection with *new* life through the practice of organ donation/transplantation[3]. The families who make this new life possible by consenting to the donation of organs from their heart-beating, brain dead relative are the focus of this work. In particular, the experience of five parents consenting to the donation of their child's organs inform this inquiry. Throughout this thesis it will be shown how this new death is intimately connected with organ transplantation and the subsequent need for people to consent to donate their organs in order that the transplantation programme be successful.

Advances in biotechnology have resulted in people who suffer irreversible loss of brain function (brain death), but still have an intact cardio-vascular system, now being considered as *potential donors* of kidneys, heart, lungs, liver, pancreas, bone and tissue

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[2] As brain death is a death peculiar to biomedical technology and its application as found in intensive care units, brain death is a death common only amongst intensive care nurses.

[3] The terms donation and transplantation are used synonomously throughout this thesis since, at present, without donation we could not have transplantation and without the practice of tranplantation we would have no need to consider consenting to organ donation.

(Coslovich 1996; Dahlenburg 1996). Acute head injury is the most common cause of brain death (Dye 1995; Scheinkestel, Tuxen, Cooper & Butt 1995; Sass 1992). Road trauma, in the form of motor vehicle, motor bike or pedestrian accidents present the largest proportion of patients with acute head trauma. Once diagnosed as brain dead they are deemed to be suitable organ donors. One of the sad legacies of youth in our society is that most road trauma victims are between the ages of sixteen and thirty (NISU 1991). Entering adulthood and consummed by the freedom associated with this passage many have this freedom struck short by their accidental involvement in a violent road trauma of some form or another. Having this inquiry focus on the experiences of donor parents therefore seems pertinent, as parents consenting to the donation of their child's organs are the relatives that nurses most frequently attempt to support through the acceptance of a brain death diagnosis and the consenting to organ donation.

Background to the Study

From the outset it is important for the reader to realise that this thesis developed from my involvement in a national study into the social practices and discourses surrounding organ donation in Australia entitled: *The ambiguity of 'The Gift of Life': exploring the experiences of donor families and health workers and the public discourse on organ donation* (Pearson & Hickson 1995). Involvement in this study as a research assistant/PhD student helped shape my understandings of the organ transplantation practice in Australia and so informed any subsequent interpretations of the participants (donor parents') experiences that I made for my thesis. Work as a research assistant always preceeded research for my thesis and so my thesis was constantly informed by interpretations and conclusions being made in the larger study. This cyclical process where my interpretations reveal my understandings which in turn rewrite any further interpretations that I make is a critical process of this entire thesis. In the following section of this introduction I attempt to explicate further and discuss the interpretive influences of the national study on this thesis. Background discussion of this thesis therefore primarily attends to what I learned about organ donation from being involved

in this national study and relates how involvement and interpretation for this study situated all subsequent interpretations of the parents experiences.

Learning from the National Study

Organ transplantation is without doubt a miracle of modern medicine. No longer are people with chronic end-stage organ failure having to face a future of suboptimal quality of life and premature death. They now appear to have a choice. If however the national and international statistics regarding donation rates are any indication, this choice is not easy. Despite Australia being a key participant throughout the world in the scientific development and application of transplantation technologies, Australia's organ donation rate remains one of the lowest in the developed world (Dye 1995; McBride & Chapman 1995). Lack of understanding about what is involved, coupled with a cultural hesitation to carefully consider one's mortality, are all considered principle reasons for the public's general unwillingness to consent (Northrop 1997). Subsequently, considerable time and government funding is spent on trying to educate the public and increase their awareness of what is promoted as the 'Gift of Life'.

To date, opinion polls show that such campaigns have tended to have a positive effect. The public do, on the whole, appear to support this rhetoric of the 'gift' (Noury, Carre, Auger, Le Sant, Pinault & Jacob 1995). Donation rates, however, remain low and in some states of Australia, such as Western Australia, the donation rates are steadily declining. A pertinent question for policy makers has become, why? Why do a public, who appear to support the value of this miracle of modern medicine hesitate to substantiate this support through consenting to donate their organs?

A modest, yet compelling, reason offered (and a reason that influenced the inception of this thesis) is that people continue to struggle, albeit at times subconsciously, with the way that transplantation technology calls into question many of our basic cultural assumptions about life and death, self and humanity. A struggle, that because of its strong moral undertones, will not subside easily.

Never was a debate more contentious, especially since society is repeatedly called upon to consent to donate and help reduce the burdening public health care cost of caring for people with end-stage organ failure (Pearson & Hickson 1995). The *Ambiguity of the Gift of Life* study developed in response to this obvious disparity between public opinion and actual practice. A perceived paucity in public awareness about the emotional, psychological and spiritual complexities involved in consenting to donate a loved one's organs is realised by the chief investigators of the national study as formative of these inconsistencies and worthy of further debate. Central to the main argument of the national study is an appreciation that, to date, both the public and professional debates about organ donation lack the critical insight which can be gained from listening to the stories of people who are directly involved in the experience; in particular donor families, nurse and doctors (Pearson & Hickson 1995). These stories are invaluable sources of knowledge especially when it is appreciated that without such experiential information any decisions made about further advances in transplantation technology have a tendency to become institutionally isolated and ultimately technocratic.

Nevertheless, few people would deny the value of organ donation. This appreciation though should not impede informed debate about the future direction and application of organ transplantation practice and policies in our daily lives. In writing about the continuous uniformed advancement of biotechnologies by the public they are meant to serve, Bartels (1987, p.2) suggests that:

> *There is a great danger that the agenda for research and development is set according to judgments of what is 'technically sweet', to use the phrase coined by Robert Oppenheimer for describing the drive behind the development of the atomic bomb. This means that research projects are executed and put into practice just because scientists find the work intellectually stimulating, and not because there is a broad-based public endorsement of the scientific and technological advances.*

An informed debate is one where all concerned have the opportunity to voice and have heard their fears and concerns regarding the current practice. As a research assistant I interviewed and analysed the stories of twenty donor families, sixteen doctors and twenty nurses in an attempt to provide the current debate with a rich and complex

source of meaning that could help inform and modify choice being made regarding the policies of organ procurement. For the past two years I dialogued (analysed) with these stories and from this period of analysis two fundamental issues became apparent:

1. That a disparity exists between the rhetoric about organ donation and the experience of organ donation as it is lived by the surviving friends and family.

2. That an uneasy tension exists between an expectation of technology to provide us (the public) with liberation and disburdenment of our mortal frailties; versus a feeling that we are victims of an autonomous technology that leaves us with minimal choice about its presence and application in our daily lives.

Through my research I came to appreciate that this disparity between rhetoric and meaning as lived is not surprising as it can be understood to be reflective of a fundamental cultural dichotomy over fact versus value; science versus humanities; practice versus theory; rational versus irrational. Put simply, I came to realise that the discourse of organ donation/transplantation and the experience of the participants as lived were seriously out of kilter. Attention to this disparity became an important focus of my evolving thesis.

With my interpretation of the participants' experiences occuring in tandem with other interpretations of various philosophical, sociological and cultural theory texts, I developed an understanding that this disparity exists primarily because of our cultural obsession for certainty which is underpinned by our somewhat automatic deference of lived experience for expert opinion and definitions. Doubt and uncertainty are distressing conditions from which humankind passionately desires release (Storr 1997, p.174). I came to believe that because of a predominant existential fear of death, we as a culture have nurtured the development of a highly rationalistic, utilitarian technology that deems to afford us unlimited power, but at a considerable moral expense. Subsequently, all questions for my thesis were developed and persued under the rubric of this central contention.

The second issue identified from the analysis of the national study is somewhat more complex and multifaceted. Each group, although having a different story to tell, share a sense of being part of an experience over which they feel they had no control. This feeling of no control, however, is neither new nor rare. In his book *Cosmos, Chaos, and the World to Come,* the historian Cohn (1993) demonstrates how a belief that an underlying order of the cosmos will triumph over the disorder of chaos is a fundamental belief of humankind that buoys many against the overwhelming randomness of the surrounding universe. Listening to the nurses, families and doctors talk about their experiences I was taken aback with how their frustration with needing to make decisions about organ donation tends to reflect a dominant desire for certainty in most everything that we do. Despite their persistent uncertainty about brain death they felt compelled to make a decision that was so final and complete in its implications.

The participants however are not alone in their uncertainty about brain death as their moral and intellectual profundities about the presentation and diagnosis of brain death are consistent with other cultural and social inquiries into this phenomenon (Martinelli 1993; Pelletier 1993a; Ohnuki-Tierney 1994; Pearson & Zurynski 1995; Sque & Payne 1996; Pelletier-Hibbert 1998). Confusion over brain death appears to be a linchpin that connects each person's sharing of the experience. Each person`s confusion and uncertainty appears enhanced by the relative lack of choice they have in being able to halt the process of transplantation until a more informed understanding supporting acceptance of brain death can occur.

However, against this moral and intellectual uncertainty, brain death, as a narrative, is understood in this thesis as the culmination of our culture's existential angst with death and our passionate need to remove or control its presence in our lives. Fear of the unknown (with death being our most constant and uncompromising example) is critiqued throughout this thesis as supportive of advancing a technology that promises to appease these uncertainties: a technology that promises to keep us safe. It comes as no surprise then to find that implicit in each person's story (from the national study) is an expectation that accidents should be controllable and death postponed for as long as

possible. In our rush for certainty and security, the cost of such control is never truly anticipated. Biomedicine has created an ambiguity in trying to uphold or meet these expectations. The general lack of certainty felt by those who live the experience of organ donation has left many feeling as if they are 'victims' of a technology they have not chosen. It is as if the technology has failed in its promise to reduce their fears and uncertainty. Instead of feeling rewarded for being part of this 'Gift of Life', this miracle of contemporary medicine seems to have made life and death appear all the more uncertain and confusing.

Fear of uncertainty becomes a central discussion of this thesis as I argue that we have become a society governed by experts whose social contract with the rest of us seems to be one of making 'tolerable' certain attempts by science to play 'God' with our bodies. Through various avenues of genetic engineering and other biotechnologies experts attempt to inform us about how to control the bodies in which we live (Young 1989). On first impression, choice in the development of these technologies does not appear to be ours. Rarely are we given the chance to determine the need or value of these technologies. Instead, we seem to become part of the evolutionary equation of these technologies at the stage of their application. Subsequently, we always seem to be in the process of reacting and adapting to new technologies—running to catch-up with how they have been placed in our lives and how our lives are being forced to change as a consequence of their application.

Autonomous technology, however, is not a guiding theory of this thesis. Instead, organ donation and brain death are theorised in this thesis as social realities. They are understood to be practices that arise out of a totality of cultural practices and relationships and not some manifestation of independent, biological or precultural facts. As a society we conceive and shape our facts and values in particular ways according to particular relationships and activities (Fish 1979; Fiske & Schweder 1986). In particular,

for the past three hundred years, we have deferred to science[4] for wisdom and guidance about our daily lives. We have sought from science a basis for our goals and the ordering of society that can assure us some sense of certainty in a world that appears alien, hostile and ultimately beyond our control. Scientists have subsequently become like secular priests as they are perceived to be in possession of essential knowledge that can help us conduct our work and order the world in which we live.

Science and technology have become as Haraway (1991) suggests the centre of our ambivalent fantasies and nothing in the world seems able to resist the intrusion of technology into every facet of our lives. In biomedicine, practically every stage on life's way is undergoing dramatic development: artificial fertilization and transplantation; sex diagnosis (and therefore choice through abortion) and change; fetoprotein, ultrasound and amniocentisis and other diagnostic techniques for foetal abnormalities; host mothers; hormone treatments; cerebral stimulation and implantation (including remote control); spare-part surgery; international organ banks; purchasing of organs in the Third World for transplantation; cryogenesis for indefinite cold storage of ovum, sperm, and cloning, are just some of the perceived miracles of modern medicine.

In many ways, the contemporary fetishisation of technology has led to science becoming an ideology of power, a totalising world view which can produce a fatalism on the one hand, and an amenability to technological manipulation on the other (Young 1977; Haraway 1991). Responsibility for the meaning of our lives has been deferred to specialists and so our lives have become a constant effort to live according to someone else's theory and standards (Rorty 1991). The standards, methods and objectivity of science are readily accepted and expected, by the majority of people, as the models or touchstones for their meaning making of the world that surrounds them. Science and its *facts* have become the dominate partner our conversations—our 'habit of mind'. Feeling

[4] For ease of discussion, science and medicine (since they arise from the same standard method of knowledge acquisition) are used in a generic sense throughout this thesis to avoid tedious repetition of science, technology and medicine.

as if we are victims of a cold, uncaring *technocracy* is not an uncommon end point of living life according to the experts.

As Schroyer (1971, p. 300) one of Habermas' disciples argues:

> *... more and more spheres of decision-making are being seen in a technological and scientific way, requiring information and instrumental strategies formulated by experts, and are therefore removed from political and moral debate.*

Mystified and manipulated by a promise of safety and control we have learned to defer our decision making to experts which tends to nurture a climate of reaction rather than proaction toward science and its progress.

However, an alternative, more affirmative perspective is available. Notwithstanding the obvious sense of helplessness and uncertainty that many of the participants from the national study experienced, regarding technology as autonomous (technological determinism) is not a preferred position/interpretation of this study. Although technological determinism seems an easy way to understand the participants' position I came to realise this view as a somewhat superficial interpretation. A deeper, more critical interpretation did however evolve as I continued to interpret and understand the surrounding social and cultural context of organ donation/transplantation. Working with a belief that the changes biomedicine imparts in our everyday lives and institutions are ultimately negotiable and alterable by us if diligent effort is placed into listening to stories of peoples' experiences is one way of achieving a more positive perspective. Mutual, collaborative change through the realisation and acceptance of our agency in the making of our social realities is the emphasis of this inquiry's purpose and epistemological orientation. Being seen as active participants in the creation of our social realities makes our responsibility to create institutions that promote proaction rather than reaction more obvious.

To begin to free ourselves from a fatalistic (victimhood) approach to technology we need first to demystify the specious objectivity that dominates positive science and results in the treatment of human beings as things, completely assimilable to the 'laws of

nature'. One way to overcome a constant deference to experts for the truth about our lives is to get into the habit of, *'subjecting every fetishised matter to the glaring light of naive questions, which are notoriously the most testing, the most promising and the most far-reaching'* (Reich 1933, p.44). I witnessed that such naive questioning is apparent in the present tense expression of the participants' conversations about their experiences. I learned that what shines through in these conversations is not past versions and rhetoric of other peoples' interpretations but rather potential alternate views about the organ donation/transplantation (informed by past experiences) from which we can all learn.

An effort of this thesis, therefore, is not to extend an alienation and denial of transplantation technologies. Indeed, these technologies bring an end to suffering for many. The effort instead is to create a space for further meaning making and understanding of the participants' (in particular the parents) experiences which are intricately wedded with these technologies. In doing so we can hopefully broaden our understanding of what it means to be a parent and give consent to the organ donation of a brain dead, heart-beating child within a technologically dominant world.

A Critical Reflection Informed by the Participants' Stories from the National Study

That transplantation technology is not an autonomous event which occurs because it is part of some natural accretion of scientific facts has proven to be a dominant idea influencing my interpretations for this thesis. I am supported in this position by many scholars (notibly Kuhn 1970) who have taken issue with a belief in the objective, neutral stance of science and its facts. Such critique has encouraged within the academy an alternate view to technological determinism. That science and its products cannot be defined in terms of immutable truths as if they are somehow separate from our everyday lives is reflective of this position. Science is not considered to be value neutral. Instead, science is realised as the product of our social relations, wants and desires. As Basalla (1988, p.14) proclaims:

> *... human technology is a material manifestation of the various ways*[in which] *men and women throughout time have chosen to define and pursue existence ... technology is thus an integral part*

> *of the history of human aspirations and the plethora of made things are a product of human minds replete with fantasies, longings, wants, and desires.*

For the past half century science and its products have been critiqued to reflect a specific set of societal assumptions and values (Marcuse 1964b; Habermas 1969). The technology of organ transplantation can be understood as just another example of this ongoing critique. However, belief in the human ability to control nature, prolong life and avert death has been and remains one of the central tenets of modern science and Western society as a whole. Consequently, the assumption that biotechnology exists, by definition, to meet and avenge human suffering and premature death makes its ever advancing penetration into the finer workings and mysteries of our bodies all the more acceptable and unchallenged by the majority of people.

The biotechnology of transplantation is understood in this thesis not to be outside our social relationships but deeply embedded in the desires and aspirations of our culture. As Koenig (1988, p. 465-7) argues:

> *Images of dramatic technological progress dominate our understanding of modern medicine ... As a culture we are fascinated with the details of medicine's most recent miraculous advance. The limits of technology seem boundless. Although increasingly aware that progress sometimes occurs at a significant cost, both social and economic, we wait eagerly news of the latest test-tube baby or liver transplant ... Clearly, the use of technology cannot be independent of its social context. Especially in the case of medical technology. with its potential for evoking strong feelings carrying potent symbolic references to the body, life and death, the relationship between machine as object and its user is multifaceted.*

The participants are part of a society and culture that has nurtured, however unwittingly, the technological manipulation of their lives. The choices they make about the comfort and certainty/safety of their daily lives are implicit in presenting them with the moral uncertainties they face in their present experience. Medical science and technology, bear the brunt of the participants' sense of victimhood. Yet science is not to blame—it has been wonderfully successful, given the task set.

We as a society do have a choice about what technology survives and what becomes either appropriately valued or strategically forgotten. Hence, despite the uncertainty and confusion the participants convey in their stories what cannot be forgotten is that, we have all capitulated, however unwittingly, in biomedicine's habitual focus on the control and repair of individual bodies and body parts. Because of a deeply sedimented desire to reduce human suffering and premature death we have celebrated the biomedical successes and granted medicine almost unlimited access to our bodies. An unforseen consequence of these choices is that:

> *In a technologically biased society, the assumption is generally made that a new technology will be an improvement, and the onus of proof is more strictly put on those who doubt its usefulness than on those who claim its benefits* (Bates & Linder-Pelz 1987, p. 119).

Given authority and free reign over our bodies, all aspects of life from birth to death have been conceptualised and theorised by biomedicine as essentially biological events to be managed. Biomedical rhetoric and discourse about our bodies have increasingly replaced the personal theories we develop as we live from day to day. The body has been readily theorised as an aggregation of natural facts amendable to rational experimentation and manipulation. In the case of modern biology it is common for causes of illness and disease to be regarded as separate, independent entities, assumed to be at a finite individual level; whether as an individual gene or a defective organ. When disease and illness is explained as being caused by single, isolatable phenomena the desired outcomes can then appear clear and easily achievable with the successes more forthcoming.

Surgery is arguably the most important 'healing' technique amidst this causative theory of biomedicine (Ohnuki-Tierney 1994). Transplantation surgery therefore—with its promise of 'new' life—is at the pinnacle of the healing promise of medicine and appreciated by the majority of people as such. Despite our general support and appreciation for the practice of medicine, concern and consternation is present and forthcoming. The confusion and uncertainty that the participants' of this study experienced encourages a necessary caution and want for critical reflection about what

seems to be an unquestioning faith in the experts. Too often are we willing to forgo our embodied understandings that arise from our personal experiences if they conflict with the opinion of experts. In support of this notion Mendelsohn's (1981, p. 23) calls for a 'reasonable scepticism' with regards to the sweeping claims that biomedicine makes to our understandings of the human body:

> *[M]odern medicine gives daily evidence of its ability to challenge death and promote health and longevity. Today's science probes the very boundaries of matter and the most intimate conditions of life. An aura of rationality and promise seems to surround these achievements (and potentialities) of the new worlds of science, technology and medicine ... Yet in the face of achievements undreamed of even by Utopians ... serious questions have come to be asked about the place of science and technology in our societies ... some of the questions have been present from the very beginnings of the seventeenth-century scientific revolution, while other doubts are more recent and more clearly tied to explicit modes of use or misuse of modern knowledge and techniques* (p. 22).

Mendelsohn (1981) argues that even though the prejudice of science for single or primary causes has received sharp and just criticism over the past decades, positivism remains for many scientists their prefered ideal. With this cautionary note in mind and influenced by the two central issues raised from interpretation of the participants' stories, I was encouraged about the value and significance of interpretive research methodologies for understanding the parents' experiences. I became firmer in my belief that listening to the stories of people who participate and have experience of these new technologies can help raise our understandings about the immediate and long term implications of these technologies in our lives. With these personal experiences informing our decisions we can inturn develop an informed critique of transplantation technology and the subsequent practices that support its use/application.

Of particular importance to me in this research is the way each participant's story indicates how organ transplantation is radically challenging the way we understand and relate to our bodies. Through listening and attempting to understand the descriptions of their experiences these challenges are realised not just as abstract theories and definitions, but as immediate responses with strong afffective power. Any person who

attempts to cloak these emotions through hiding behind well defined and rationalised explanations of the practice is risking the promotion of what Kass (1992, p. 44) proposes is:

> *... a coarsening of our sensibilities and attitudes ... there is a sad irony in our biomedical project ... We expend enormous energy and vast sums of money to preserve and prolong life, but in the process our embodied life is stripped of its gravity and much of its dignity. This is, in a word, progress as tragedy.*

Kass adds:

> *... we are embarked on a journey, we cannot go back. Yet we are increasingly troubled by the growing awareness that there is neither a natural nor rational place to stop. Precedent justifies extension, so does rational calculation; we are in a warm bath that warms up so imperceptibly that we don't know when to scream* (p.43).

Kass (1992) helps to remind us about the importance of transcending the rhetoric of expert opinion and theory in order to listen and value the stories that people have to share about their experiences. Through taking time to listen to the rich and complex descriptions of peoples experiences nurses are granted invaluable insight into the effect and significance of their daily practice and policies. Listening to questions arising from peoples' experiences with illness and various medical technologies can help nurses make proactive rather than reactive policy decisions and plans.

Technology is valuable and helps to potentiate our lives so long as choices regarding its application are continuously informed by the rich data arising from the stories people have to tell about its effect(s) in their lives. The theories of Habermas (1969) and Marcuse (1964a) are supported in this thesis as they encourage an understanding that there is nothing inherently wrong with the development and application of medical technology since the endeavour is ultimately intended to meet universal human needs and reduce human suffering. However, while their theories promote this positive attitude, a mindfulness of technological progress is also encouraged. Scientific truths are not considered to be the outcome of a completely rational, utilitarian succession of scientific facts. Instead, the influence of our choices on the creation of a need and setting

of an agenda for scientific progress is upheld. Acknowledging the influence that human choice has on the progress of technology is important motif of their work because without it the interests of 'powerful elites' can be veiled and the essential open debate about technologies effect on our daily lives can surreptitiously disappear from the public sphere (Marcuse 1964b). Technological determinism is readily promoted and accepted in such a climate as our agency or ability to choose otherwise appears distressingly absent.

In this thesis I attempt to raise the ontological primacy of donor parents' experiences to challenge the rhetoric of the professional debate. In doing so it is hoped that a re-engagement and resensitisation of our emotions will be encouraged to what at times is realised as nothing more than a utilitarian, rational advance of biomedicine's social mandate to control nature and avert death. As Koenig (1988, p. 490) suggests:

> *Since high technology medicine seems to be a direct embodiment of scientific knowledge, we wish to believe that the application of these new machines to patients is objectively determined, comprehensible to all ...* [yet] *even in the seemingly rational world of medical science one cannot ignore the social realm—encompassing the highly subjective experiences of participants in medical innovation. A full understanding of the relentless advance of medical technology requires knowledge of the social world in which medical machinery is developed and used. [because] As routinisation occurs and a new meaning for a medical technique solidifies, policy options narrow.*

After listening to donor families, nurses and doctors from the national study speak about their experience I have learned that organ donation/transplantation, this miracle of biomedical technology, places into question many of our assumed beliefs about life and death, personhood and embodiment that defy easy interpretation. Each of these issue will be discussed in further detail under the following five headings:

- The Remaking of Death: New Death—New Lives
- Tinkering at the Boundary Between Life and Death
- Shifting Personhood from Embodiment to Consciousness

- The Remaking of Death into a 'Gift of Life'
- Crossing the Boundary Between Self and Other

In the following sections, I discuss these five issues in more detail from the hope that such discussions will help to situate further, for each person who reads this thesis, my interpretations of the parents' experiences. In doing so I intend to make explicit my contention that the parents' experiences are not easily defined as a consequence of a technological determinism of which they are victims. Rather, their experiences are understood here to be the result of a complex interplay of social relations of which they are intimate players through the choices they have and do make.

The Remaking of Death: New Death—New Lives

Without a doubt, organ transplantation can give rise to perplexing moral, spiritual, psychological dilemmas about life and death. The clinical inception of brain death, which at first was promoted as a simple refashioning of an outmoded romantic definition of death (Veatch 1975) has developed into a complex thirty-year ideological battle regarding fundamental notions of the meaning of death, indeed life itself, and what it is to be human. The heart of the complexity is nestled into the way that the *life* of the heart beating donor has become a valuable community resource. As a valuable community resource the donor's life and death have become a moral hurdle for donor families to overcome before they can consent to donate their loved one's organs:

> It's I mean it's all, it's difficult, the whole business of organ donation is a very emotive thing. Clearly from a medical point of view, it's a good thing to get people off dialysis and not necessarily all the other types of organ donation are things that I think are always wonderful. But a part of that is that it's a learning process with the whole business as well as time goes by. And you wonder about an alcoholic who's destroyed their liver and who then gets a new liver and then destroys it with alcohol. You sort of think well is this actually a sensible use of resources? But it's very hard to make those judgements so you sort of go ahead with supporting the whole thing. I, as a personal thing, I have a driver's licence which doesn't have the organ donation box ticked. I have talked about it with my wife and I've said basically to do whatever she feels comfortable with. If my wife was brain injured, I don't know what I'd do. But as you say, it's like at the moment of grief, you don't know, do you?...Yeah and I mean even thinking about it, it could be like a day beforehand I would probably agree to her being an

> organ donor. But it's not clear cut in my mind (Doctor L/ p. 13: 4-22).

This redefining of death, although it concerns every single human being, predominately occurs silently and without reference to public concerns or sensibilities. Giving death a new persona has primarily been an isolated event for medicine which occured as if it were a consequence of some natural evolution toward unravelling the biological facts about life and death. For the majority of public, however, death transcends the mere physical demise of the individual. Death is considered to be far more than a simple biological fact (Aries 1975; Adams 1997). This lack of acknowledgement for the fundamental cultural implications and assumptions about death is not surprising since the medicine, on the whole, tend to regard death as a biological, precultural fact to be managed and manipulated by an ever advancing technology.

Despite the definition of brain death being proclaimed by the medical profession to be the irreversible loss of all brain function, a corresponding, widely accepted narrative explaining exactly why brain dead patients are dead is lacking (Youngner 1994). The general public are still attempting to accept this new death while still firmly immersed in the meanings and significance of earlier definitions. Not only is there uncertainty amongst the public, the 'experts' too are unable to achieve any firm consensus:

> *[D]espite apparently authoritative statements, the medical community does not have a single, clearly defined, and universally applied standard for defining and diagnosing brain death. The diagnosis is, indeed, a result of negotiation among various interested parties in context specific interactions-the recipient of an organ and his/her family, transplant surgeons in need of organs, third-party payers unwilling to pay for prolonged intensive care of a dead brain in a live body-in which the status of the donor as a potentially living entity works against the interests of all the others* (Raper & Fisher 1995, p. 17).

Clearly, uncertainties and inconsistencies such as these become disconcerting for a public under pressure to value the heroics of transplantation technology and also for those who have consented and are now living in a state of constant debate and contention.

To date, the necessary evolution of norms and rituals to support the presence and practice of this new death have not occurred. The debate about organ transplantation and its implication for the moral and ethical foundations of what it is to be alive and human has remained predominately a professional matter. The public are mainly showered by media reports of the lives saved and future hopes and dreams made ripe by another successful transplantation. The ambiguities that transplantation practice bring to our understandings about our mortality remain silent amidst a media and public imagination more focused on the lives saved than on the donor's death and the family's loss.

Unknown to the majority of people remains the ambiguity that parents and relatives, like Sarah[5], face in having to consider her son dead when she can still feel the warmth of his skin, hear his breath and see the beat of his heart. Silent remains the confusion Sarah feels when she buries her son feeling that part of David continues to live on in another. A confusion that can be further concretised when she receives letters from the transplant coordinator and possibly the recipients of David's organs:

> No I hadn't thought he'd died, no, no I hadn't, that hadn't crossed my mind. Do you know what I mean? I don't know when he died, I don't know when he died. I haven't even looked at the point on the file that says time of death, because there is no point in looking up that. Because when did he die? Did he die when they told me he was brain dead? Was he brain dead at about 10 past 12? He certainly was, probably in the same state at that very early hour in the morning. That was 6 when he [the doctor] came back on duty because he was going to do the last test then. Presumably those last tests then would have maybe been the same. Although this was the one later on. When, after they measured him and the temperature going up and his eyes flickered at one stage during the night. So at the time, there wasn't, it was the same sort of thing as the temperature and the measuring ... And I was actually standing at the bedside when it happened, and I thought Oh that's good, that's good, oh that's good, oh good, oh that's good. His eyes flickered, that's good. But I didn't think about that for weeks later. So when did he die? Well in fact I don't know whether he is actually dead now. That sounds like a pathological thing to say. But in fact, the reality of it is that he isn't really dead, because he's actually alive in all these other people. There could be pathologists who will, or psychologists or psychiatrists who would say I'm

[5] Sarah's story found in the Prologue of this thesis, although fictitious, is one constructed from my reflections on the stories of the five parents who consented to be involved in this research.

> crazy. But they don't know what I mean. They don't know what it means to have bits of someone alive somewhere else. So in fact how, is he dead? (Daniel/ p. 42: 23-24; p. 43: 1-22).

Tinkering at the Boundary between Life and Death

The participants' stories also made apparent to me many of the ways that advances in biotechnology are radically altering the way we relate to ourselves and each other:

> ... they are a person. Even though we say that they are dead, they are still a person. Like just because we have this, like we do do these tests and it says this is when you're dead, that's what we say in the medical field, but if they, these people that are around her, they still see her lying there alive. I mean they've got to come to terms with all that, like yeah the machine is making her chest go up and down, and it's very hard. They're pink and they look normal and usually they've got no other, no injuries because they're either asthmatics or a cerebral bleed ... They [the family] sort of say "Well, how come? She looks so good" or "She's this or She's that" and you are able to sort of say "Well the part, the conscious part of her brain is not" you know. And you try and make it very simple without sort of saying stuff like "Coma", which they think that you're going to wake up from. And yes, it's being very careful about the words that you use. And they will say, use the words that are on the telly and in the media and you say "No". And it's unfortunate you know, you may see things about where they may say that people, they use the words brain dead. And people say "Oh but you wake up from that". People will ask those sorts of questions and you say "No" (Nurse 23/ p. 9: 6-21; p. 10: 1-4).

With the history of biomedicine driven by a social mandate to release humankind from suffering and premature death the subsequent development of advanced life support equipment and its accompanying plethora of pharmaceuticals that can mimic the intricate functioning of the human body's biochemistry has been its celebrated success. The price of this success though has been the occurrence of a 'suspended' existence that achieves no consensus as to whether it is life or death (Farrell & Levin 1993; Truog 1997; Evanisko, Beasley, Capossela, Cosgrove, Light, Mellor, Poretsky & McNamara 1998).

In a generation where cryogenics and advanced life support are the old successes of biomedicine, medical science has reached a point where it can delay our deaths, it would appear, indefinitely. In reaching this point however, medicine has created a paradox: a

paradox of *the living dead.* I came to understand heart beating donors, donor families and recipients as '*products*' of a choice about biomedical technology that has advanced to a juncture where the anticipated boundary between life and death has become unclear. This confusion however is not new.

In 1968, the ad hoc committee of the Harvard Medical School, convened to try and determine once and for all what this *suspended life* is and how it should be managed. The committee sought a definition that would provide doctors with the legal sanctity to terminate these suspended existences. They sought a means to avoid the '*unnecessary indignity of ventilating corpses'* until the patient's asystole provided the criteria considered acceptable for the diagnosis of death (Daar 1992. p. 2207). Asystole is not however the inevitable outcome of many brain dead patients. Given that intensive care units have become analogous to *'surrogate brainstems'* (Truog 1997. p. 30) asystole is more the result of a decision; a pragmatic choice that has far more to do with economic rationalism, the availability of beds and quality of life questions than a 'natural' progression of the patient's death. Hence, the redefining of death to include the criteria of brain death provides a necessary platform from which these decisions could and can be made.

In its deliberations the committee (1968) gives two reasons for trying to establish a clearer definition of death:

- that increased burdens on patients, families, and hospital resources were caused by improvements in resuscitative and support measures, making the old definition of cardiopulmonary death obsolete.

- that obsolete criteria for the definition of death led to controversy and reduced success in attempts to obtain organs for transplantation.

With the latter criteria as a constant reminder, the use of the diagnosis: brain death, has been intimately linked, from its official announcement, with transplantation technology and the increasing need for *fresh* organs (Futterman 1995).

Shifting Personhood from Embodiment to Consciousness

Given that biomedicine's heritage is undeniably steeped in an enlightenment philosophy which holds rationality as the most important criterion for humanness, the redefining of death as the loss of brain function seems at best predestined. With the brain identified as the seat of consciousness and rational thought, a person ceases to exist when their brain function is tested and proved to be irreversibly lost (Hassaballah 1996; Truog 1997). Having the definition of brain death governed by the physiological functioning of particular biological structures results in the determination of death being re-affirmed as a purely objective, clinical, precultural event. Holding faith in the rational parameters of the medical criteria of death makes life nothing more than the integration of particular structures and their biological functions (Freeman 1995). Such a determination rests on a pragmatic faith that subtly removes the moral and ethical angst so typically associated with trying to determine where personhood resides. In formulating this definition of death biomedicine strategically side steps the centuries old metaphysical debate about where the person is located and what is personhood for a more clinically expedient process of organ function assessment and diagnosis (Moussa & Shannon 1992).

Biomedicine's redefining of death as brain death is realised and argued by many scholars (Moussa and Shannon 1992; Ohnuki-Tierney 1994; Truog 1997) as a return to the mind-body dualism of Descartes where the examined life is the only life considered significant and where the body is seen as nothing more than an appendage to the brain. Within this rationalist tradition the body has simply become an object that is easily manipulated and maintained by biomedical technology.

> ... I had no problem at all with the concept of giving, donating his organs or with the whole procedure. But the ambiguity of having a patient on a ventilator with all the monitors still beeping, with 14 other patients who are still alive and ... just basically the difficulty in knowing quite how to proceed. Because you had a patient that you knew was effectively, clinically dead but you had to maintain a semblance of life in order to preserve organ function enough, well enough to actually make it worthwhile. So I'm still getting the same sorts of queries from the nursing staff as to the ongoing care, if you like, of this patient. But knowing all the time that they were actually dead. And that was rather bizarre. Um and sort of a conflict, I didn't know quite how to proceed, in terms of largely ignoring the requests for the usual ICU interventions in regards monitoring changes and so forth or actually getting aggressively

> involved. In the end, I sort of took the middle ground. So apart from that, everything went smoothly. The patient was taken down to theatre at the prescribed time and I gather it was a successful procedure, in as much as his heart went to a recipient in Melbourne and other organs were, were salvaged. So um he, it was a worthwhile exercise (Doctor F/ p. 1: 6-20).

Death as brain death reinforces the preeminence of the brain above all other body parts and the notion of personhood as an embodied intelligence: a notion of the body as a way of knowing and as integrated with the mind is further contested (Scheper-Huges & Lock 1987; Benner & Wrubel 1989; Moussa and Shannon 1992; Holmes 1994). When the body is understood as nothing more than an object, the assumption that the existential seat of personhood is the simple presence of a living body is contested and not understood as being continuous with the person. Personhood is relegated back to being the idle musings of metaphysics or psychotherapy while death of the person has been re-defined as a consequence of the irreversible loss of the whole brain function—an event which medicine assures us that it diagnoses with utmost precision:

> And I explain, I don't explain the actual tests that I do, but I explain that it is quite a rigid thing, a rigid program, protocol that we follow and at the end of it, I'm absolutely sure that I'm right. But to be sure that I'm sure, I get another doctor to do it in 2 hours time. And people find that quite sort of heartening that there's, they don't want a mistake. And so if you make a big issue of the fact that you don't make mistakes, you know that's what you get paid for, that's what you're good at, that seems to make it easier (Doctor E/ p. 2: 2-8).

The Remaking of Death into a Gift of Life

Engaging in this national study and listening to the choices that each person needed to make made me realise the complex social responsibility that organ donation has become:

> But I always, after I've said that they're dead, I run through the line about you know, "This is a terrible tragedy and nothing can ever replace the loss that you've suffered, but the one chance that we have of having something good from this horrible thing that's happened to you, is if through his or her death, there is the opportunity for somebody else to live" ... And so you sort of say Well there are people who are dying because they don't have a functioning heart, kidneys or whatever and you have the opportunity, well your relative has the opportunity to give that gift now you know, to this other person (Doctor E/ p. 4: 18-21; p. 5: 1-4).

Organ donation is presented to the public as the greatest *gift* that one human can give to another (Loewy 1996). Many transplant surgeons make obvious the social responsibility they believe organ donation 'to be' by referring in print and on television to the 'alarming number of patients who die waiting for organs' and by describing the situation as 'a public health crisis' in which we are all implicit (Randall 1991). The following story is from a public health education pamphlet and is typical of the donor lobby's effort to establish the notion of the *gift of life*. They hope to increase the donor rates by appealing to a person's social conscience to help their fellow human being(s):

> *[B]rian's heart went to a 35 year-old father of two. The liver forestalled death in a 20 year-old college student. One of Brian's kidneys went to a teacher who had been on dialysis for five years; the other kidney went to a young wife and mother of three youngsters. Brian's eyes were removed so that his corneas could restore sight to two blind people. His donated skin helped save the life of a severely burned baby. Bone from Brian's legs and hips was removed so that a 14 year-old boy would not have to undergo amputation of a leg due to bone cancer and so that another child's severely deformed face could be reconstructed by a plastic surgeon. From this single tragedy sprung new life, new health, and new hope for nine of Brian's fellow humans and ... their families* (cited in Ohnuki-Tierney, 1994, p. 236).

So powerful is the 'gift of life' made, that choice is distressingly absent to those who are asked to consent (Tymstra, Heyink, Prium & Slooff 1992; Robertson-Malt 1998). Through brain death being inextricably linked to organ donation, death has become a intricate exchange of lives. The death of a potential organ donor is no longer death of just one person. In choosing not to donate, families can labour under the guilt of knowing that the death they have chosen for their loved one may now mark the death of many.

The stories from the national study made me question whether or not the current process of organ donation is appropriately portrayed as a gift. A critical element of gift giving, as identified by Mauss (1969), is the interdependence of people in valued obligation. Organ donation ostensibly lacks the essential ingredient of gift giving which is the development and maintenance of a meaningful social relationship. The current policies of not disclosing the donor or recipient's identity has fostered an enormous bureaucracy with a 'gatekeeping' mentality that actively dissuades any personal contact

between donor families and recipients (Sque and Payne 1996; Robertson-Malt 1998). It came as no surprise to me during the analysis of the national study to hear donor families feeling forgotten and used in the aftermath of their gift, when their need to make contact with the recipients, if only to see the life(s) that has been saved, are not encouraged nor forthcoming (Pelletier 1993(b); Sque & Payne 1994; Pearson, Hickson, Robertson-Malt, Greenwood & Metcalf 1996). These emotions of disappointment and anger however remain silent in a society where organ donation is so tightly wrapped in the rhetoric of the gift that altruism: an act of charity, has become the preferred public image of the donor families consent (Petrin & Koutsogiannopoulos 1991; Pirrie 1995; Robertson-Malt 1998).

Seeing the donor families silenced by a higher ideal of altruism is not surprising as we exist within a society that has been characterised as having a 'fetishization' of life (Illich 1990). With the economic advantages of transplantation being continuously argued, the social responsibility implicit in the request to donate makes the volition to consent nothing short of a social obligation. As Fox and Swazey (1992) write the 'tyranny' of the donor families gift is inevitable as the act of donation can never be mistaken as a value-free endeavor. Since its very inception, at the very minimum, altrusim has been implicit in the practices of organ donation; and altruism has a social face of grace and humility, never one of expectation or regret.

The current drive therefore to *maximise* the availability of organs appears to be primarily grounded in a utilitarian assumption that organs must be made available for the *greater good* (Prottas 1983; FitzGerald 1990; Redfern 1997). Included in this assumption is a major debate about whether or not the buying and selling of organs should be established (Kass 1992; Rapaport 1993; Rowinski, Walaszewski, Madej, Szmidt & Lao 1993). No longer is the debate dominated by moral and ethical concerns about whether or not transplantation should take place. We seem to be traversing a passage that if it is technically possible then it is morally negotiable. It is as if the social good of transplantation has been accepted and issues about the organisation and

application of the process have now become the primary concern (Norris 1990; Northrop 1997).

Questions such as, 'What is the most appropriate way to approach the public and make contact with potential donors and their families?' (Miranda 1995; Pearson, Bazeley, Spencer-Plane, Chapman & Robertson 1995; Somerville 1985) and 'Is it morally and ethically appropriate to adopt a market model for obtaining organs?' are displacing the moral and ethical concerns about the very practice of organ transplantation (Chadwick 1991; Northrop 1997). Should the body be considered a form of property to be sold is another question that keeps the debate actively reworking previously held assumptions about our body's significance and value (Andrews 1986). As such debates seem to do more to maintain the distance between recipient and donors than help to establish their relationship, the impersonalisation of the organ donation process continues, and resistance to notions about the commodification of human body parts slowly declines (Daar 1992). And so the bath, as Kass (1992, p. 44) suggests, keeps warming inperceptibly and so we no longer know when to scream.

Crossing the Boundaries Between Self and Other

Through transplantation technology making the exchange of body parts an acceptable and routine event, the notion of 'me' or 'self'—the sense of personhood as experienced in the uniqueness of each body is challenged (Moussa and Shannon 1992; Ohnuki-Tierney 1994). The stories from the national study emphasise how the self/other distinction is transgressed in the most immediate and psychologically powerful way with transplantation technology. Influenced by the theoretical musings of psychology and sociology, the 'I' has been realised as that which is experienced through the lived body and constructed through our relationships with others and their physical presence (Turner 1992). Hence, transplant technology carried to its logical extremes or conclusion, can lead to the creation of a 'hybrid human' as the recipient can become a composite being of some artificial organs made in a laboratory, plus organs procured from another human or nonhuman animal (Mostyn 1994; Ohnuki-Tierney 1994; NHMRC 1996).

Similarly, the uniqueness of each person as signatured in every cell of their body is an obstacle that biomedicine has to overcome before organ transplantation can be hailed a success (Lorber 1994). The biomedical specialty of cellular immunology evolved originally from transplantation technology's need to develop a drug such as Cyclosporin that suppresses the 'self's' recognition of self (Starzl & Fung 1990; Lorber 1994). Without this medication, the recipient rejects the donated organ and the transplant is a failure. With the success of transplantation being largely dependent upon immunosuppressant drugs such as Cyclosporin, all those involved are reminded that the amalgamation of self and other is never complete, and that this transgression of boundaries is achieved only through deliberate technological wizardry and masking. The daily medication of Cyclosporin can leave recipients living with the constant reminder that they have *other* inside them helping to keep them alive and if their body was to recognise *other* they would die.

With all these issues at hand I believe that assumed knowledge will never be sufficient to guide policies of practice as we are, like Sarah was before her experience, relatively unfamliar with this new technologically manipulated death. The dramatic manipulations of life and death that brain death and organ transplantation present demands a need for greater understanding about their effects on our day-to-day lives as they are more than the simple demise of a physical body. 'Who' has died has far more significance than 'what' has died. The who of the donor as known and loved by their family can never be found in the *functions* of biological structures alone. The 'who' that we are encompasses every intricate aspect of our physiology and more. The rationalist tradition is not universal and for many individuals the identity of a person is more than consciousness, it is at minimum, embodied: a state of being where the person is as complex as the structure of a Deoxyribonucleic Acid (DNA) molecule and as profound as their smile. Each participant's story establishes death of a person as being far more than a simple biological definition. Instead, their stories explicate how death of a person is a complex social reality which is steeped in a history and culture so diffuse and multifaceted that consensus about its origin or location is rarely achieved.

Listening to the stories of people who live through these events challenges our assummed knowledge about life, death, embodiment, self and other and can place nursing in a better position to question the value and significance of current practice and policy. Reflection on these challenges can help us to modify our acceptance of biomedicine's ongoing application of new technologies, and guide us in the development of ways to support all those who become entangled in these practices.

Purpose for the study

> *We, each of us, injure the humanity of our fellow suffers each time we fail to privilege their voice, their experience*
>
> (Kleinman & Kleinman)

Clearly this inquiry concerns the need to generate understandings about organ donation/transplantation that are informed by the personal stories of those who live the experience. In reflecting on the purpose for this research I am encouraged by Benner & Wrubel (1989) who consider that the very effort to understanding a person's interpretation of their experience is, in itself, a form of healing. Quite simply, the sharing that arises comes from truly listening and conversing with the story people have to tell about their experiences can often help them to overcome any feelings of alienation and loss of self-understanding and social integration that they may be experiencing. In turn, the rich, contextually pertinent knowledge arising from the analysis of these stories can help inform the health care practices and policies that surround their care.

I posit that since nurses work amidst a technology that dramatically challenges one's tacit understandings about life and death, they have a moral responsibility as a caring profession to acknowledge these challenges and so not assume to know what the families are experiencing. With a goal of nursing practice being to assist people to develop potential that is uniquely theirs, research that will give practitioners information to enhance the depth and complexity of their understandings about an individual's experiences is needed. As Williams (cited in Rosenberg 1978) urges, we have got to go

see, hear and listen to the people we care for in order to let them be our guides about practice:

> *We've got to learn to stop ourselves; we've got to learn to surrender to 'them'—to our patients. They have stories to tell, too—lines of poetry in them; bad dreams and good ones; pictures to give us—of their wounds, and their smiles, and the deep worry-lines on their faces* (p.8).

My primary concern is that as a social group, donor families are praised for their generosity and altruism in their *gift of life;* yet as individuals the loss they experience remains essentially unacknowledged. The current need then, is not to try and stop organ donation until we as a society *catch up,* because this retreat neither can nor ever could happen. We, as a society, have grown to accept that biomedical technology's blinding pace into the unknown future will always present us with ethical questions and dilemmas.

Donor parents are an essential part of the organ donor experience whose stories need to be heard without fear that they will dampen an already fragile public support of organ donation. Yet, in the past, those who had doubts about the bold certainty of the transplantation technology had to struggle to find a suitable language with which to articulate their discomfort. Any voice that tried to question the epistemological grounds on which medicine (science) determines death is often heard as irrational since comparatively speaking their questions appear steeped in a language which is ladened with emotional adjectives. Nevertheless, donor parents' stories provide a social, human face to a debate that is otherwise predominately clinical and devoid of emotion. Consequently, for the benefit of all concerned their personal stories must not get lost amidst the capacious glorifications that serve to shield the technology of organ donation/transplantation from rigorous critique.

Conclusion

Consenting to organ donation of a heart-beating brain dead child is a messy, confusing and puzzling experience that demands informed public contemplation of all the issues involved. Rather than silenced as problematic and detrimental to a greater good their

stories need to become a visible part of the conversation we as a society are having about organ donation. Research needs to support those in current practice to prise open a space for the donor parents' voices. This space should not be defined as too emotive to be informative, but instead valued for its depth and clarity of insight into the worth and success of our current practice and policies. These perspectives, unearthed through donor families stories, will challenge and raise necessary questions to confront the austere, shiny rhetoric of much of the current reasoning about organ donation/transplantation. In doing so we can possibly begin to redress some of the disparities identified in the national study.

Having drawn a close to this introductory chapter the remainder of this thesis is concerned with the interpretive inquiry into the lived experience of donor parents consenting to the donation of their brain dead, heart-beating, child's organs. It is my hope that the interpretations arising from this study will provide clinicians with the necessary information/insight to create a space for the voicing of the donor parents experiences. An overview of each chapter follows this discussion and concludes this introduction to the thesis.

Overview of the Thesis

Chapter One introduced the research and makes explicit that the subsequent interpretations of this thesis are primarily informed by my involvement in the national study. Quite clearly, my involvement in the national study stimulated in me a critical awareness of the cultural and social relationships that help to shape the practices of organ donation/transplantation in our society. I convey in this chapter my understanding of the participants' sense of being lost amidst a technological experience that they feel they have no control over. I discuss how such a situation can nurture a culture of reaction rather than proaction toward the insidious nature of technology and its effects both on and in our daily lives. I identify however my determination to be affirmative and therefore proactive in my philosophical, hence methodological, approach to understanding the parents' disparate relationships with the biotechnology that is so much a part of their experience to be understood.

Chapter Two is primarily concerned with a discussion about methodology and closely adheres to FitzGerald's (1995) comment about methodology which is that:

> *the term methodology is derived from the Greek 'methodos', meaning pursuit of knowledge or orderly mode of investigation. It is a combination of meta, meaning 'nature of a higher order' and hodos, meaning 'way'. In modern usage 'method' denotes a systematic way of obtaining an object. 'Ology' derives from the Greek noun logos for 'word', meaing 'discourse or speech surrounding a particular subject'. In modern usage methodology denotes the study of method* (p. 48).

My methodology chapter contends with the *why* of *how* I develop an understanding of the parents' experiences. Chapter Two begins with an overview of the study design and I discuss the basic ontological and epistemological tenets of how I question and understand the donor parents' experiences. This is followed by a more in-depth discussion of the philosophical underpinnings of these tenets. Although Heidegger and Gadamer primarily inform my philosophical position of inquiry this is not a phenomenological study in the traditional sense of the term. The phenomenologists' work is complimented by equal reference to social constructionist scholars in particular Rorty (1980, 1982, 1989, 1991), Haraway (1991) and Shotter (1990, 1993, 1995). This chapter therefore attempts to establish this thesis as a piece of interpretive research *informed* by theoretical positions of numerous scholars.

The framework of discussion for the methodology begins and revolves around beliefs about how we question experience and the implicit role that I see the language of our relationships has to play in generating our understandings about this experience. Although Heidegger's magnum opus *Being and Time* (1962) underpins a significant portion of this discussion my preference and use is for Heidegger's latter works[6]. It is in his latter years, post *Being and Time* and especially with *Poetry, Language, Thought* that Heidegger attends greater emphasis to hermeneutics and the role that language plays

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[6] Heidegger's latter works include titles such as, *Poetry, Language; Thought (1971); What Is Metaphysics (1965); The Way to Language (1971); Letters on Humanism (1976).* Critique of Heidegger's scholarship is commonly viewed as either pre or post the 'linguistic turn'. Despite there being no consensus as to when this 'turn' occured aggreement does exists as to what this turn involved.

in the making of our meaning about our experiences. My use of Heidegger's work draws primarily from this latter work while continuing to value the notions of temporality or the *event* (partial and situated) nature of understanding that *Being and Time* helps to establish.

Throughout this discussion on methodology, constant emphasis is placed on the situated dependence of our interpretations and how our past, present and future anticipations are combined for our making of meaning. With these principles in mind and considering that a central focus of this thesis is the parents' experiences of a 'new death' **Chapter Three** consists of a review of death's paradoxical stance in society as our certain uncertainty:

> *Shall I change for you this beautiful contexture of things? Death is the condition of your creation, it is a part of you; you are fleeing from your own selves. This being of yours that you enjoy is equally divided between death and life. The first day of your birth leads you toward death as toward life: The hour which gave us life led to its end.*
>
> (Seneca, Vol. I)

The critique in this chapter is intended to provide a broad overview of the social and cultural understandings of death which, when coupled with my understandings from the national study, help to further situate the parents' experiences and my interpretations of their child's death.

Chapter Four is about the *how* (method) I came to understand the parents' experiences. Considering that the *how* is primarily a hermeneutic process, this chapter begins with a necessary discussion of the hermeneutic process as an ontological act rather than epistemological rule. In this chapter the hermeneutic process is realised as dialogical: a process of truth that appears at the intersection of epistemology and ontology where knowing and being co-determine one another (Di Censo 1990). The remainder of the chapter is dedicated to explicating the phases of question and answer that occured in my dialogical process of analysis, which, when reflected upon can be understood as the method which led to the final understanding presented in Chapter Six.

Chapter Five is the interpretations of the parents' experiences which are presented in a way that explicates the hermeneutic process (in action) as a dialogical interplay between the various parts and wholes. What needs to be noted is that these stories are my interpretation/reconstructions of their experiences as told to me. Throughout this chapter a series of themes form the parts against which the parents' stories (the wholes) are interpreted and retold. The greatest portion of this chapter is dedicated to the telling of each of the parent's story as I argue that it is through the dynamic movement of the telling and retelling of these stories that meaning is made. The meaning of each parent's experiences is revealed in the retelling of their stories; shown by the way in which the language they use to communicate their experience merges with the reader's history of meaning which in turn helps to shape their descriptions into meaningful wholes.

Finally, **Chapter Six** is an understanding that I offer about the parents' experiences that has developed from my interpretations. This understanding I call a Crisis of Limitations, and attempts to draw upon and consolidate discussion of the various threads of meaning that have been raised throughout the thesis. Reference to theoretical works such as Jaspers' (1951) notion of limitations and Walker's (1997) concept of the *Archetype of Surrender* are called upon during this chapter to further explicate my understandings of the parents' experiences.

Explanation of Key Terms and Styles Used Throughout the Thesis

Key Terms

- **Being**: Is the most universal concept of Heidegger's hermeneutic phenomenology. Being does not describe an entity or thing per se but rather the existential ground of existence itself and all that this encompasses.

- **Dasein:** Is the term Heidegger gave to the existential process of Being: the living, pandimensional experience/witness of the moment.

- **Dialogical:** Is a conversational relationship that is expressed in a multitude of mediums from music to paintings.

- **Text:** Is the written translation of this dialogue.

Styles

Quotations from participants: Throughout Chapters One and Five a series of quotes appear which are taken from the participants' stories. These quotes are formatted in plain text font followed by a reference (e.g. p. 1: 2-22 the numbers following the page number are the line numbers of each formatted page) that indicates the exact location of the text within the participant's transcript.

- **Quotations from texts:** Throughout the thesis various direct quotations have been taken from scholarly texts. These quotes differ from the participants' quotations and are formatted in an italized font.

Chapter Two

Methodology

> *... the deep structure of any given language embodies a particular syntax of perception, and the extent an individual develops the deep structure of his* [sic] *native language, he simultaneously learns to construct, and thus perceive, a particular type of descriptive reality, embedded, as it were, in the language structure itself. From that momentous point on ... the structure of his language is the structure of his self and the limits of his world.*

(Ken Wilbur)

Introduction

This chapter commences with an overview of the various ontological and epistemological prejudices which orientate the style of questioning that generates the meaning making of this inquiry. Following this overview is a review of the philosophical positions of hermeneutic phenomenology and social constructionism that inform these philosophical prejudices. Although I readily acknowledge there are considerable differences between these philosophical stances, for the purpose of this methodology I unite them through their shared rejection of fundamental truths, and preference for the performative role of language in the meaning making of our experiences, our realities. Both of these philosophical perspectives maintain that human meaning making is a purposive process occuring in language and so arises within and through the conversations of our everyday relationships.

The use of the personal pronoun throughout this discussion attempts to make evident that this methodology is a construction of my interpretations of the various scholars and their epistemological positions to suit the particular needs of this inquiry. As a nurse and mother, I am particularly interested in the effect that donating your child's organs has on the parents and how each parent makes sense of this situation. I believe that through listening and attempting to understand the particular, situated experiences of donor parents, nurses can be afforded some invaluable insight into the effect that

donation/transplantation technologies have on our social ethic and how such practices are influencing our relationships with patients and their families.

In the following section I provide an in-depth critique of my philosophical orientation and its guiding influence on how I question and understand the parents' experiences. This critique will include a discussion of my understandings of technological determinism and how such beliefs can nurture a culture of reaction rather than proaction toward biomedical technology and the choices we make about the role it plays in shaping our understandings about life and death.

Philosophical Orientations

Primarily, my philosophical prejudices are influenced by a guiding interest in how people experience their world and a sincere belief that each interpretation of the world is unique and situationally dependent (contingent). In seeking to research and learn about donor parents and their experiences I did not wish to tell a causal tale as I do not believe there is a *typical* or *normal* donor parent's experience. Instead, my research attempts to generate understandings that particular people in a particular place at a particular time have about an event in their lives. I want to open a conversation with donor parents that multiplies rather than reduces the possible associations and relations of meaning making that they and others have about their experience. In taking this approach to inquiry where the donor parents experiences are understood as multifocal and multifaceted, I hope to replace any simple answers and causes for their experiences with a plurality of issues that continuously provoke further questions and understandings.

That theories are our experience and experiences are our theories is the epistemological premise of this thesis. Hermeneutists' and social constructionists argue that it is through making conversation—listening to the stories of peoples' lives and experiences—that a space is opened for further meaning, theory and understanding to be made:

> *Conversation is funny stuff. It is a way of creating a shared place that can be used for many different purposes. How we use language, and other means, to communicate with those around us makes the world, for us, the way it is. It is one of the main ways by which we learn from each other. We engage in it to inform*

> *ourselves and others that it's time to do things differently. Through conversation we can also know that we are doing things OK. We can also come to a sense of "We're in this together."It is much more than 'just talk' for it is in, and through, conversation that we ask the questions that help us work out what is important. Questions that lead us to experiment and take good risks. For if we are to remain alert to opportunities to undertake 'change for the better' we have to 'let go' of beliefs and patterns that hold us back* (Stewart 1998, p.24).

This theoretical primacy of language and experience provides an alternative basis for legitimising and valuing the experiences of donor parents as it redirects truth from being an abstract reified phenomenon toward being a highly contextual phenomena of our lived experiences. The phenomenon of interest no longer is a 'thing' per se but rather an event of human experience.

The parents' stories provide a wellspring of information for generating new understandings about the changing landscape of their lives amidst the application of ever advancing biomedical technologies. The retelling of the parents' experiences raises them to the level of story telling. All the emotion, thinking, actions, mystery and metaphor of their experience is their to be reflected upon by the attentive listener (Lumby 1994). Their stories detail experiences from which nurses can learn, change and possible advance practice in the care of other families in similar circumstances. Additionally, the stories can help nurses to remain appropriately critical of the ethical implications of supporting the application of these technologies.

My ontological prejudice is hermeneutical as I consider knowledge to be relative and dialogical. Knowledge arises from out of our conversations with others[7] and so is appreciated as a situated event rather than a universal truth. I do not deny the existence of a physical reality and I cannot deny that the world continues to exist without my being present. However, I can only seek meaning or achieve an understanding about this reality through my engagement with and relationship to it. This relational primacy of understanding makes the long held separation between the knower and the known or the

[7] Others is not simply another person but instead everything I am in conversation with.

observer and the observed, illusory. Knowledge is not a purely mental construct (as an idealist would argue) but rather knowledge is understood to be a relational event that is constituted by a history of meanings, practices and social relationships. Even though I may generate various theories about the parents' experiences, the interpretations I make are not something that arise from the solitary recesses of my mind. Instead, my understandings arise from an ongoing and recursive union of shared meanings.

The second theoretical premise of this thesis is that understanding is a situational meaning that is located in the stories people share about their lives. I understand meaning to be made in and through our relationship with 'others'. This meaning becomes apparent to us in our conversations (our stories) about these relationships. Such knowledge is as ontologically relative as it is existentially temporal. It is the product and so belongs to the very relationships from which it arises. Our conversations are the 'performers' in the play of our lives.

Language as performance (Gergen & Gergen 1991) forms the epistemological vehicle of this thesis. Instead of being considered as nothing more than a device for mapping or picturing the world language is appreciated as being constituitive of our meaning making. Theorising in terms of formal principles therefore gives way to a process that is far more open and poetic. Meaning is not sought and found by following a predefined map but rather made in each moment of communicating and sharing with another (Shotter 1990, p. 417).

The parents' stories and my ongoing conversations with, and interpretations of these stories, are the meaning generating process of this thesis. From this situation dependent perspective knowledge is considered neither a purely subjective nor objective phenomenon. As an attempt to see experience as neither subjective nor objective but as a phenomenon, or event of being, the hermenutic phenomenological orientation to inquiry is deeply concerned with the relationship between language and experience. It is through language and expression that phenomenon as experience is realised (Kestenbaum 1982, p.15). Knowledge is not found within individual minds but collectively generated within the language of our conversations about our experiences. The interpretations that

each parent makes of their experience is never complete. Always partial it is in a process of becoming, depending on their ongoing relationships and conversation[8] with others.

Nevertheless, despite the thesis design being predominately interpretive in focus I am critical of the way human experience can be reduced to a single cause and how particular interpretations can serve particular needs. I support plural, partial and multivocal positions of understanding rather than single, normative ideals. No one interpretation is accepted or positioned as more 'true' or realisitic than another. Although mindful of the various players in the social context of organ donation, I make no assumptions as to each player's position of power; because for me sources and origins of power are ubiquitous. I understand people to have situated freedom and so are neither radically free and powerful nor radically unfree and powerless in any given situation:

> ... *people enter into situations* [relationships] *with their own sets of meanings, habits and perspectives. And the particular ways of being in the situation set up particular actions and possibilities. New possibilities can be learned, but they are encountered or introduced only in the context of the old habits, skills, practices and expectations. This is what it means to live in a meaningful world* (Benner & Wrubel 1989, p.24).

For me, any attempt to trace and uncover sources of power seems specious as what or who is considered powerful in one context may not be in or to another. Judgments of power and disempowerment tend to arise from the use of criteria that in order to be valid assume to stand exterior to the immediate experience. Assertions that someone is disempowered tends to force upon them an objective criteria of truth/reality while failing to acknowledge (remain open to) situationally dependent criteria that, if realised, could give rise to an alternate understanding. There is however another way of thinking which revolves around the experience of knowledge as intimacy rather than power (Griffin 1995). Working from a perspective that there are no situationless or context free

[8] Conversation here is realised as more than the linguistic or verbal presence of our spoken language as it is instead considered to be the ontological primacy of our existence. Language is the house of being, the place where our realities are made and realised. Our realities are made evident in our conversations with others. Through our stories we share in the making of a social reality that is constantly shifting as is our conversation about that shared reality.

interpretations I make an effort in this inquiry to refrain from the arrogance of objective truths and uphold an ethical foundation of my thesis which is never to assume to know another person's truth better than they.

Understanding as opposed to emancipation remains the primary intent of this interpretive inquiry. Attempting to understand an experience is considered to be the necessary first step toward developing a proactive rather than reactive change in practice and policy. Achieving voluntary emancipation as opposed to involuntary or enforced change is only possible while ever the change is informed from experience rather than assumption.

The emphasis of this study is placed on expanding the current understanding of the parents' experiences through a process of interpretation that adds dimension to present understandings and shared anticipations of their experience. Through a recursive dialogical process of conversation and storytelling current shared meanings are opened out to allow for the possible generation of new, different meanings. This is not a postmodern process of deconstruction and reconstruction as the new interpretations are adding to, not rejecting the present shared meanings and understandings of each parent's experience.

Through this process of dialogical conversations we increase our understanding of a phenomena by keeping such dialogues and conversations open rather than closed. Demands for certainty and claims of truth are one way that conversations about a phenomenon can be drawn to a close. With certainty a valued criteria in our society, many conversations about our daily lives have been superficially closed or limited by the belief that all that can be known about a particular phenomenon has already been achieved. Yet, in spite of our existential desire for certainty, uncertainty is fuel for the very questions that are the agents for the conversation of our being[9]. As Storr (1997, p. 176) suggests, *'man [sic] is a creative creature because he is spurred by doubt, by*

[9] The word 'being serves as both a noun and the present participle of the verb to be. I shall hyphenate it, be-ing, whenever I use it as a verbal noun (gerund) to convey an activity, not a static condition.

confusion, and by dissatisfaction with what is, both within and without.' Put simply, we question our lives and question some more, and amidst this questioning we make and remake the meaning of our lives.

This thesis supports an approach to inquiry that attempts to overcome this obsession for answers and final truths about a phenomenon. Care is taken in trying to realize more fully the language of donor parents' experiences through supporting into view the expression of alternate voices or perspectives:

> *The kind of language that can do this is language that is conversational and collegial. It is language that is, so to speak, still 'young' rather than fixed and objectifying, looking forward, prospectively, toward novel relational possibilities, rather than looking backwards, retrospectively, toward representations and explanations within old, already existing categories* (Katz & Shotter 1996, p.929).

This valuing of non reductionist, antifundamental perspectives of knowledge generation is supported by the philosophical works of Heidegger (1962) and Gadamer (1976), as well as the social constructionists/feminist epistemologies of Haraway (1991), Rorty (1991) and Shotter (1990). For these scholars understanding is a continuous process of becoming. These philosophers emphasise in their inquiries process more than stasis, existence rather than essence, organism more than mechanism, history rather than eternity, the changing more than the unchanging. Accordingly, each scholar agrees on the centrality of time and language in the making of human Be-ing (meaning). For each scholar there is a strong (though not exclusive) tendency to place the locus of meaning within the process of interaction itself. That is, individual subjectivity is abandoned as the primary site on which meaning is originated or understanding takes place. Attention moves from locations within to sites between 'conversational realities' (Shotter 1995). Language is seen as primarily rooted in people's embodied, dialogical activities, and not as grounded either in their minds, or in the world around them. Instead of understanding being formulated in terms of laws, principles, or rules supposedly governing repetitive events, these scholars provoke a wholly different approach to understanding that is relational and responsive. A kind of understanding, not to do with what something 'is' in itself, but with a practical grasp of changing, moment-by-moment links and relations

between events and their surroundings. The ultimate value of each scholar's disparate yet relational, dialogical approach to human inquiry is that they give us a way to grasp what it is we are doing, and in our doing of it. No attempt is made to step outside the ongoing flow of an activity for reflection and critique as such efforts only prove to distort rather than improve meaning making.

Making Meaning

> *Indeed, a quite special but [relatively] unrecognised kind of knowledge is involved here; it is not a 'knowing-that' (theoretical knowledge) for it is practical knowledge known to us only in practice, but neither is it a 'knowing how' (technical knowledge) for it is particular to the properties of its social situation. It is a third kind of knowledge of a practical-moral kind. Ignoring it leads us to ignore the unique nature of situations and the people within them.*
>
> (John Shotter)

For each of the previously mentioned scholars, meaning making begins with a question. For them curiosity, the desire to understand and to know, lies at the root of all science and philosophy (Haverson 1981). To question marks a willingness to understand life or a phenomenon differently. Yet questions can be open or closed. History has shown that a person's style of questioning influences greatly the outcome of their quest (Heidegger 1962; Young 1973; Gadamer 1976; Hekman 1986; Haraway 1991; Rorty 1991). Ultimately, a person's style of questioning tends to reflect their worldview as we all tend to question and answer from within an historically contingent worldview:

> *It is not particular statements or theses, then, which are genuinely at issue in a philosophical dispute, but rather rich, more or less systematic world views. A philosophical encounter is like the collision of two icebergs. What lies beneath the surface is larger than, and gives shape and force to, what is visible above the waters. These philosophical world views have a special sort of comprehensiveness and elasticity. They shape our whole way of seeing the world, Opposition among them is dialectical* (Rosenberg 1978, p. 25).

Dickson (1974, p. 30) cautions that a dominant world view can become an 'encoding' or 'generative' structure (a habit of mind) for the whole of society and its process of inquiry. Positivism and its belief in, and search for, ultimate rules and laws of existence

is well recognised as the dominant epistemology of Western society, with science and the scientific method acknowledged as its primary progenitor:

> *... the cosmology of modern science lays down the metaphysical assumptions in terms of which scientists and other experts think, ask questions, evaluate, answer, control nature and other people and are controlled. It is very deep an abstract and not on the surface of every day life and science, at the same time that its forms define and generate the rules, vocabulary and definitions of what we experience as the stuff of experience itself, of facts, of theories, of sciences, of worlds, of the comology: the logos of our cosmos is the scientific cosmology. We learn it by living it* (Dickson 1974, p. 31).

The metaphysics of Western epistemology have their origins in early Greek thought, with Plato's writings being by far the most foundational. Since Plato, humankind's questioning has been dominated by a search for answers. Epistemological endeavours have been driven by a form of questioning that concentrates on the objective analytic or rational 'what is there' rather than an ontological or situation dependent questioning of 'How or why is there something rather than nothing?' Classically, we have thought of ourselves as self-contained individuals relating to our surroundings as if viewing them from a distance. Such a perspective has tended to lead us to regard the world as an external, immutable world. It has become 'natural' for us, so to speak, to think of ourselves as subjects, set over against a world containing certain object-like, or object-ive 'things', and for us to talk of ourselves as only having knowledge of these 'things' and of acting with reference to them in terms of our 'inner representations' of them.

Historically humankind's quest for certainty has developed from a belief that inquiry ought to proceed on the basis of priviledged, incorrigible or indubitable foundations (Peerenboom 1990). We have come to prefer just one form of knowledge and way of talking to the almost total exclusion of all other views. In particular we have priviledged orderly, theoretical knowledge, meant to 'picture' in some way a hidden order behind appearances. In doing so we have failed to develop fully that kind of practical-moral knowledge of life as lived which is to do with 'knowing our way about' within our own social world (Shotter 1993).

These traditions of inquiry reflect an ardent search for fundamental truths as opposed to an inquiry which seeks to provoke more questions than answers—questions which help to maintain the conversation of our being open and evolving. Hence, the pursuit of knowledge has been dominated by a systematic process of gathering data, advancing a generalisation (hypothesis) that is supported by this data, testing that generalisation's truth against identified variables, reviewing that generalisation and testing it again and again until a generalisation is finally achieved that appears to be consistent with all the *known facts*. The *cold, hard, facts,* have become our guiding truths.

Turning away from Experience

Instead of knowledge being the event of living, knowledge throughout the centuries has became specialised, reified and idealised. Human inquiry has shifted from an ontological inquiry of everyday experience into a transcendental search for truths—as a theory of knowledge was considered necessary before a theory of the world could be realised and accepted (Tarnas 1991; Solomon & Higgins 1997). Over the centuries human inquiry—our ontological search for meaning—has become an epistemological endeavour that perceives truth and knowledge to be available, but only to those who have been well prepared to receive such knowledge. Consequently, the type of question(s) asked have become discipline bound and driven by dominant methodological and method biases.

To question according to the Platonic heritage—to seek cause and effect or final answers—results in a dualistic perspective that has dominated humankind's effort to reason for centuries. Standing from the vantage of contemporary philosophy the style of questions that have prevailed throughout the centuries past can be broadly polarised into two distinct and often antagonistic positions depending on the discipline's ontological tenets about what is real and therefore 'true' (their worldview).

The following summaries are representive of the extremes of this polarity, Realism versus Idealism.

Realism

The natural sciences, where the philosophical positions of Descartes' subjective Realism, and Francis Bacon's objective Rationalism, lay the foundations for the advancement of a method that is highly pragmatic and successful in isolating those aspects of the 'object' world that are considered to be the essential pillars of what is real and therefore true: 'facts'. Truth is ratified as existing beyond the vagaries of human interpretation and understanding. A method that controls the bias of human emotion has been developed so that ultimate truth can be realised. Such a position extends from a Platonistic tradition where truth is considered foundational, eternal and unchanging.

Idealism

The human sciences, who in reaction to the alienating, impersonal nature of the natural sciences, took their lead from a philosophical position that thrives on the notion of the individual or self. The theory and epistemological significance of the human sciences gained strength during the late eighteenth and early nineteenth century from the works of the Romatic poets and philosophers such as *Goethe (1749-1832), Wordsworth (1770-1850) and Rousseau (1712-1778)*, who in contrast to the rationalism of the scientific revolution saw nature as *'... a live vessel of spirit, a translucent source of mystery and revelation'* (Tarnas 1991, p. 367). Coupled with Kant's Idealism and epistemology of *Categorical Imperatives* knowledge is realised as a subjective rather than objective truth. Kant's epistemology claims truth to be interpretive and therefore subject dependent (Solomon and Higgins 1997). Although Kant has an appreciation for the mechanistic certainty of Newtonian physics, which he regards as *a priori* fundamental laws of the universe, he considers humankind's knowledge of these laws as interpretive and therefore '*neither absolute nor unequivocally objective'* (Tarnas 1991, p. 359). With his categorical imperatives Kant makes absolutes and certainty reside within the subjective conscience. For Kant, there is nothing but the subjective perspective. For him, the fundamental laws of the universe, that science has and continues to explicate, are of a universe already ordered by the mind's own cognitive apparatus (Solomon and Higgins 1997).

Today however, such distinctions between disciplines as to the questions asked and the consequent methods used to answer these questions are no longer as distinct nor polarised (Holmes 1991). For many scholars, the postmodern turn encourages a blurring of disciplinary boundaries and their particular claims to knowledge (Holmes 1991; Lumby 1994). A reassessment of metaphysical dualities and dichotomies has occured which encourages a welcome and refreshing willingness to advance many different methods of understanding, or coming to know our lifeworld(s). Even contemporary science, the dominant discipline for centuries, has itself become increasingly aware and more critically reflective of its epistemological and existential limitations and thereby less prone to a naive scientism (Guba 1990).

Opening the Quest

In virtually all contemporary disciplines the prodigious complexity, subtlety and multivalence of reality is being recognised as transcending the grasp of any one intellectual approach (Tarnas 1991, p. 404). Such awareness has encouraged a receptive commitment amongst scholars to the interplay of disparite perspectives of how we come to know or understand our world (Tarnas 1991, p. 404). Each discipline still has a characteristic way of asking questions, but their willingness to accept that there are many different ways to advance an understanding about their particular disciplinary interests is the hallmark of a contemporary research climate. And nursing is no different.

In all positions however (both within and across disciplinary boundaries), there remains an apodictic point of departure—a difference that ultimately taints the way in which they formulate their questions. Whether or not they believe in foundational truth(s), essences or apriori(s) of the world appears to be the telling difference (Hekman 1983; Rorty 1991). This difference proves to be one that ultimately orientates a person's inquiry toward either seeking closure of the questioning, or attempting to keep the conversation and questioning about the phenomenon ongoing. This difference is a difference in priorities of truth-seeking that inevitably influences the questions asked and the meanings made (and sadly, at this present stage, the funding given).

Nursing's Quest

A brief perusal of nursing journals will show that nursing's ongoing pursuit to understand its practice world is a contingent part of this postmodern change. For decades nursing scholars have attempted to make evident their contribution to human knowledge about people, health and the environment in their research efforts and through their particular way of questioning the world. In doing so they attempt to lay claim to nursing's importance as a discipline and its significance to the contribution of human knowledge (Allen, Benner, Dickelmann 1986). Like all disciplines, nursing originally fell comfortably into the dominant ethos or belief that knowledge is something to obtain and hold onto (Pearson 1991; Watson 1994). Nursing scholars, not unlike most others, in their efforts toward establishing their relative disciplines, have tended to glorify the rationalism of the scientific method as the best way to answer all questions (Abdellah & Levine 1994; Meleis 1997). In doing so however, nursing scholars have achieved little more than the propensity of nursing to maintain its allegience and professional subservience to medicine.

Consequently, despite the pragmatics of the scientific method for advancing nursing knowledge, difficulties arose when this method was seen as the only way to establish and advance nursing's knowledge base. As a practice discipline, much of nursing's knowledge is shared in the form of anecdotes, stories, jokes and seemingly scattered observations that ellude quantification (Meleis 1997). The silent moments and development of supportive relationships, that most would agree are the therapeutic credence of nursing, defy all efforts to contain and define (Pearson 1991; Lumby 1994; Watson 1994). This messy disorderly world of practice provides many questions, but questions that are largely unsupported by the dominant scientific method and its demand for rigor.

Many unorthodox and frustrating ways of knowing are sought and advanced through nursing research that create conflicts with our surrounding peers who cannot see the value of such 'fuzzy knowledge'. Instead, if we are to be taken seriously as a profession, a more concrete form of reasoning, that is historically governed and socially

sanctioned with a method of certainty, is required (Meleis 1997). It can be argued that being the *new kid on the block* [as well as a female-dominated/driven profession] nursing lacked the political nous and social strength to differ.

Some nursing scholars felt the demand to follow suit and so attempted to dismiss this knowledge as 'soft' as it is non-verifiable according to the dominant criteria of science (Allen, Benner et al. 1986; Lumby 1994; Watson 1995). Determined not to waste time with the 'undefinable' and 'uncontrollable', they have focused their time and effort on the platitudes of truth seeking and certainty, looking for the essence or rules of our practice world. For them, nursing needed to be defined and in that definition was the hope that nursing would aquire the strength and direction to stake its claim in the health care industry as providing a valid and worthwhile contribution to the health care needs of society. Overall, such efforts that can be understood as an act of survival, are both compelling and seemingly unavoidable in an economically rational climate that readily dismissed any discipline that proved otherwise.

Many scholars of nursing however soon realised the loss in practice knowledge inherent with following the pathway towards absolute certainty (Rogers 1990; Meleis 1997). Nursing's characteristic way of viewing the world was being relegated to align with one method or perspective. That our characteristic way of questioning practice is not always to be found in a definition but instead in the recollective critique of the very questioning itself proved problematic. Our lack of definition, our openness and humility to acknowledge the value and credence of the various philosophical positions regarding the human condition was and still is, recognised and seized upon as a weakness. In an effort to comply with this perspective many scholars curbed, instead of expanded, their research methods and therefore practice knowledge. Our theories and knowledge, instead of gaining significance and meaning, seemed to loose 'something' as a result.

Holding tight to the well defined and certain, nursing as a discipline became blind to the overtness of change that confronts nurses in every facet of their daily practice. As nurses participate and interrelate with the extremes and vagaries of human experience—of life and death—change is the constant. Our daily practice is a forum

where a person is compelled to witness, to acknowledge change as inherent to their very Being. Illness and other major life events such as birth and death can encourage in the person a critical reflection that can help them to transcend the normalizing nature of their routine existence and in doing so encourage a different understanding to their present circumstances. The patients' journey great change during these times and nurses are there sharing these moments with them. Lumby (1994) suggests that such humility and sharing was threatened with extinction as the discipline of nursing attempted to shed its innocence to join the hierarchial ranks of specialised truth seekers. Nursing, in an effort to have its therapeutic significance to the patient's experience recognised, adopted the dominant trend of trying to claim certainty about what is nursing knowledge and therefore identifying nursing's diffference and uniqueness from other disciplines such as medicine, psychology, sociology. Nursing inquiry became dominated by questions that sought single answers. Nursing practice was subsequently reduced into well defined and manageable theories of care (Meleis 1997).

Within the confines of the rational and factual, nursing's significance was sequestered into the common trends and patterns of the more dominant counterpart: medicine, which would always claim greater degrees of accuracy in its assessment of what is real and therefore true. But in forever being regarded as the poor relative when it comes to efforts in theorizing about 'reality', nurses unwittingly acquired a humility (Taylor 1994). One that is not so readily apparent in practitioners from other disciplines, such as medicine who are so certain—to the extremes of being arrogant—with their knowledge or access to 'truth' about the human condition.

Nursing is realised in a variety of ways with the substance of its practice knowledge being generated from borrowed as well as original sources from within the practice of nursing (Allen, Benner et al. 1986; Pearson 1992). From its struggle for professional independence, nursing has acquired a humility that is expressed through many of its practitioners' willingness to adapt and modify any and all forms of knowing for the patient's benefit, and in doing so nurture and continually modify and expand their understanding about the human-health-environment. Willingness of nursing practitioners

to remain open to the possibility of the therapeutic value of a particular treatment, despite a discipline's particular claim to that knowledge, nurtures a flexibility in perspective that promotes this humility.

In a legacy repeatedly extoled by Rogers (1980), nursing exists in relation to other disciplines and nursing knowledge (like all other disciplines) is a synthesis and resynthesis of this relation with other knowledge(s) and perspectives about the world. Such a relation 'with' other disciplines leads not to nursing being the simple summation or mere application of these other facts and principles, but instead realises nursing knowledge as an emergent, new understanding about human being and their living wellness. In trying to make evident nursing's unique contribution to humankind's knowledge about its living process, Rogers (1962, p. 5) states that *'... a particular theory may be shared by many disciplines. It is however in the particular aggregate of theories that nursing knowledge achieves its uniqueness.'* A uniqueness that Rogers explicates as the Science of Unitary Human Being.

Arguably, nursing's therapeutic edge comes from its diversity of theories and flexibility in the development of relationships that help people to cope with the constant flux and change of their lives (Lumby 1992; Phillips 1996). This therapeutic use of 'self' is considered by Taylor (1994) to characterise the nurse-patient relationship with partnership, intimacy and reciprocity. Exploring this relationship can help to explicate the healing value of therapeutic nursing. This relationship is dynamic and synergistic and cannot be reduced into clearly defined parts that compose the whole.

This resistance to reduction, nursing's inability (apprehension) to be reduced to a definition or achieve any certainty about where its knowledge begins and ends is considered problematic, rather than productive in a society that has been educated or enculturated to value the counter (i.e. specialisation). Nevertheless, the humility and openess of nursing practitioners, which feeds their willingness to adopt a plurality of methods and approaches to their care, needs to be realised as a strength rather than a weakness (Allen & Jensen 1990). As Meleis (1997, p. 82) conveys, this plurality is congruent with nursing's commitment to human beings and the dynamic, multifarious

shades of their experiences as it is '... *a perspective that accepts, and values ... multiple realities.*'

However, within nursing's history, which is marked by a struggle for professional independence, this openness and humility is not always easily found. In nursing's determination to claim its own theories of practice a backlash against medicine's dominance was inevitable and evident as the scientific method was lauded as the reason for all of nursing's failings. The scientific method was subsequently pushed aside to allow for other methods and methodologies considered more suitable. This was an invaluable period (1960-1980) for nursing as a plethora of different ways of knowing emerged that increasingly placed the patient and their experience to the centre of the nursing question(s).

These changes were just as much political as they were pragmatic. Medicine became the perfect opposite: the antagonist (other) against which nursing created (birthed) its independence and significance. Any value that the scientific method had to offer nursing scholars in their efforts to understand the world of practice was increasingly marginalised and taken to the extreme with some claiming that such methods and the knowledge they produced are antithetical to the 'essence' of nursing and therefore should not be used (Darbyshire 1997; Meleis 1997). One form of elitism or absolutism was being rapidly replaced with another and the ways of knowing in nursing were not liberated as hoped but were once again restrained and limited.

The present day debate about the value of evidence based nursing is symptomatic of this kind of polarised thinking that has plagued nursing's efforts to claim its independence from medicine, and in doing so clouded its humility with a perpetuation of boundaries and dichotomies that seem debilitating or futile in this postmodern era. Evidence based nursing is regarded by many as a fatalistic return, a 'sellout' to the dominant paradigm of positivism (Walker 1994); a position from which many nursing scholars tried to distance themselves. Such a debate makes evident that despite the struggle to be free from hegemonic idealogies there are nurses who continue to propagate the very restraints they try to transcend. In their distancing from and rejection of the

scientific method, the very demon that many nurses so galantly fought against has been recreated (Darbyshire 1997). Many nurses propagated an 'us versus them' mentality and in doing so claimed absolutes about what is or is not nursing; and in their very efforts tend, once again, towards confining so much of their practice world that if understood differently could be significant for the patients.

Becoming narrow and rigid in focus results in the generation of superficial and impoverished knowledge:

> *... Empirics removed from the context of the whole of knowing produces control and manipulation ... Ethics removed from the context of the whole of knowing produces rigid doctrine and insensitivity to the rights of others ... Personal knowing removed from the context of the whole of knowing produces isolation and self distortion ... Esthetics removed from the context of the whole of knowing produces prejudice, bigotry and lack of appreciation for meaning* (Chinn & Kramer 1995, p. 15)

There are still many nursing scholars and clinicians that need to release their hold on what they feel nursing *is*. In claiming that a definition of nursing can empower itself through giving focus and direction to the discipline, the reverse also needs to be conceded. A definition can just as readily constrain and confine the discipline's growth by erecting borders around specific domains of care regarded *to be* nursing.

The significance of nursing depends on many factors that are far from static, nor readily defined (Hockey 1991). The health care setting is changing rapidly and the nursing profession must not be reactive but more importantly proactive toward these changes. Before nursing can achieve this stance however, many nursing practitioners and scholars need to overcome their fear of nursing being decimated or displaced by the demands and criteria for truth perceived as owned by another. Many nurses need to have faith in nursing's ability to remain open and balanced and still have focus and direction for future efforts of knowledge development. Such faith can be enlivened by the likes of Hockey (1991, p. xiii) who argues that, *' ... what constitutes nursing must never be allowed to become a static set of activities engraved on tablets of stone.'*

Nursing research has a central role to play in making obvious to other disciplines nursing's characteristic way of viewing the world and the significance of the questions that nurses ask for humankind's understanding about life. A pluralistic orientation in the use of research methods can help the discipline make evident its flexibility and proactive approach to understanding nursing and its therapeutic value to the health and well being of society at large. The diversity in nursing, captured by nurses and their cultural, educational and socioeconomic backgrounds, is realised by Meleis (1997) as a strength for nursing's openess and continual growth as a profession. Meleis regards such diversity of views and perspectives to be a *' ... safeguard against premature closure in a phenomena and against narrow definitions dominating our practice'*(p. 65). Diversity and change then, becomes nursing's strength, not its weakness.

The evidence based movement, like other methods of inquiry, needs to be realised as just one of a plurality of ways to understand the phenomena of interest to nursing,. This plurality proceeds with what Capra (1997, p. 68) believes is the future of epistemology where there are no firm foundations or theories of truth. A future of inquiry where the tired metaphor of 'building' knowledge (giving credence to a hierarchy of truths) is replaced by a metaphor that speaks of the interrelation of knowledge with experience. From this perspective, knowledge is viewed as a system or 'web' of human relationships. A network of meaning making in which all parts are considered equal and no part or idea is believed to be more fundamental than another. As Haraway (1991) suggests, this changing view of human inquiry realises knowledge or meaning making as a partial and 'situated event' rather than a universal and omnipotent singularity. Yes, it can be argued that one methodology and method will be more appropriate depending on the question asked; but the realisation and acceptance that no singular question about a particular situation is more significant than another, nor that the questioning will ever cease, is a perspective that is commanding greater attention as it is far more liberating and conducive to knowledge growth.

However, in order to embrace this plurality what is needed is a different style of thinking that supports this openess of questioning. A style of thinking that as Maly

(1993, p.227) suggests, realises change as the only certainty we have. A style of thinking, that is not locked into the semantic, logically consistent dialectic of working with opposites in a linear fashion from cause to effect, or from a position of not knowing to knowing; but a style of thinking that remains forever open to the potential for yet other way(s) to understand our experience. From this perspective knowledge becomes an 'event', a process of momentarily coming into realisation and then passing away into new possibilities and understandings (Heidegger 1996). An 'event' that is not realised as a fleeting connection with the ultimate truth of reality, but an event that considers truth to be a momentary or 'positioned rationality' and where the outcome is not a view from above but a joining in conversation of *' ... partial views and halting voices that promise a vision of the means of our ongoing finite embodiment, of living within limits and contradictions, i.e. views from somewhere.'* (Haraway 1991, p.196).

Consequently, a challenge for the methodologies that guide the pursuit of knowledge in nursing is similiar to what Tarnas (1991, p. 412) sees for all epistemological pursuits which is to try and evolve a disciplinary perspective that while not imposing any a priori limits on the possible range of legitimate interpretations of its practice world, does somehow allow a fruitful coherence of the pluralities at play. This perspective has an orientation to meaning making and questioning, that while affording a sense of purpose and direction for the discipline of nursing, does so in a manner that is not confining and restraining, but instead continues to provide and sustain a fertile ground for the generation of unanticipated new perspectives and possibilities about the human-health-environment.

Settling on a Position of Inquiry: Situating the Inquiry

Hermeneutic phenomenology, as informed by Heidegger (1962) and Gadamer (1975) is a philosophical position that addresses this challenge, as it refrains from essentialism or determinism and instead acknowledges all ways of knowing as significant. Their perspective is one that through upholding a premise of no dominance from enforced dualities gives value to the grass roots, the everyday knowings, versus the expert positions of a specialist critique. Subsequently, heremeneutic phenomenology is the

dominant philosophical position underpinning this research perspective and so provides a lens through which the participants' experiences are interpreted.

Heidegger's (1962) non essentialism arises from his primary effort which is to release humankind from the 'metaphysical straight jacket' of certainty (Solomon and Higgins 1997). Heidegger's ontology is one of realising human beings as:

> *... unique among the earth's creatures because they question the ground of their being. But this questioning is not to be understood as the cynicism or "sheer addiction to doubt" of the naysayer. Nor, however, is it to be understood as either the heroic self assertion or the religious faith of the yea-sayers. Rather, it is defined by an anxious wonder. Pious questioning is both a yes and a no: Yes to an openness to the mystery and yes to the letting-be of what is; no to calculative reason that would shield us from the nothingness lying at the heart of everything and the contingency lying at the heart of our Being, and no to answers that would terminate fundamental questioning in religious faith or pragmatic concerns* (cited in Thiele 1995, p. 113).

Heidegger (1962) seeks a different style of questioning from the one he considers has dominated Western epistemology since Plato. In attending to this difference, Heidegger looks toward the presocratic philosophy of Heraclitus for encouragement. Heidegger found in the presocratic writings, a realisation of impermanence not readily found in traditional metaphysics. Heraclitus appeared to accept change as being the only certainty of life as opposed to Plato who appealed for eternal, unchanging truths.

In being a witness to the sad and alienating consequence of a history of reasoning that attempted in everyway to 'cover over' the significance of change, Heidegger encourages a return to a mode of questioning that is mindful of the centrality of change to our Being, and in being so remains open and free from the constraints and capacious illusions of a final answer. Heidegger uses the existential of temporality:[10] the pandimensional, non-linear notion of 'lived time', as a way of returning the fluidity and flow of change to our everyday quest for understanding. Heidegger calls this temporal existence 'there-being'

[10] Heidegger worked with the notion of temporality as the ground or horizon that makes possible a meaningful human existence. As a metaphor temporality is the field on which one plays all the varied games that form one's life as a human being.

or *Dasein*. The centrality of change to Heidegger's fundamental ontology encourages human inquiry to remain forward into the possibilities potential in our living (there-being), rather than 'falling' back and dwelling amongst the already realised: living amidst the static unchanging normalacy of single truths and reasonings as given to us by experts (a state of there-being that Heidegger (1971) regards as the *Das mein* or inauthentic mode of reasoning).

Heidegger was by no means the first or last philosopher to critique metaphysics in this way. Bergson (1998), like Heidegger, spent his time explicating the process of human experience as *duration*. He too criticises classic schools of philosophy for failing to take *duration* or *becoming* seriously. Reality says Bergson (1998) does not consist of things but only things in the making. There are no self maintaining states, only states of being that are in constant flux. According to Bergson (1998) the *essence* of a phenomenon is not found through reducing it to static objects and parts. Instead, its essence is its dynamic, thriving, pulsing, living existence. For him traditional, reductive analysis interrupts this *duration* (temporalness) by seperating experience into several independent and static parts which in reality are unified, organic and dynamic.

Bergson talks about *intuition* as apposed to analysis as the way to understand the world. To think intuitvely is for Bergson to think in duration. Analysis according to Bergson:

> *... starts with the static and reconstructs movement with immobilities in juxtaposition. By contrast intuition starts from movement, posits it, or rather perceives it as reality itself, and sees in immobility only an abstract moment, a snapshot taken by our mind* (cited in Stumpf 1993, p. 437).

Indeed, Heidegger's ideas have been influential in the work of many contemporary scholars from Foucault and Derrida to Hesse, Cioux, Haraway, Rorty and Irigaray. They in turn have been influential in the works of many nursing scholars who have found interpretive or critical inquiry an invaluable means of helping to generate knowledge about nursing practice (Lumby 1994; Taylor 1994; Holmes 1995). In emphasising the embodied nature of knowledge these scholars support the notion that knowledge legitimation about our practice world is primarily local, plural and immanent (Parker

1995). A more indepth discussion of some of the principle tenets of Heidegger's hermeneutic phenomenology such as:

- Relationality: Being-in-the-world-with-other
- Language as the House of Being
- Contextuality: 'We understand because we understand.'
- Historicity: forethought, foreconception and foresight

will be the focus of the remainder of this chapter. This deliberation attempts to make evident the platform/worldview from which my questionings arise and subsequent interpretations unfold.

Situating Heidegger

Heidegger's fundamental ontology can be realised as a philosophical perspective that is positioned between the two philosophical extremes of his time: Idealism and Realism, in a location coined by Dreyfus (Dreyfus 1991, p. 29) as Plural Realism. Heidegger is against all forms of imposed dualisms such as mind/body and the very notions of consciousness and reality as they support the central dichotomy of fact versus value, or object versus subject[11] (Solomon and Higgins 1997, p. 121). Heidegger appeals against the legacy of dualities set in place by Plato as he considers such dualities have informed centuries of division and fragmentation of human experience. Through Plato's petition for eternal truths, a separation between the soul and body was created and extended into a social reality, that for centuries has been divided by double truths such as the divide between faith and reason of the Medieval era and the treacherous division between science and religion of the Renaissance period. Many other dualities such as the subject-object/inner-outer discord of the Romantic era and the sciences/humanities divide of

[11] Dichotomous terms such as object/subject or fact/value are terms that Heidegger adamantly resisted and made evident by his persistant neoglisms such as Dasein; there-being; being-in-the-world-with-other. Attending particular attention to the language of metaphor used in our conversations about the world was all an effort on Heidegger's behalf to reinstate understanding as something that is alive and forever changing rather than transcendental, static and defeated by its very definition.

contemporary debate are other examples of the legacy of transcendental forms as theorised by Plato. In spite of Plato's scholarly intent being to derive order out of chaos these divisions have instead resulted in a social ethic of double truths and intellectual schisms that, if anything, create the modern era's absolute lack of certainty despite centuries of effort to achieve otherwise (Tarnas 1991).

Such dogmatic reasoning is apparent to Heidegger (1967) as inherently alienating as it oppresses and hierarchises our everyday lives. Heidegger demonstrates throughout his work that this tradition of questioning creates an intellectually imperious way of being and thinking that ultimately leads to an existential and cultural impoverishment:

> ... *the world is darkening. The essential episodes of this darkening are: the flight of gods, the destruction of the earth, the standardization of man,*[and] *the pre-eminence of the mediocre* (p. viii).

For Heidegger, and many other scholars, this impoverished way of thinking needed to be challenged as it lent to the technological domination of human Being and nature as well as the socio-political domination of others (Tarnas 1991, p. 400). It is a mode of thinking that lacks moral and ethical integrity as it grows in strength and domination from the defeat or deridement of the world into a thing, an object to be manipulated and controlled (Heidegger 1967). On the other hand, phenomenology, as Kestenbaum (1982) suggests, acquires an ethical significance of paramount importance to health professionals. Phenomenology does this, not through the identification of objects and recommendation of specific courses of action but rather through encouraging us to alter the ways in which we think and question the world of everyday experience.

Crossing the Divide—Relating to Other

> *Man* [sic] *is but a network of relationships, and these alone matter to him*
>
> (St. Exupery)

To Heidegger (1962), rather than objectify the existence of our everyday existence our very capacity to make meaning of our experience is dependent on our relationships with *other*. This meaning is thereby starved and thwarted by a reasoning that imposes a division and separation from *other*. Heidegger (1977) suggests that opposites are the complementary parts of a free flowing unity called *Dasein,* rather than the antagonistic extremes of static, immuntable differences. Consequently, he argues that the problem with traditional reasoning is that it has denied this interrelation of subject and object and sought instead a more verifiable reality that is somehow separate from this relationship. The rarified theory of mathematics—and its cultural glorification—is considered by Heidegger (1996, p. 292) to be such an attempt as it:

> *... is the anticipation of the essence of things, of bodies, thus the basic blueprint of the structure of everything and its relation to every other thing is stretched in advance ... now nature is no longer an inner capacity of body, determining its form of motion and its place* [vis-a-vis Aristotle] *... nature is now the realm of the uniform space, time context of motion which is outlined in the axiomatic project of mathematic ... bodies have no concealed qualities, powers and capacities ... natural bodies are now only what they 'show themselves as, within this projected realm* [of mathematical truths].

Guided by the 'authority' of fundamental mathematical rules of nature, the questions science asks of the world have become as evaluative and qualitative as desired. In order to achieve credibility, answers have to be presented in terms of matter, motion and number (Young 1977). Heidegger proposes that these demands inherently alienate human experience from being realised an essential ingredient of any equation/answer.

Heidegger refers to Galileo—who is neither interested in the apple nor the tree but only in measuring the fall of the apple—as an example of the alienating process of this form of questioning (Richardson 1993). Driven by a certitude in the purity of mathematics

from the impurity of human reasoning, Gallileo's relation with the world is primarily one of searching for the mathematical truth of all that is; searching for a truth which he believes is separate and eternal from his very practice of inquiry. With his measurements achieving apparent prediction and control of time and space, Gallileo believes he is uncovering a fact that exists despite his very existence. He believes he is engaged with the eternal, unchanging truth which Plato promised is there to be found.

This mechanistic, highly objectified and ordered world-view that Galileo and Newton helped to create replaced an organismic, chaotic world where reality was considered to include far more than what simply met the eye. In this way, abstraction from the sensuous particularity of persons became the rule and what mattered became the manipulation of things and processes. From this practice of studying material existence apart from any consideration of spirit, or intrinsic meaning, a world of matter apart from spirit, of function without significance, is unwittingly created (Griffin 1995, p. 33). In his book *One Dimensional Man* Marcuse (1964b), provides a chilling critique of particular import to this research, of the contemporary consequences of an epistemology that reduces human beings and their world to mere objects:

> *The scientific concept of a universally controllable nature projected nature as endless matter-in-function, the mere stuff of theory and practice. In this form, the object-world entered the construction of a technological universe-a universe of mental and physical instrumentalities, means in themselves ... Only in the medium of technology, man* [sic] *and nature become fungible objects of organisations. The universal effectiveness and productivity of the apparatus under which they are subsumed veil the particular interests that organise the apparatus. In other words technology has become the great vehicle of reification—reification in its most mature and effective form. The social position of the individual and his relation to others appear not only to be determined by objective qualities and laws, but these qualities and laws seem to lose their mysterious and uncontrollable character; they appear as calculable manifestations of (scientific) rationality. The world tends to become the stuff of total administration, which absorbs even the administrators. The web of domination has become the web of reason itself, and this society is fatally entangled in it. And the transcending modes of thought seem to transcend reason itself* (p. 136-7).

Heidegger does not deny the existence of a physical world. The objectification of existence is not, according to Heidegger (1977), to be dismissed as being without value.

The quantification of the physical world has helped humankind to achieve what in ancient times would have been considered miracles of an omnipotent force. No scholar truly rejects such values. However, as with most things balance is desirable. Heidegger's plural realism can be understood as an attempt for such balance. Heidegger's preference for realism over idealism extends from his belief that there is a world separate and ongoing from us, into which we are 'thrown', versus the proponents of idealism who claim that the world is thrown forth by the person.

The world according to Heidegger (1971), is more than just a subjective fabrication. For Heidegger (1971) there is the 'Earth' (physical world) which, as a consequence of our *Being-in-the-world* and our engagement and relationship with it, is realised as *Worldhood.* Earth is for Heidegger not mere 'stuff' but that out of which everything comes forth and into which everything disappears (Gadamer 1976, p. 223). The earth is an 'other' with which we are in constant relationship. This relationship creates the domain of our existence.

Those who support the tenets of realism, however, tend to appeal for the fundamental truth of this earth as somehow separate from our experience. Heidegger (1971) considers such a position to be specious, as there is never any way of knowing this 'truth' other than through our relationship with and to it (Kisiel 1993). As Heidegger proposes:

> ... *nature is whatever it is and has whatever causal properties it has independently of us.* [Having its own agency and is thereby not a silent 'resource' to be conquered and controlled]. *Different questions, such as Aristotle's and Gallileo's reveal different natural kinds and different kinds of causal properities. Different cultural interpretations of reality reveal different aspects of the real, too. But there is no right answer to the question, "what is the ultimate reality in terms of which everything else can be intelligible?" The only answer to this metaphysical question is Dasein (there-being), because it is the source and sense of the understanding of being and of reality* [and] *is the being in terms of whose practices all aspects of the real show up* (Heidegger cited in Dreyfus 1991, p. 39).

For Heidegger (1971, p. 44) this participant contingent world is more than any sum total of countable or uncountable, familiar and unfamiliar objects that are simply there before us. The world is not a screen, ground or resource to be conquered by the master who in

doing so closes off the dialectic *'... in his* [sic] *unique agency and authorship of 'objective' knowledge'* (Haraway 1991, p. 198). Rather, the world or worlds are as Heidegger (1971, p. 44) proposes *'... more fully in Being than the tangible and perceptible realm in which we believe ourselves to be at home* [the earth]'. Never an object that can stand before us for discernment and objectification, Heidegger's notion of world is thereby not another example of the correspondence or 'mirror' theory of reality that dominates traditional metaphysics (Caputo 1985, p. 254). Instead, the world is an emodied, situated knowledge which Heidegger calls *worldhood* and so is regarded as *'... the ever non-objective to which we are subject* [as in experience or relation] *as long as the paths of birth and death, blessing and curse keep us transported into Being* (Heidegger 1971, p.45)'. Understanding reality is therefore not a product of a subjective truth but instead an outcome of the mutal dependence and interrelation of our Being-in-the-world-with-other (Risser 1997). Understanding is a dialogical process which arises out of a relationship between subject and object. For Heidegger, knowledge needs to be relocated and rethought as a process of knowing in the realm of social activity, rather than as a thing in the heads of individuals or in the a priori, transcendental laws of the universe.

Knowledge = A Dynamic Relationship Between Self and Other

Heidegger's pluralism arises from his belief that there is no one way of knowing the world and his suggestions that our different ways of knowing are determined by the questions we ask (our care/*sorge*). Along with many of his contemporaries Heidegger rejects the metaphysical tradition of hierarchialising knowledge into degrees of truth according to their 'verifiability'. Truth to Heidegger is existentially contingent and therefore situated and forever partial (Heidegger 1966). To Heidegger the Being of our existence is not the ego centre subject of Idealism but instead an experiential 'there-Being' a being that is defined and brought forth by its very relationships with other; its very Being-in-the-world.

Such notions of plurality, however, encourage a strong criticism of relativistism and/or nihilism. Heidegger's non essentialism is believed to create a human being who is cast

adrift in a world that he/she is incapable of exerting any control over, or influencing any change upon. This argument I believe, is unfounded as it tends to be borne from a Cartesian anxiety about uncertainties which, if effort is placed into supporting the certitudes of the world as already defined and made evident by science (to be discussed in greater detail in Chapter Three), can be avoided.

A central concept of Heidegger's approach to realism: that we are 'thrown' into a world already predefined, redresses these claims of nihilism. To Heidegger, Dasein's embeddedness in a history and context of meaning making makes claims of relativism and therefore nihilism misguided. As thrown beings, our questioning is consumate of, and contingent with, this history of meaning. We have choices but our choices in any particular situation or relation are made finite by our histories that form the horizon of our possible understandings. In Benner and Wrubel's (1989) use of Heidegger's fundamental ontology they call this context dependent choice 'situated freedom', which they suggest is the *'... view that persons come to situations with their own meanings, habits, and perspectives and that this history actually sets up the possibilities in the situation.'* (p.23). This non-determinate historical contingency of our meaning making is made clearer by Marx (1961) who suggests simply that people make their own histories but in conditions not chosen by them.

Nevertheless, any anticipation of being able to predict these choices is once again losing sight of the temporality of the *there-being*, and the infinite possibility of interpretations that this temporality induces in every moment. Without slipping into the nihilism of relativism, this situated, partial knowledge is as Haraway (1991, p.191) proposes an alternative to relativism as each researcher takes responsiblity for their own contingency. Relativism on the other hand tends to underserve this responsibility by attempting to be nowhere yet everwhere equally; a position that Haraway suggests leaves relativism mirroring the very irresponsible ideals of universalism that it claims is the dominant practice of fundamentalism.

Knowledge as an Event of Relationships

Heidegger's work is often classified as existentialist or belonging to the transcendental school of Idealism as it is easy to fall into thinking of his thesis of Dasein as a construct of the 'self'. Heidegger (1962) however is more than adamant in insisting that Dasein is not an object or subject itself but the *clearing* (the matrix of relationships) in which all beings may appear and reveal themselves, as what they are. The inseperability of the subject from object or vice versa, the co-extensive nature of the two in Dasein, is the legacy of Heidegger's plural realism and reflects his concerted separation from the Idealism of Husserl's transcendental consciousness, and the solipstic tendencies, or glorification of the individual, so readily found in the epistemologies of Humanism and Existentialism. As Heidegger explains:

> *Dasein is always to be seen as Being-in-the-world, as the caring about things and caring for, as the being-with the human beings it encounters, never as a self contained subject. Moreover, it is always to be seen as standing within the clearing, as sojourn with the things that it encounters, i.e., as disclosure for those beings that come to the encounter. Sojourn is always at the same time a comportment with-other* (cited in Scott 1993, p. 54).

For Heidegger, even the 'I' as known is not an object self of any permanent stature, but instead a relational self; a self that is realised temporarily at any one time in its situationally dependent experiences. The self does not exist in isolation.

Through the matrix of relations which help compose the meaning of who we are, Heidegger understands this situational expression of self as an event (or sojourn) since:

> *... who 'I' am can be said only through this sojourn, and in the sojourn lies at the same time what I sojourn with, and with whom and how I comport myself with them* (cited in Richardson 1993, p. 61).

Our very capacity to know 'self' as such, is dependent on our Being-in-the-world-with-other. Who 'I' am or what I know is therefore always contingent on the totality of involvements with 'other' (both animate and inanimate) in a particular situation (cited in Richardson 1993, p. 55). Since a sojourn is a momentary, passing event, Heidegger's use of the term re-emphasises his prioritisation of change and temporality in our being-in-

the-world. All understanding or theorising about our experience is subsequently understood as only a momentary coming into being and then passing away into other interpretations.

However, trapped within a metaphysical tradition which has nutured an epistemology of expectation, or as Heidegger (1966) states a 'logic of validity', we have a tendency to make Dasein's meaning anything but situationally dependent (contingent). We instead 'fall' into accepting the meaning and purpose of the world as already defined. On the whole, such a mode of being is favoured as it tends to support our expectations or anticipations of the future—our habits of mind. We have become creatures of repetition prefering the security of the already realised as opposed to the 'not yet' understood. Our futures subsequently remain closed and stifled of all potential meaning as the predefined takes precedence in making meaning and significance of our daily lives. All meaning is already given in the certainty of the predefined. We become trapped in epistemological theories as there appears to be no need to engage with that which is already known. And so, the relational nature of our Being-in-the-world-with-other is continuously 'covered over'. We in a sense become alienated from our very ontology, our Being-in-the-world-with-other, through an arrogance of knowledge. We have come to prioritise theory and method over immediate experience.

Heidegger's fundamental ontology of *there-being* denies the linear conceptualisation of knowledge where the person moves from a position of not knowing to knowing (or from a vantage of question to answer). Heidegger instead brings the two ends of the linear equation back upon each other to form a recursive circle, an intimate dance between experience-knowing-being-and language. From this perspective there are no spaces that separate and divide each process of being, only a contingency that unifies. A contingency of meaning making that Heidegger (1962) realises as the hermeneutic circle.

According to Heidegger, the contingency or pattern of meaning that binds and unites this circle of experience is language:

> *Throwness and understanding belong reciprocally together in a correlation whose unity is determined through language.*

> *Language here is to be thought of as saying, in which beings, i.e., from the viewpoint of their Being, show themselves. Only on the grounds of the correlation of throwness and understanding through language as saying is mankind* [sic] *able to be beings* (cited in Scott 1993, p. 55).

Understanding becomes a task of being attentive to the voice of *other*. A voice made evident by and through language since language is understood to speak of our belonging with other; to speak of our relationships with other. Hermeneutic phenomenology as a philosophy is the articulation of this relationship as a dialogue between self and other; a dialogue which is acknowledged as the ontological primacy of our everyday meaning making.

The Language of Our Everyday Lives

In an attempt to see experience as neither subjective nor objective but as phenomenon/or an event, the phenomenological 'habit of mind' is deeply concerned with the relationship between language and experience. Because it is through the mediums of language and expression that we attempt to see phenomena as experience (Kestenbaum 1982, p. 15).

Language is considered by Heidegger (1971) to be more than a tool of verbal communication. Language is not just something we pickup when needed and displace when not in use. To make meaning manifest through expression, the use of a creative medium through which the meaning can take form is required. A word is not just a representation of reality; a map that locates the world. As Heidegger (cited in Kisiel 1993, p. 159) explains:

> *... it is the word which articulates these relations among everything actual, and so itself is the mediation which holds and retains beings in Being. Without the holding and relating word, the totality of things, the 'world', sinks into darkness. Language accordingly institutes the network of relations which is our historical world in its particular differentiations and bounded by its particular horizon.*

From a hermeneutic perspective words are performative in the making of meaning and a word's meaning is situationally dependent (although it has a shared definition). A word

therefore is seen to gain substance and form through its particular, situated expression. As Shotter (1990, p. 25) explains:

> *Perhaps, rather than already having a meaning, we should see the use of a word as a means (but only as one means among many others) in the social making of a meaning. Thus then, 'making sense', the production of meaning, would not be a simple 'one-pass' matter of an individual saying a sentence, but would be a complex back-and-forth process of negotiation between speaker and hearer, involving tests and assumptions, the use of the present context, the waiting for something later to make clear what was meant before, and the use of many other 'seen but unnoticed' background features of everyday scenes.*

Heidegger (1971) understands language to be the 'house of Being', or the showing forth, the letting-be-seen, of the meaning one encounters within the world. To Heidegger, language is not simply an act of thought or speech but an interpretation, an interpretation which he calls hermeneutical. This *movement of understanding* that is hemeneutics is for Heidegger (1967, p. 261) the very way of Dasein's Being. But where Heidegger leaves this notion of our being-in-the-world as hermeneutical to a few paragraphs in his thesis of *Being and Time*, Gadamer, his student, develops a philosophical position, dedicating his life's work to the explication of the hermeneutic nature of our Being-in-the-world-with-other. For Gadamer (1975) experience itself happens through language which makes language our most basic prejudice[12].

Gadamer's Hermeneutic Legacy

The composite nature of language with our experience (our Being), our cultural meanings, is central to the notion of philosophical hermeneutics as expressed by Gadamer (1976, p. 8) who insists that:

> *... in all our knowledge of ourselves and in all our knowledge of the world, we are always already encompassed by the language that is our own. We grow up and become aquainted with* [others] *and in doing so ourselves when we dialogue, when we talk.*

[12] Our prejudice is our historical contingency. We move in a dimension of meaning common with our ancestors precisely through the transmission, the tradition of language (Gadamer 1975).

Against the notion of language as separate from our being and thereby nothing but a tool Gadamer insists, as does Heidegger, that learning a language does not mean we are acquiring the use of a third dimension that exists over and above reality; a dimension that strives to be in perfect correspondence with (mirrors) that reality. Instead, language as acquired is understood both by Gadamer and Heidegger to be at the same time an acquisition of the substance and form of our being. The words we use and their contingent meanings have been handed down to us through centuries of history. As Griffin (1995, p. 51) states '... *The shape of my psyche, how I see, even what I think of as my needs, certainly my desires have come to me through the complex and refined processes of a particular linguistic culture'*. Language and Being are not separate from each other but co-extensive—they are one and the same. In language the self and the world are bound together (Hogan 1976, p.5). Language is the all-embracing medium in which understanding itself happens; and both Gadamer and Heidegger propose that interpretation is one way in which the happening of understanding takes place.

This notion of language as the ontological primacy of our being is appreciated by many scholars. In working with the notions of hermeneutics there has emerged a major shift, in some quarters at least, toward an understanding of human reality as a conversation. For example the following extracts are reflective of such shifts in perspective:

> *The primary human reality is persons in conversation* (Harré 1983, p. 58)

> *Conversation, understood widely enough, is the form of human transactions in general* (MacIntyre 1981, p. 197).

> *If we see knowing not as having an essence, to be described by scientists or philosophers, but rather as a right, by current standards, to believe, then we are well on the way to seeing conversation as the ultimate context within which knowledge is to be understood* (Rorty 1980, p. 389).

> *The actual reality of language-speech is not the abstract system of linguistic forms, not the isolated monologic utterances, and not the psychophysiological act of its implementation, but the social event of verbal interaction implemented in an utterance or utterances. Thus, verbal interaction is the basic reality of language* (Volosinov 1973, p. 94).

Maturana (1991) conceeds that to be human is to exist in language and he describes this state of being as 'languaging'. According to Maturana every human act takes place in language implying that there is no language-free experience:

> *... whatever we distinguish we distinguish it in language, whatever we experience we experience it as we distinguish in language ... Experience, the happening of living, is not the problem for us; our problem arises with our explanations of our experiences and the demands that they impose upon us and those other human beings with whom we coexist. We human beings live a world of explanations and descriptions in language of our experiences as we bring them forth in language, and we even kill each other defending our explanations when we are in discordance about the* (p. 48).

This shift I believe, from the noun 'language' to its verb 'languaging' supports Heidegger and Gadamer's preference for the *performance* or hermeneutic orientation of language in our making of meaning.

In refering to language as performance Reason (1988) demonstrates that there are many language forms throughout our everyday lives in which meaning can be created and communicated, for example:

> *... the language of words which can lead to stories and poetry; the languages of action which can lead to mime, gesture and drama; the languages of silence and stillness which are part of meditation* (p. 81).

When we communicate we work to make meaning of our experiences through these various forms of expression and once again the medium (language) and the meaning (interpretation) are interdependent.

A central tenet of Rorty's (1991) critique of epistemology is that there are no spaces between our thoughts and their expression that can provide a foothold or platform from where the validity or accuracy of the other can be judged. Rorty (1980, p. 96) considers rational certainty or truth to be a '*... matter of conversation between persons, rather than a matter of interaction with a nonhuman reality.*' In having this view I believe Rorty is clearly aligning himself with Gadamer's (1976) claim that, that being that has meaning, has meaning in and through language.

By accepting language as performance our meaning making takes on a self reflexive ethic. Language is no longer considered to be objective, univocal and propositional[13] but instead situated, multivocal and provocative (Hesse 1994, p. 453). Stated more clearly, our language shifts from being considered representative or mirror-like in its correspondence with reality to being realised as primarily constituitive of our thoughts and actions. As Maturana (1991) suggests this ethic is conveyed in the way that:

> *a person stops believing that he or she is the owner of a truth, or the legitimate defender of some principle, or the possessor of some transcendental knowledge, or the rightful owner of some entity, or the deserving meritor of some distinction* (p. 51).

Consequently, instead of searching for universal truths each person becomes aware of their engagment in 'webs of meaning' which reflect the numerous ways they are coping with the particular situations they are in (Rorty 1982, p. 199).

Throughout his work Rorty suggests that the dawning of new awareness or different understandings about an experience can be made evident through a different description of our lives—an effort to break free, or, to see the habits of mind that orientate our meaning making. To introduce a new word or extend a familiar concept in an unfamiliar way is what Rorty explains as breathing 'life' (living metaphor) into our language as it is in these moments that we step outside the area of forced agreement of language as definition and invite the languaging community to think differently about an experience (Kolenda 1990). The creation of new metaphors can therefore be likened to being at the edifice of understanding(s). Heidegger (1971), Gadamer (1976), Rorty (1989) and Haraway (1991) all pay special attention to the use of metaphor as this is a place where they consider the living nature of our language to be at play. Rorty used the concept of 'living metaphor' to help reinforce an understanding of language as performance.

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[13] By univocal I mean as Mary Hesse (1994, p. 453) approaches the issue 'that words have unique, unambiguous meanings, and by propositional I mean that their standard form theories and observation statements are reducible to the conditions of propositional logic, namely that their terms are univocal, they have definite truth-values, and that inference relations are strictly deductive.'

When language is realised as performance, metaphors are understood as more than ways of speaking; they are understood as ways of perceiving, feeling and existing (Lakoff & Johnson 1980). When language is realised in this manner, epistemological advancement can be understood as contingent with our changing descriptions of experience(s). As our Being-in-the-world is temporal and forever changing so too then is our languaging about our experiences. Metaphors can help us 'paint' a picture with words, particularly when the semantic confinements of our language tend to stiffle any meaning being made. It is at this point of language creation, or when using a word in an unfamiliar way and manner, that the realisation of the inherent unlimited potential of knowing our being-in-the-world-with-others is fully embraced. With the help of metaphors we can push the boundaries of confinement, the stasis of theory or the predefined. With metaphors we help to open the doors outward on the already realised and known toward new horizons of potential meanings.

The living metaphor is never contrived. Kolenda (1990) suggests that the living metaphor is an instance of blindly and unexpectedly hitting on a locution, as does the poet, that encourages us to put familiar language to new use. This use of metaphor is not an expected event, but a moment of what Heidegger (1962, p. 353) calls resoluteness: a willingness to explicate the meaning of our being in the most immediate and tendentious way possible. To be resolute is understood by Heidegger as being in the most authentic mode of Being-in-the-world-with-others. Resoluteness is that Being which is not fallen into the they but always reaching forward onto the 'not-yet' of its own most possibility.

Language and being when understood from this vantage of the hermeneutic circle and the living metaphor I believe successfully captures the fluidity or temporality that Heidegger hailed was missing in the question making of his contemporaries. However, that language has become a tool for defining our world (propogating the ontic) is also true. As Heidegger (cited in Richardson 1993, p.55) states: '... *every phenomenon shows itself* [to other humans] *only in the domain of language. In a word, language is the original openness of whatever is that is preserved in different ways by mankind* [sic]'.

As Kolenda (1990, p.6) explains we have created a world of shared meaning, a storehouse of definitions and statements that many people believe are 'facts'. We are *thrown* into this world that has been objectified, labelled, predefined and realised as such in and through our language; an object world that Heidegger refers to as the 'present-to-hand'.

The Synergy of the Authentic for the Inauthentic

Although stifling to the inherent potential of Being and meaning making, the ontic (static/present-to-hand) or representative nature of language is considered by Heidegger (1962) to be of great social and cultural significance. The present-to-hand paradox of language affords us a commonality, a foundation in which to relate, to make conversation with one another. As Gadamer (1979) suggests we move in a dimension of meaning common with our ancestors precisely through the transmission and tradition of language. Hence there is a paradoxical interdependence between the ontic and ontological nature of language that cannot be avoided as Heidegger's (Heidegger 1996) infamous tautology makes apparent: 'We understand because we understand'. A tautology that highlights the unresolvable tension of the hermeneutic event of meaning making.

The very nature of language creates an object to be realised; an objectification that all hermeneuts try to avoid but inevitably face on all accounts:

> *... language is not only an object in our hands, it is the reservoir of tradition and the medium through which we exist and perceive our world. Understanding and interpretation are linguistic through and through* (Hogan 1976, p. 5).

The very act of speaking or writing encourages a finiteness of meaning making that proves a constant frustration to the researcher, especially those who wish to conduct research while still encouraging a sense of openness and ongoingness in their understandings:

> *... in every attempt to think being, being always gets turned the wrong way and changed into `a` being—and thus destroyed in what it is in its core. And yet: Being in its otherness from beings cannot be denied* (Heidegger cited in Maly 1993, p. 22).

The binary or didactic nature of language can encourage a sense of objectification which supports an acceptance, as if given, of a dichotomy between value and fact; subject and object. In using metaphor to explain this ambiguity Wood (1993, p. 146) states *'... the caged creature* [of dialogue] *is only released into a pen, in which the bars are stronger and the locks are more secure.'* This tautology of language is a frustrating but inevitable tension that is beautifully captured by Lather (1991, p.xix) who realises that *'... as I write, I face the inescapability of reductionism. Language is delimiting* [but it is a] *strategic limitation of possible meanings. It frames; it brings into focus by that which goes unmarked.'*

Subsequently, the frustration of the hermeneut is inevitable because of this impossibility of being able to describe or write about one aspect of the ontological circle of experience, thought and language, without in turn temporarily encouraging a sense of 'stepping off' the hermeneutic circle. The interpretation of a text momentarily encourages a sense of capturing the essence of the text's meaning which promotes an illusion of finality to the process of meaning making. Our historical predisposition to regard language as a tool adds to this illusion of finality. We learn to read with books which always have a beginning , middle and end. We engage in conversation in a similar manner. Each circumstance creates a situation that unwittingly encourages a sense [an illusion] of reaching a final point from which we can then draw a conclusion. A belief that the text does somehow have an essence or final meaning seems unavoidable. However, as Gadamer (1976) and Rorty (1989) suggest, a book or text does not have an end or beginning, but just a never ending reader.

So, language is at once the ground for engaging in the process of meaning making while at the same time acting as the boundary, the cage that can restrain and inhibit further meaning making from occuring. That we rest comfortably in this predefined world, remain blind to the unlimited potential in that which is already defined or supposedly known, is what Heidegger, Gadamer, Rorty and Haraway continuously appeal against. The effort is not to succumb to a need for final truths or answers as they only act to confine or cover-over the potential of further understanding. Instead, the challenge is to

realise the ongoingness, the 'not yet' of our understandings as we interrelate (dialogue) with each other and question the meaning of our experiences, the meaning of our lives.

Returning to the Question

In order to remain open and authentic to the possible interpretations that can be gleaned from the parents' experiences I need to remain forever cautious and critical of the tendency to 'cover over' any possible new understandings I make with the already given or predefined meanings that this experience throws forth. The entire hermeneutic phenomenological approach (and theory of social constructionism) to understanding commences with this very caution:

> *[A]ny genuine method is based on viewing in advance in an appropriate way the basic constitution of the 'object' to be disclosed, or of the domain within which the object lies* (Heidegger 1962, p. 350).

Such a perspective is a call for critical reflection that encourages a questioning of the tendency to classify hermeneutic phenomenological inquiry as uncritical since it is considered to do nothing more than merely describe human experience. I suggest however to the contrary (along with others such as Hekman (1984) and Crotty (1997)) that hermeneutic phenomenology is highly critical as it encourages a calling into question the very foundations of our interpretations.

Without doubt understanding is the primary intent of hermeneutic phenomenology. Yet through the reflexive dynamics of hermeneutics, change is integral to this understanding and needs to be appreciated as such (Hekman 1984). In addition, the situational change of hermeneutic phenomenology is of moral value for participants of research. The change that can arise from a hermeneutic inquiry is an integrated change: a change that has arisen from the very process of 'their-being' (the participants' their-being). The change is not a 'form' of change that has been identified soley by me, and placed upon the participants under the rhetoric of emancipation. To me, this outside, predefined change, reeks of arrogance as it tends to work from the assumption that the researcher is the expert who can see or know the phenomenon/experience better than the 'indigenous'

experiencer. In this thesis, the strategy for generating meaning capitalises on the potential of the parents to articulate and expand on the linguistic conventions in which they are already enmeshed. Each parents' description therefore becomes a reflection of their particular interpretation of a shared meaning, and is continuously valued as such.

The context (Chapter Three) presented in this thesis is the first stage of this research process as it helps to explicate an ontological expression of the relationship between the living tradition, or shared meaning, of the parents' experience and its present ongoing particular interpretation. Each parent's expression of their experience is a consequence of their living in a world that is already predefined, flooded with meaning that makes understanding or meaning making possible in the first place. As Gadamer (1975, p. 293) maintains:

> *... the hermeneutic circle describes understanding as the interplay of the movement of tradition and the movement of the interpreter. The anticipation of meaning that governs our understanding of a text is not an act of subjectivity, but proceeds from the communality that binds us to tradition. But this communality is constantly being formed in our relation to the tradition. Tradition is not simply a permanent precondition; rather, we produce it ourselves inasmuch as we understand, participate in the happening of tradition, and hence further determine it ourselves. Thus the circle of understanding is not a methodological circle, but describes an element of the ontological structure of understanding.*

Each parent's interpretation and expression of their experience is thereby an outcome of a dialogue between their particular lived experience within a shared, common culture; a dialogue that gains its momentum for meaning making from the very way in which they (as we all are) are *thrown* into a world of which they are ahead of themselves because of their own historicity: their belonging to a world of shared meaning.

History, through the lens of phenomenology, becomes the very rhythm of hermeneutics, the very contingency of our particular, situation dependent interpretations. In hermeneutic phenomenology history is the expression of the interweaving of our past, present and future into what is understood as our situated or present state of being-with-other. Our meanings are simultaneously created and manifested through our relationships and their expression. The very prejudice of one's tradition makes

understanding possible. Although some prejudices are obstacles which need to be overcome, it is the pivotal prejudice of language which provides the medium in which understanding can happen (Gadamer 1979).

Heidegger's (1962) reasoning that Dasein does not simply have a history but 'is' historical in its very Being means that our interpretations not only have a history but also make history through their very process of conversation/expression:

> *... as epoch-making, it* [Dasein] *determines 'a future' 'in the present'. Here "history" signifies a context of events and 'effects', which draws on through 'the past', the 'present', and the 'future'. On this view the past has no special priority* (p. 430).

According to Heidegger (1962, p. 275) an ontological interpretation of an entity is an 'event' of laying the phenomena bare with regard to its own state of Being, its historicity. From this statement, it would be easy to interpret Heidegger as refering to some *a priori* or fundamental essence of being to be uncovered, but this, I would suggest is to the contrary. Heidegger insists that the only *priori* is change and so in this instance of ontological interpretation he is refering to the explication of the world of meaning that gives this experience significance in the first place: the predefined world that is the situation's historically dependent context.

Yet in presenting a context of the parents' experiences the term context is not to be regarded as some well defined phenomenon that can be managed and analysed repeatedly with the same certainty. Instead, context here is textual not structural as it is fluid and highly relative, depending on the interpreter and questions asked. For Gadamer (1975, p. 129):

> *... the dialectic of question and answer is there all along in advance of the dialectic of interpretation. It is the dialectic that lends understanding the determinate quality of an event.*

The 'event' which occurs at the meeting of question and answer is understanding (Hogan 1976). Hence the context sought in this thesis is, in a broad sense, a general web of

interrelations on a social and cultural level that give rise to the intricacies and uniqueness of each parent's experience.

This approach to context understands human experience, not from a deterministic, linear, behaviouralist perspective, but from a hermeneutic vantage that respects the dialogical and recursive nature of meaning making, where our histories are forever dissipating into yet another possible interpretation—another way of telling the story (Heidegger 1996).

Calling upon the understandings of Heidegger (1977) and Gadamer (1976) context is considered here to be more than just the deliberate act of throwing a signification over some naked thing which is present-at-hand. Instead, context is understood as the 'totality of comportments/involvements' that provide the forestructure for the experience to be understood or realised in the first place (Heidegger 1962, p.150). Benner and Wrubel (1989) called this forestructure 'background meaning' which is neither subjective nor prepositional as it is:

> ... *what a culture gives a person from birth: it is that which determines what counts as real for that person. It is shared, public understanding of what is. Background understanding is not itself a 'thing', it is rather a way of understanding the world* (p. 46).

Each interpretation is 'historical' or what Heidegger (1962, p. 96) realises as a complex dance of interdependence between our fore-having[14] or prepossession, our fore-sight or preview, and our fore-conception or preconception of the phenomenon's meaning.

More specifically, the explication of a context for interpretation is a philosophical premise of hermeneutic phenomenology which holds that the parents' experiences are embedded in a 'totality of involvements' already anticipated or understood by the

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[14] All intepretation according to Heidegger presupposes acquaintance with, or familiarity with, the phenomenon interpreted since the process of interpretation is based on the circular (hermeneutic) interplay between a) Fore-having (vorhabe)— understanding something in terms of a totality of involvements; (b) fore-sight (vorsicht)—seeing something in advance from a point of view; (c) fore-conception (vorgriff) — the final or provisional way in which we conceive of something or, in other words, the preconception informing an interpretation.

researcher. So from a position of research pragmatics, explicating a context is an act of offering a glimpse [a sojourn] of some of the common possibilites of existence (ways-of-being-in-the-world) that give substance to the parents' experiences, and makes evident that the subsequent research interpretations are a composite of fore-sight, fore-conception and fore-having. As Haraway (1991) suggests explicating a context is an act of responsibility by the researcher for the interpretations being made by 'someone from somewhere'.

The explication of a context can also be understood as a process which Heidegger calls (1962, p. 146) *making room* amidst the reader's multiplicity of preunderstandings for an understanding of the parents' experiences; a process of giving these experiences some shape and perspective from where further interpretations and understandings can unfold.

In trying to create this space we are once again confronted by the inevitable tension between the ontic and ontological aspects of language as this very process of contextualising the experience has a tendency to momentarily suspend or bind an experience into a superficial, yet pragmatic, zone of reasoning. This process is however only transient as each reading, each time the text of this thesis is revisited, the living, fluid nature of the meaning is lifted and released from the static, eternal print on the page and placed into the context of the reader. Through dialogue, the interpreter makes the written word speak anew (Hogan 1976). Each reading places the written interpretation into the living context of the reader and so the circle of meaning making, languaging of the parents' experience, keeps spinning.

The challenge for the reader of this thesis therefore is to remain mindful of the temporalness underpinning the thesis meaning and realise that the context, as presented in the following chapter, is not intended as a formal structure that has some fundamental or a priori claim upon the parents' experiences. Nor should the context be understood as a product of purely subjective or objective musings on the researcher's behalf. Instead, the language of the context, like all language as hermeneutical, is realised as the locale for the merger of past and present and where understanding as an event is realised as a:

> *... historically operative process taking place in a historically operative consciousness in which the horizon of the past merges with that of the present* (Hogan 1976, p.3).

When reflecting upon the interdependence of meaning and interpretation and the dynamic of language in the conversation between self and other a fascinating tension is elluded to that exists between the researcher and the researched in projects such as this when a context for understanding is put forward. Ultimately, the context presented is borne of choices that I have made about what needs to be discussed in order to ground the interpretations I am making. Therefore, the context as realised can, in many ways, be seen to primarily convey more about me and how the question influences my being in the world (what issues the questioning of the experience throws forth for me) than it does of the parents. This contextual bias however is an irony that, in my opinion, is inevitable simply because of my inability to stand removed from my own historicity in a totally unbiased and non judgmental fashion.

I therefore do not support traditional metaphysicians' thoughts that there is a position of judgment that stands removed from my interpretations nor a position that removes both my influence upon the parents stories and their stories influence upon me. Instead, I embrace Heidegger's philosophical modesty which as Carson (1980, p. 413) suggests is *'... his refusal to delineate a privileged region of knowledge.'* Heidegger recognises the impossibility of trying to stand outside all subject areas. His theorising about fundamental ontology is an ontology that arises from looking at the meaning of an experience while standing within it—forever immersed in our histories of meaning making— and so always having a partial view from somewhere.

Subsequently, no explication of context could exhaust or do complete justice to the multitude of possible issues that bind this experience for the parents. Instead, an interpretive inquiry such as this begins with a context that is the reflective recovery of some vague average understanding of what this experience could mean—realising that this context is just one possible interpretation where each interpretation has the tendency to *cover over* as many possible interpretations as it *uncovers*.

Conclusion

Accepting this prejudiced interpretation as an inevitable outcome of not only a research project but also our whole way of meaning making is an important arrival for the progress of a research project premised on hermeneutic phenomenology and social constructionism. Generating an understanding according to both Heidegger and Gadamer is (cited in Risser 1997, p. 53) always an event and not an:

> *... act of subjectivity where a non objectifying consciousness always accompanies the process of understanding, but rather that understanding is not suitably conceived at all as the consciousness of something, since the whole process of understanding itself enters into an event, is brought about by it, and is permeated by it. The freedom of reflection, this presumed being-with-itself, does not occur at all in understanding, so much is understanding conditioned at every moment by the historicity of existence.*

The context (Chapter Three) is thereby understood for what it serves and that is as a pragmatic tool to 'make a space' and give the reader a general, broad brush stroke discussion of the backdrop against which the parents' experiences unfold and from where my intepretation is made.

A fortunate consequence of this thesis being attached to a larger research project that sought to understand not only the families experience, but also the experience as understood by doctors and nurses, is that I was afforded a constant cross referencing of possible understandings and perceptions of the experience and its context between the three groups. Through this involvement I was able to set in place a constant dialogue of questioning where I was forced to reflect upon the decision or choices I was making and determine the significance of these choices to the parents' experience as understood and conveyed to me. The context presented therefore evolves from this vantage of continuously critiquing the questions I was asking myself of these three groups. My aim in this forthcoming chapter is to open up discussion of the complex web of psycho-social, cultural, societal factors that embedded the parents' experiences to be understood.

Chapter Three

Context: Situating the Experience

Introduction

Given the portentous issues raised and discussed in the foregoing chapters, notions about death invariably form the contextual structure: the *foresight* and *foreconception*, the *preview* and *preconception*, of an understanding of the parents experience as lived. In this chapter I explicate this context and suggest that how we as a society cope, manage and engage with our sense of mortality is implicit in the parents' meaning making of their experience, and so too any interpretation of their experience.

While acknowledging fear of mortality as a cultural nexus for the situated event of the parents' experience this chapter also attempts to reinstate an understanding that the death the parents witness is far more complex than the *traditional* death being stillness of breath, heartbeat and flow of blood. As already eluded to in the introductory chapter, organ donation deals with a *new death*: a medically orchestrated and legislated death called 'brain death' that defies each parent's anticipation of death's presence or reality. This chapter further critiques this new death and extends the discussion to a number of other pressing issues that invariably influence the parents' experiences, such as concepts of personhood and embodiment.

In making notions about personhood and embodiment questions for concern in this discussion, I am not in turn suggesting that they are new in regards to our cultural attempts to understand death. If anything they have remained throughout history the 'close friends' of any philosophical, religious or scientific discussion about death. This new death however, has shed light, a new intensity, on their significance when considering death. Moreover, one cannot discuss the social and cultural context of death without also critiquing the central role that medicine has taken in the modern era with not only defining death but determining the parameters death places on our lives.

Invariably, in talking about the medicalisation of death the institutionalisation of death is also thrown forth.

The social or cultural expectations of parenthood will also be discussed from the vantage point of death and include a discussion of research that has investigated what it means for a parent to lose a child. Particular to the contextualisation of donor parents' experiences lies an acknowledgment that their experience takes place in a circumstance and environment where the innate responsibilities or expectations of parenthood—such as protection of their child against pending danger or pain—are displaced. Medicine, the modern era's *conquistador* against our mortality, is rightly or wrongly seen as central in this displacement of the parents' role. A review of the dominant role that medical science plays with informing our social and cultural understandings of death and how it is best managed, becomes central to this discussion.

Any discussions in this chapter about medicine primarily focus on the social authority that the medical profession has been granted in defining and diagnosing the dramatic begining and end points of our lives. As a highly organised and regulated professional body medicine is seen to possess the necessary knowledge and insight to unleash us from our fate; to keep at bay our ever present mortality (which under the medical gaze has become our morbidity). With medicine's aid, death has become something to be manipulated and postponed. In being so however, a multifarious array of decisions, which in themselves induce more questions than answers, have been ushered toward the bedside of the dying patient. I highlight how despite the deluge of moral and ethical uncertainties that biomedical technology tends to produce, medicine's ever increasing ability to intervene and disrupt life's inherent sequence (from birth to death) holds contemporary society mesmerised:

> *Science promises a kind of heaven on earth, a brave new world made even better through technology. And if by Western religion meaning is deferred to a future afterlife in which accounts will be not only taken but also understood, science also defers ultimate meaning to a future not only happier with material fulfillment but one in which a unified theory has revealed the true nature of the universe* (Griffin 1995, p.35).

I discuss how, despite medicine's constant promise, we seem to have lost touch with a subtle, yet profound, humility which acknowledges death as the only certainty we have. We seem to have lost sight that despite their unceasing heroic efforts, no doctor has ever 'conquered' death but only defered the inevitable. Instead, we have attempted to appease our existential angst by establishing a firm faith in the successes of medical science; a faith that despite its efforts has only seemed to further extend our avoidance of death.

Hence a review of death's certain presence but uncertain timing and purpose in our lives forms the central theme of this chapter's review. A review that situates us all (parents, researcher and reader) within a society that has an entrenched and somewhat debilitating obsession with attempting to achieve some certainty about our existence despite its ever present, overt impermanence.

Death: Our Greatest Paradox—The Certainty of Uncertainty

> *Planning for the future is like going fishing in a dry gulch; Nothing ever works out as you wanted, so give up all your schemes and ambitions. If you have got to think about something— Make it the uncertainty of the hour of your death.*
>
> (Sogyal Rinpoche)

For me, Sarah's questioning, which begs for some sense of purpose or reason from which to understand her child's death, resonates with a fundamental inquiry that has been intimate with the human quest for knowledge since the dawn of reasoning. According to Marcel (1973) the essential problems or questions of life are posed by a conflict that we all have between the powers of love and death. What ultimately matters to us is not our own death but the death of someone we love. So, although we cannot experience our own death, death as Carson (1980, p. 467) suggests is primarily understood by the 'radical discontinuity' it creates in our relationships with others.

Attempting to accept death as the 'natural' end or final boundary of life is made difficult when death involves the people we love:

> *All of us eventually experience the death of someone we love. The pain of loss can be searing to the soul of a person. The realisation that the beloved is gone forever—as far as the world is concerned—can be so overwhelming that nothing means anything any more. The world that we built around this person suddenly comes crashing to our feet, a nothing. From the depth's of one's being arises a cry that no one else can understand—except the one whom we loved. Across the infinite chasm that death causes between us, we touch* (Lonergan 1975, p. 23).

As Carson (1980, p. 467) states *'... we do not completely belong to ourselves'*. Our personhood is always intimately created and extended in our ongoing relationship with others (Heidegger 1962); and death is the one event that makes this so obvious. The death of someone we hold dear has the capacity to disrupt the narrative of our shared history and we are often left feeling lost and uncertain of how to go on. Left to continue on, the patterns of our lives will never be the same (Attig 1995). The often heard lament of a person in grief that, 'I feel as though a part of me has died' subsequently takes on a new dimension when understood from this relational perspective.

With our sense of meaning and purpose arising from the dynamic of our relationships, the discontinuity or rupture that death brings to these relationships, has the effect of bringing a part of our self meaning, our sense of personhood, to an end (Kastenbaum & Aisenberg 1979; Carson 1980; Gilbert 1996). In many ways, the vacuous questionings, the endless *whys*? that commonly accompany our experience of death, reflect this interconnecting lesson of death's presence for life's purpose. These at first incipient, seeking *whys* tend to search more broadly and deeply than the immediate need to understand the death of our loved one. Indeed, these *whys'* can be realised as intimately bound to other more personal and profound questionings about life itself such as, why is there life?, why am I alive?, is there any purpose to this life, my life, that appears to be so transient and finite? These questions, all compelling and life transforming, have throughout history defied easy answers—in spite of death's constant presence in our lives.

Death is our ultimate existential boundary and how we cope with or manage it is intimately bound to our cultural and historical prejudices. This paradoxical significance of death for life's purpose appears to hold centre stage upon which life's meanings,

uncertainties and ironies get played out. Some of the greatest literature in the West is inspired by a tension we create between on the one hand our desire for an ultimate, immutable reality (immortality) which could help to redeem the loss, versus an inchoate conviction that, in reality, such a place does not exist (Dollimore 1998, p. xiii). Death is seen by many scholars (Choron 1963; Cassell 1975; Carson 1980; Aries 1981; Carey & Sorensen 1997) as our greatest taboo. Yet ironically, death has remained throughout history a cardinal theme for our literary and visual entertainment. We pay money to be entertained with themes of death, while readily dismissing death as part of our everyday conversation. We are a society that seems caught in a continuous tug-of-war between our wish to know as much as we can about death (perhaps to understand it but more likely to possibly control it), and our need to avoid or dismiss such discussions as they confront us with our ever present finality.

Death: Our Constant Companion

> *'... mutability destroys not only living things but all human endeavour'*
>
> (Dollimore)

The process of change and our decline over time is typically more disturbing than the idea of not being at all. Human beings are confronted by the transient (changing) nature of their existence in the very matrix of the world that surrounds them. From the changing of seasons to the budding and decay of a rose, change has and is experienced as a fundamental process of human existence:

> *... life is nothing but a continuing dance of birth and death, a dance of change. Every time I hear the rush of a mountain stream, or the waves crashing on the shore, or my own heartbeat, I hear the sound of impermanence. These changes, these small deaths, are our living links with death. They are death's pulse, death's heartbeat, prompting us to let go of all the things we cling to* (Rinpoche 1992, p. 33).

It is often noted that we are the only beings in creation who can contemplate our own graves, make plans upon that anticipated calamity and actually sense death's approach (Taylor 1963). Indeed, one of humankind's oldest recorded text is from the presocratic

scholar *Anaximander (610-547 B.C.)* who through his writings makes evident humankind's centuries-old preoccupation with trying to seek meaning to death's unyeilding presence in our lives:

> *Things perish into those things out of which they have their birth, according to which is ordained; for they give reparation to another and pay the penalty of their injustice according to the disposition of time* [cited in Choron 1963, p. 34].

What can the grand purpose of death be?, is a question that has preoccupied the greatest minds for centuries past. Is there any purpose to our mortal existence other than the obvious lineality of, being born, living and then dying? Why is there such a thing as death? If we die only to live again beyond death, as many religions suggest, then why should we die at all? Is reality just an illusion, or as Descartes (1955) feared, some intolerable trick played on us by some evil genius. Demand for an answer to all these questions about life's purpose is so potent that all philosophical pursuits from the humanities to physics can be reduced to this central inquiry about life's meaning.

However, while Anaximander's writings reflect something of the modern era's angst, and condemned struggle against death's certainty, the presocratic philosophers such as *Heraclitus (c. 535-475 B.C)* pursued this inquiry with an optimism and modesty that appeared to accept life's finiteness. Heraclitus suggests that, '*... the fairest order in the universe is a heap of random sweepings'* (Heraclitus cxxv, cited Dollimore, p. 5). For Heraclitus the reciprocal extremes of our being and non-being create a unity, an interdependence where life is the bow and death is its work (Choron 1963, p. 36). Throughout his work there is a profound sense of equivalence between life and death as, '*... immortals are mortal, mortals immortal, living the other's death, dead in the other's life* (Heraclitus xcii, cited Dollimore, p. 6).

Heraclitus understood change to be the basic characteristic of life and so his questioning of life's purpose was enamoured with a humility of inquiry that demanded neither a single answer, nor final certainty:

> *... one cannot step twice into the same river, nor can one grasp any mortal substance in a stable condition, but it scatters and again*

> *gathers; it forms and dissolves, and approaches and departs* (Heraclitus cited in Kahn 1979, p. li).

Instead of needing final truths and answers about life's purpose the presocratic philosophers found the questioning or process of inquiry itself to be the very answer. Heidegger (1937) had faith in the modesty of this presocratic thought. For him their style of questioning required an utter openness of mind. A mind willing to suspend a need for certainties and thereby remain unclouded by any beliefs or presuppositions about existence. Despite the apparent modesty of such questioning Heidegger (1962) reveals a similar stance to be exceedingly difficult in the modern era; as such questioning is totally alien to the modern day demand for answers. In contemporary society such an open ended process of inquiry can create an anxiety, fan an existential angst in a mind that has been conditioned by centuries of truth seeking to expect the security of certainty:

> *... the search for certainty is the basis of Western metaphysics, and a crucial influence on Christianity; it is the most influential attempt to escape from the mortal world of flux and change and decay. Nothing lasts; everything is transient: but for Socrates—and later for Plato—'pure knowledge' is possible. it is achieved by the soul's recognition that every mutable thing derives its identity from an original 'form'* (Dollimore 1998, p. 9).

Death: Our Existential Angst

> *[W]hat is life but this dance of transient forms? Isn't everything always changing: the leaves on the trees in the park, the light in your room as you read this, the seasons, the weather, the time of day, the people passing you in the street? And what about us? Doesn't everything we have done in the past seem like a dream now? The friends we grew up with, the childhood haunts, those views and opinion we once held with such single-minded passion: We have left them all behind ... The cells of our body are dying, the neurons in our brain are decaying, even the expression on our face is always changing, depending on our mood. What we call our basic character is only a `mindstream`, nothing more. Today we feel good because things are going well; tomorrow we feel the opposite. Where did that feeling go? New influences took us over as circumstances changed: We are impermanent, the influences are impermanent, and there is nothing solid or lasting anywhere that we can point to ... The only thing we really have is nowness, is now.*
>
> (Sogyal Rinpoche)

All contemporary theories about death and life and in particular the present day debates about the redefining of death as brain death can be classed, in an appropriately broad sense, as stemming from either Plato's[15] notions of immortality and dualism or Aristotle's theorising about monism and mortality (Flew 1987). Put more simply, our contemporary attitudes about death can be understood to revolve in a mutiplicity of shades around a belief in either our immortality (Plato) or our mortality (Aristotle). It seems that when pressured we all ultimately make a fundamental choice, between conceptualising our death as either an ending or a new beginning. Like most dualisms or division however, this is a deceivingly easy one because despite such theorising about death its inherent uncertainty makes all efforts to claim one position in favour of the other mere supposition.

The weight of death's significance in our lives seems to be that it is the ultimate force of change in our temporal relations and that we have no certainty as to whether this change is an end of something past or the begining of something new. This lack of certainty has subsequently made death our constant angst and lorded to be our greatest enemy. There is however another way to realise this lack of certainty which is to perceive it as a possible liberation. In not being able to live to tell of our experience of death, our relationship with death is open and compelling as it is inherently uncertain and thus full of potential. Death is always a future possibility, the 'not-yet' or horizon against which we are in a constant process of becoming (Carson 1980).

Throughout history though, the liberating quality of this uncertainty of death has not been embraced. Our general lack of certainty in the face of death creates an anxiety that has encouraged centuries of need to build theories and disciplines of thought that claim to have the answer(s) to which we can cling (Adams 1997; Flew 1987; Aries 1981; Carson 1980). With these answers we attempt to transcend our anxiety or sense of meaninglessness in the face of death's certain uncertainty.

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15 Plato compared the soul of man to " a pair of winged horses and a charioteer", one of the horse being "upright and cleanly made ... a lover of honor and modesty and temperance", while the other is "a crooked lumbering animal" filled with lust and insolence and pride (cited in Marsh 1985, p.55)

Having a sense of purpose is an invaluable ingredient in our capacity to survive life's struggles. Certainty and purpose however have been linked throughout our society's history with deleterious effects. Holding too tight to certainty as our means and sense of purpose has culminated in our increasing sense of alienation within a predefined and well ordered world (Neitzche 1956; Tarnas 1991; Capra 1997; Suzuki 1997):

> *... science has left a void. In the domain of reason, no cohesive vision, no reason for one's own existence, or existence at all, remains ... the system designed to protect us from nature creates an unnatural frailty. Divided from life processes which cannot be extricated from death, from earth, the grounding of being, the self is confused* (Griffin 1995, p. 52).

Philosophers since Socrates have stumbled through euphemisms in an attempt to find purpose to their mortality and in doing so raise human existence above nihilism and scepticism towards some purpose and reason. Although their efforts are inherently meaningful, achieving answers or certainty about death is forever thwarted by our inability to experience it in any other way than vicariously. Death therefore remains forever unfamiliar and fraught with uncertainties as death understood is the death experienced by another—and few travellers have returned to tell their story.

In spite of any solemn belief in the continuance of the person after their death the elaborate social rituals of funeral ceremonies and cultural acts of mourning make innuedo of death's finality. These rituals of mourning tend to signature the commencement of our permanent loss of relation with this person, and they are rituals that firmly reinstate the mortal boundary that death's presence in our lives make so obvious.

However, despite the lack of certainty that surrounds our understanding about death, throughout history death has paradoxically helped us to define life—give life its meaning. Many scholars, especially those of an existential persuasion, suggest that death's purpose is achieved by the very boundary it imposes upon our lives and relations with others. This boundary helps to provide our lives with a distinct shape and character. Heidegger (1962, p. 378) in particular, embraces this paradoxical nature of death. Instead of regarding death's paradoxical stance upon life's meaning as a crisis of reason he celebrates death for this very characteristic. Death's presence in our lives is

understood by Heidegger (1994) to at once limit but also determine the possibilities of our human existence (Dasein). Of all the possibilities potential to our being, Heidegger (1988) realises death to be the most unavoidable, yet thoroughly necessary. Death is realised as the very horizon that gives momentum to the hermeneutic event of our lives. Without death affording life a finite horizon it has been argued that there could be no experience (Choron 1963; Carson 1980; Kastenbaum 1988; Adams 1997). '*... for if our vision had no limits, if by looking long and carefully enough we could see everything, we would then see nothing*' (Carson 1980, p 3).

For Heidegger (1962) all tenacity to whatever certainties we have of existence are shattered by death's constant paradoxical presence of being a certain uncertainty. Heidegger (1962, p. 308) thereby understands death to be humankind's greatest liberator as death '*... discloses to existence that its uttermost possibilities lie in our future uncertainties.*' Acknowledging the inevitability of our mortality is regarded by Heidegger (1962, p. 379) as a '*... necessary condition of living the best human life possible.*'

Death awareness and acceptance is suggested by Heidegger (1962) as necessary for encouraging in us an intent to do something worthwhile with our lives. When faced with mortality our life suddenly becomes finite in its possibilities which in can create a necessary tension (a care) to question ' *... what is really best given the powers or potencies of the specifically human existence in which we find ourselves*' (cited in Page 1995, p.141). Because life is limited, our time becomes precious. Through our death awareness we are 'thrown back' on our life's activities and events with what Heidegger (1962) calls a *mood* or existential comportment of care, that orientates us to seek purpose and meaning about our lives. Death's certainty in our lives thereby results in our lives becoming not just a matter of surviving but provides us with the intention to have a good life, to live life with purpose, whatever that sense of purpose may be (Page 1995). That death's certainty is so uncertain is upheld by Heidegger as the means by which we can cope with its inevitability.

Throughout history the certainty of our death has encouraged, for many, a critical reflection of human existence. Death's certainty has opened a conceptual space for life's

purpose to be duly critiqued. Our mortality has functioned in our social psyche to 'bracket a space' for the possibility of finite achievements and failures in finite situations, and consequently the growth and development of character (Hick 1976). Life, when seen through the lens of death, can gain a cohesiveness, a sense of wholeness and closure which would possibly[16] be absent in a sea of immortality. In creating this horizon or sense of closure to our lives death helps to frame the various pages of our existence into a life story, and in doing so helps to give life a sense of purpose and meaning. Without our awareness of death our momentum as a civilsation to know and gain purpose and hence create domains of reasoning such as art, science, philosophy and religion, would waver. It is, according to Adams (1997, p.46) because we die that *'... we create civilisations, philosophies and beliefs that are finally death defying and death denying.'*

Our capacity to cope with life under the constant threat of death tends to be reliant on our having a sense of purpose or belief in some spiritual doctrine[17] about life after death. Religious faith has always been a way of placating our existential angst through encouraging adherance to an authoratative narrative about what happens to us when we die. Through the nurturing of faith in an omnipotent being and the expression of the soul, religious narrative(s) help many people to escape the conceptual void of nothingness that seems to be its alternative.

In what is arguably the longest standing and most enamoured dualism: the eternal soul and the ephemeral body, death in the hands of religious control has become something that can be transcended. There are however, rules about how death is to be transcended from being a potential for oblivion to being the entrance to eternal life. Because of its ordained communication with the only and greatest authority, religion claims to know how life is designed and therefore purposeful. Under the tutelage of religion, fear of death is used as a potent enforcer of faith, the crucible against which the quality of living

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[16] 'possibly' being the guiding term here because as said before nobody knows with any certainty about life after death.

[17] these spiritual doctrines are as varied and unique as are the individuals who nurture them.

(evil versus good) is judged. Death becomes the entrance to either eternal damnation, suffering and darkness or release into eternal peace and light. Humankind's desire for certainty has been an expedient ingredient for the continual polarisation of mind and body; faith and reason; rational and irrational; purpose and myth.

However, where some turn to religion for faith and guidance about their uncertainties, in the modern era, this religious zeal of a soft, intangible omnipotent god has been exchanged for the harder more tangible reasoning of science. Science has become the contemporary sooth sayer and demi-god for many people.

The Need for Certainty

Humankind's need for certainty in the face of life's mutability found its saviour in Descartes (1596-1650) who, in standing on the shoulders of Copernicus and Galileo, shifted the social psyche from mysticism to mechanism and in doing so ushered in the scientific revolution (Solomon and Higgins 1997). An expectation of certainty was the legacy of Descartes era and the centuries of protagonists to follow. Humankind's need to be stronger and more resilient, less temporal (mutable) than nature, nurtured the birth of a paradigm of reasoning called Realism or Empiricism which was premised on a systematic method of inquiry that could remove the 'ghost from the machine' by forcing nature to reveal its essential order (Tarnas 1991).

In search of certainty, science separated from and superseded religion in determining the meaning and reason for our existence through its claim to hold the only rational answers about the meaning of life. By separating science from theology, scientists won the right to make assertions which otherwise would contradict religious descriptions of the universe (Griffin 1995, p. 33). Science replaced religion as the high priest of knowledge about life and death. Although many ideological changes in this contemporary era have seen science's certainty challenged as only provisional and increasingly esoteric, it remains in the public eye a testable truth and one that is seen to be continuously improving and practical in its effects and control of nature (Heelan 1991; Kockelmans 1991; Tarnas 1991). From agriculture and medicine to communications and warfare,

science repeatedly procures society's faith. Through a constant display of tangible evidence of its claim to render the closest thing we have to certainty[18] and control over the world that is seen to surround us, science is given our trust.

The ardent pursuit of truth by science can be seen as built upon our fears of death's uncertainty and the desire to avoid death (and uncertainty) at all cost. Harnessing scientific truths—however illusively—has helped us dominate nature. Pursuit of a method to maintain this control is arguably the driving force behind the dominance of the scientific method (Merchant 1990; Suzuki 1997). History has proved, however, even the most ardent theories arising from the use of this method temporal in nature and thus dominated (ruled) more by uncertainty than certainty (Tarnas 1991; Prigogine 1996).

Historical hindsight reveals that our understandings of the world are continuously reworked and so any attempt to control our existence is ultimately transient as there always appears to be *forces* (which we collectively label as nature) beyond our control. Through the very cycles of birth and decay humankind is intimately connected to nature whose inpermanence nurtures in many an inherent insecurity:

> *... everything is melting in nature ... An apple tree laden with fruit: how peaceful, how picturesque. But remove the rosy filter of humanism from our gaze and look again. See nature spurning and frothing, its mad spermatic bubbles endlessly spilling out and smashing in that inhuman round of waste, rot, and carnage ... Nature is the seething excess of being* (Paglia 1992, pp. 1-6, 41-42).

Nature has always been a force that despite our efforts to control, has repeatedly confronted us with our frailty, our mortality (hence our unwavering desire to try and manipulate and control it). As I write, the *El Nino* effect is reeking havoc throughout the world. Winters not experienced in decades are bringing whole cities to a standstill in Northern America, while floods are doing the same in Northern Australia. No amount of technology or theory can prevent such situations from occuring nor accurately determine

[18] An inevitable position nevertheless as science is seen to have created both the method and the criteria needed to determine its certainty.

their onset. We are always uncertain of our capacity to succeed against nature, and herein lies the central issue regarding all questions about death and all pursuits arising from its deeper contemplation: life is repleat with uncertainties of which death is the most profound.

Hence, for all of science's reasoning and claims of certainty, death remains life's secret and perpetual trump card. Against the capacity of the geneticist to reduce our physical composition to a map of Deoxyribonucleic Acid (DNA) sequencing the mystery of life, and thus the uncertainty of death, remains. Although the making of truths has long been realised to be fuelled from our uncertainties about death, to turn and embrace uncertainty for this very potential has been regarded as pessimistic or nihilistic (with Neitzsche's madman being the most striking example). So, in favouring certainty over uncertainty science and technology have helped us to keep focused on the search for universal truths with security, stability and permanency being our ever golden promise. Not only do abstract principles partake of the reified, immortal climate of heaven, but the idea of transcendence over earthly life, the life cycle, and death continues for science in another guise, and that is the notion of technological progress (Griffin 1995, p. 35).

In order to be successful science, with the social psyche in toe, needed to break its tether from religion and philosophy, but not without a risk incurred upon our humanity (Suzuki 1997; Tarnas 1991). In removing the 'ghost from the machine' all that remains is a machine devoid of any mystery and feeling. Sadly, the mystery of life that used to be the domain of the soul, is being rapidly displaced by the structure of a DNA molecule whose individual sequence gives reason and cause for the functioning of our existence. Science, in embracing determinisitic philosophies and rationalistic practices, has realised certainty as its constant reward.

Our Death Denial

Despite our incipient awareness of life's mutability, the modern era remains obsessed with certainty; an obsession that harnessess a faith in the potential of science to give us an explanation for everything. The fear of the uncertain and the mute attempts to try

and control that which fails to be understood is what has positioned our society, and its mutifarous array of healthcare industries and commodities, to perceive life as a 'battle' against death. Life and death are commonly understood as opposites *'... instead of reflections of an integrated whole* (Adams 1997, p.68). In this struggle life is held to be the goal of all effort, and so death is to be avoided at all cost. The more complex and intrusive bio-technology becomes in its attempts to avert our death, the potential for uncertainty grows and our drive for control continues (Suzuki 1990).

Subsequently, our faith in the capacity of science to breakdown the frontiers of our uncertainties, medical science's quandary to find a cause and control of our mortality, has reinforced our capacity for death denial. Our mortality and death anxiety have been targeted as weeds in that we give medical science the authority to identify, label and poison as soon as they show signs of shooting up through our *' ... carefully tended landscapes'* (Carey & Sorensen 1997, p.116). We support our death denial by sanitising death's image and hiding its victims in hospitals and hospices. Death, the inevitable and natural partner of life and purpose, has been psychologically forced into the realm of the negative counter of life, the unexpected loss.

Since the dawn of the 18th century and the birth of medicine, society turned from philosophy and religion, as the givers of knowledge about living and dying, to medical science which promises to transcend our uncertainties and control our destiny with its ever pervasive technology (Dutton 1988). Yet, one of the great ironies of medicine's success in the 20th century is that our only mortal certainty (death) has become all the more ambiguous and uncertain. This has proved to be an ambiguity that results in agonising consequences for many patients and their families. In our appreciation and support of hospitals and emergency centers for their extraordinary techniques and expertise in controlling and manipulating our living and dying we are perplexed when we find ourselves silently hoping for our own or loved one's death. Such wishing though, is made often in silence as to wish or ask for death is inappropriate to the social mandate of life at all costs. A fixation with death is labelled, morbid, and has become equated with a weakness—a mental frailty that needs to be remedied. Such circumstances

convey a sad reality. We as a society seem to have reached a moral and ethical impass that fails any capacity to reason about death as a 'natural' part of life. Through the technological manipulation of our lives we have once again extended our confrontation with uncertainty.

Technology's Promise: The Illusion of Certainty

With every new technique or process that medical science affords us to cope with our mortality we are also presented with more uncertainty in the form of questions that fail reason—evade all attempts to be answered. As medicine continues to intervene in the process of death, humankind is led into new frontiers that have no parrallels for comparison or guidance. With social sanction, doctors are creating: *'... a new kind of human being'*. Someone who evades all definitions as we frantically search our present knowledge for words, metaphors, to try and describe or explain what is happening (Suzuki 1990). It is technology, wielded in the hands of a society that desires security from certainty, that creates this sorrowful dilemma (Illich 1976; Caplan 1993). Ironically though, amidst this 'fight' for life, we in the Western world have been forced into a corner were we are being made to turn and face our finitude and to acknowledge its significance. Paradoxically, death has become the ally, as it can release us from this technological limbo that is proferred to have so much potential.

Death is no longer an act that the individual can own. Death is now a right that we have to fight for; a right that has become so entangled with legislation that if we wish to hasten our death we run the risk of being persecuted for suicide (Aries 1975; Steinfels & Veatch 1975). However doctors, nurses and families, who live with the agony of patients suspended in a technological twilight between life and death, can no longer avoid questions borne of uncertainty made all the more ambiguous by the ever increasing technological masking and wizardry of our deaths.

Questions about the meaning of life such as, do we cycle between birth and death? have we lived before and will we live again in another time and place? why do we exist? what is life all about? why are we here? have been strategically removed from the medical

arena as they are considered too subjective and therefore unrealisable as a substantial truth. Such metaphysical questions prove to be more a hinderance than a benefit in the scientific drive for certitude (Wertheim 1995). The closer reality resembles a machine that functions according to the mathematical theorems of physics the more capable science is in transcending its uncertainites (Damasio 1995).

Certainty under the rubric of the scientific method has become synonomous with proof and validity. From the rationalist perspective of science all mystery and potential is reduced and removed if equations of truth are sought. Linear paradigms of truth and reasoning have no room for mystery and potential. If something cannot be reduced and explained there must be something wrong with the method (Wertheim 1995). Although inherently pragmatic, such a perspective is proving to be science's greatest limitation as imagination and inspiration, intuitive leaps of thought, are increasingly appreciated as significant aspects of the conceptual effort considered essential for the advancement of knowledge (Harvey 1988).

Nevertheless, our faith in the capacity of science to bring us certainty has resulted in a history/experience that reveals otherwise. As we become more proficient at reducing and quantifying human existence to its most base components we are faced with an increasing array of uncertainty. In many ways the certainty of uncertainty has become the hallmark of the postmodern era.

Controlling Death

In our contemporary society where death has become associated with loss, our fear of death is intimately connected with a battle against our existential failing, our mortality. Medicine has become our shield that stands between our impassioned obsession with life and our constant uncertainty and fears of death (Cassell 1975). Arguably, the central message on which science has predicated its social mandate is control. Understand the structure of the human condition and we hold the potential to control our fate, our mortality. Medicine's dominance stems in part from its success in constructing knowledge that claims to hold the keys to averting our morbidity, and in the mean time

postpone our mortality for as long as possible (Illich 1975; Kastenbaum and Aisenberg 1979).

However, in claiming control over our mortality, medical science has made death a consequence of illness (Aries 1975; Illich 1975; Steinfels and Veatch 1975); a battle against some destructive force that when identified and labelled can be appropriately managed. 'Don't let it beat you', is a common message given to someone who has been diagnosed with a fatal illness. The subsequent legacy of such reasoning is that in Western society, as the mortality statistics from various countries will display, very few people actually die of old age. Life has become a series of events defined by a medical diagnosis. In writing about the consequences of this very issue Nuland in *How We Die* (1997, p.43) states:

> *... neither among the top fifteen causes of death nor anywhere else in that soulless summary [national mortality statistics report] is there to be found a listing for those among us who just fade away. In its obsessive tidiness, the Report assigns the specific clinical category of some fatal pathology to every octo-and nonagenarian in its neat columns. Neither do those few whose age is recorded in three digits escape the orderly nomenclature of the tabulators. Everybody is required to die of a named entity ... by the global fiat of the World Health Organisation ... everywhere in the world, it is illegal to die of old age!*

Medicine therefore does not only claim to understand life but to understand it in a manner that can make our lives better. Life is now a matter of good heath which makes death the consequence of illness or misadventure (Illich 1976; Dutton 1988).

Our death avoidance is promulgated by a culture of risk modification. We have become a propholactic society where everything from what we eat and drive to what type of sex we have and how long we spend in the sun is regulated to minimise its impact on our carefully manicured lives. Life has become a calculated risk against our mortality where medical science is setting the pace and parameters. Our actions and behaviour are calculated and judged responsible or irresponsible, according to the current parameters or criteria of risk (Sheet-Johnstone 1992). Yet the anticipated easing of anxiety as more and more aspects of our lives are brought under control is lacking. The greater control we

have achieved through such behaviours has a paradoxical effect of unveiling a message of our mortal frailty that only helps to further compound our existential angst.

Society however has great faith in medicine because of its overt success in controlling our crises. Consistent with this faith is power that society has granted medicine, as a profession, to not only control our crises of life but also our entrance and exit from this world. A highly dependent relationship for medicine has been set in place by medicine's authority over social issues of health and illness, life and death. In claiming authority over matters of life and death medicine has positioned itself in the public eye closer to certainty and thereby closer to claims of truth and reason about the fundamental questions concerning existence.

Our faith in medicine and medicine's dominance are seen to be intimitely bound and supported by what Rose (1994, p.50) calls our '*social valorization of health*'. Being given the responsibility to define death, medicine legitimates the parameters of life in a highly objective, rational and efficient manner and in so doing gains a voice of authority in the modern psyche. Society, in capitulating to biomedicine's sanitisation of suffering, has nurtured a sense of 'a' human being who is perfectible through the application of medical techniques. By determining the essential needs of life and thus the causes of death, medicine also plays a formative role in the invention of the social (Foucault 1973; Haraway 1991; Sheet-Johnstone 1992).

The very language that enframes the discipline of medicine has been readily juxtaposed into other disciplinary discourses for the understanding or theorisation of our everyday world. As Rose (1994, p. 154) helps to clarify:

> *... society as it is historically invented, is immediately accorded an organic form and thought in medical terms. As a 'social body' it is liable to sickness: that is to say, it is problematised in the vocabulary of medicine. As a social body it needs to be restored to health: that is to say, its government is conceptualised in medical terms. And, in relation to these forms of government, medical personnel enter into relations with many other authorities who come to concern themselves with issues of sickness and of health, and medical techniques such as segregation of the sick and the monitoring of contagion are accorded a special place.*

Medical science has worked hard to identify and manipulate (for our benefit) the boundaries that mark our death and birth. But if anything can and does happen outside these two poles of existence medical science has afforded no certainty except the cold hard probability of nothingness. The possibilites or attempts of science to shed some certainty on the existence of an afterlife is minimal, as science has long since separated its philosophical premises from religion in preference for the certainty promised from the material world of empirical observation (Kastenbaum 1979). We live in an era where certainty corresponds with observation (empiricism) and there are a mutifarious array of qualifications to mark the calibre of this experience. Difference is a variability that science tries to reduce or minimise rather than understand as being inherent to life (Komesaroff 1995). The dominance of rationalism and determinism for the past century and a half has resulted in a definite qualification of what can be considered true or real; life or death.

Medicine's systematic conceptualisation and presentation of the human body as a space of disease, a space that is mapped in a precise and intricate geometry of anatomy, is the design for its success in the battle against our mortality (Turner & Samson 1995). Over the last two centuries medicine's capacity to display a mode of practice that affords society a faith in its potential to cure our ails and postpone our mortality is maintained through a system of empirical reasoning. A reasoning that not only explains our morbidity but also poses material and conceptual means by which illness is rendered thinkable, describable, calculable and predictable (Sheet-Johnstone 1992; Rose 1994; White 1995). Through a process of empirical observation, a process that links physical lesions and changes to signs and symptoms, medicine is able to advance its claims of certainty over the human condition. This way of knowing the human condition has, however, been the medical profession's strength but also its greatest flaw (Dutton 1988; Damasio 1995). Through reducing illness to a cause and the body to an object medicine has been found guilty of 'failing to see the wood for the trees'; failing to acknowledge a larger context and hence multiplicity of causes and cures for our temporal human condition.

Medical science has found it difficult to respond constructively to this judgment. Reduction and quantification are the discipline's criteria for certainty (Damasio 1995). Through the medical gaze the human body has become a biological body. One that is manipulated to the point where the maintenance of life is not necessarily an intrinsically modified and regulated process, but a process dependent on and manipulated by external forces of pharmacology and technology. As a society we are at once impressed and repulsed by these advances in the control of the human condition brought forth by the pursuits of biomedicine. With remarkable faith and seeming ease we literally hand our bodies over to medicine for care (or should I say cure). On our passage into hospital, despite our ever present plea to be understood as an embodied being, we sign a consent form that has the reverse effect. We sign a consent form that presents our body as an object to be manipulated and controlled in whatever way(s) the specialists deem necessary in order to maintain our health (life) and avert our death.

Humility is meant to be the reward for advanced knowledge, yet humility is an ingredient particularly lacking in our orientation towards death. In our efforts to manipulate life and death we seem to have lost the capacity to marvel at the scale of life's complexity and in doing so generate some humility and acceptance of our mortality. We seem to have lost an understanding that despite our abilities at apparently achieving goals of certainty and battling against our mortality, to death, as Carey and Sorensen (1997, p. 117) remark *'we will always lose'*.

Anticipating Death

In contemporary society where there exists a passion for certainty, fear has become the most common emotion associated with our anticipation of death. Fear of dying has become the '*Achilles heel of intelligence'* (Adams 1997, p.55). In a society that expects answers, to be so uncertain about death results in a fear of its inherent uncertainty. Our fear of death has created a death avoidance that is marked by our tolerance to allow ourselves and loved ones to spend their end of life (sometimes months or years) tethered to a two meter tube that is attached to a machine. Whether or not such an existence can

be defined as life is central to the ethical issues surrounding the medical technology (technological imperative) that sustains such a life.

While medicine physically manipulates our death we have come to mentally manipulate the experience as being either a good or a bad death (Littlewood 1992). As we watch others around us die, die in institutions such as hospitals, nursing homes or hospices (rarely at home), like ordering our fate, we begin to design the way in which we would like to die. A good death is typically painless and takes place in old age. A bad death is often seen as painful or protracted. Ironically, the latter of these two deaths is the very death that we have come to expect (in every sense of the word) from medical technology.

Nevertheless, death of a young person strikes at the mortal fabric of a society. Not only do the young embody the parents' future, they embody society's future. Free from the weathering and fatigue of time and age, the young are seen to embody the strength a society needs to succeed. The young are the keepers of our hopes and dreams. A young death is therefore generally considered the worse death of all.

Loss of a Child: Loss of Future

Medicine's success is intimately connected with how well it protects our future. The infant mortality rate is often used as a marker/indicator of a society's health. Western medicine prides itself on the relatively rare occurence of a child's death (Gilbert 1996). Death of a child is consequently the 'dark side' (Papadatou 1997, p.577) of a health professional's work. As Papadatou discusses, a child's death is preceived by many health professionals as a triple failure:

> *... first because they did not have the means and skills, or abilities to save a life; second because in their social role as adults they were unable to protect the child from harm; and third, because they "betrayed" parents who trusted them with the most valuable being in their life* (p. 576).

Connecting with the parents' pain when encumbered with these feelings of failure and guilt can be very difficult for all who surround them. Avoiding the parents, leaving them

alone in their sadness, often becomes the easier option. The health professional may be physically present but in order to cope they may emotionally disengage and refrain from entering into any substantial conversation with the parents. Conversations, that in their very capacity to personalise the death, tend to encompass all present in a sense of loss.

The success of medical science has reduced the incidence of child death in our society. These realities leave the parents who do lose a child all the more isolated and alone in their grief. Instead of being supported by the community, the bereaved parent is typically surrounded by other parents who prefer to avoid their grief as it lays bear for them many of their greatest parental fears. As Randol's (1986, p. 30) research into parents' experiences of grief reveals, many bereaved parents find the social isolation at times so great that they often feel like 'social lepers'. Add to this the relatively unknown and poorly understood concept of brain death associated with organ donation and the amount of people that the parents can share their experiences with is painfully reduced.

With medicine's success, contemporary society has come to realise death of a child as a relatively unnatural event. Although the death of a child can be understood as every parents' unspoken terror, that it remains an imagined, unspoken thought is most parents wish. Consequently, very few parents actively anticipate the death of their children (Littlewood 1992, p. 122). When it happens, the parents' shock and disbelief is all the more profound. That a child's death happened despite the everday reality predicating its relative improbability, confronts many parents with an insecure sense of reality. Their fundamental assumptions about the world or expectations for the future, are traumatised by this radom event (Brison 1997). Life's mutability and inherent uncertainty is made apparent and at a time when its truth seems so cruel. Such circumstances result in the parents not only losing their child but also losing a trust they held in a reality they hoped was safe and secure (Gilbert 1996).

Little wonder that the death of a child is signatured throughout all forms of literature, from the novel to the research paper, as a uniquely traumatic experience for a parent. *Compassionate Friends,* an international organisation whose sole function is to support

bereaved parents, suggests that bereaved parents face a future which leaves their dreams and aspirations unfulfilled (Cline 1997, p. 163). As Raphael (1983, p. 281) conceeds:

> *Whatever the age, the death of a child is seen as untimely by his [sic] parents ... In losing the child the parent loses not only the relationship but a part of the self and a hope for the future.*

`That no death is so sad' is the slogan of the bereavement counsellors for Compassionate Friends, who themselves are bereaved parents (Cline 1997, p.163). Death of a child totally transforms a parent's life as the parent's loss of relation with the child holds within it a multitude of other losses; losses which are intimate with the parents' sense of parenthood—protector, provider, educator. Compounding all this loss is the parents' sensed loss of family. As Randol (1986, p. 10-11) explains:

> *... the parents have lost the family as they have known it. Although the family will continue after the death it will forever be changed by the irretrievable loss of the presence and role-fulfilling behaviors and functions of the deceased child. This additional secondary loss will need to be recognized, mourned, and accomodated.*

Although dead, the child continues to be a part of the parents' and thus family's psyche (Raphael 1983, p. 281):

> *Even when mourned, the child is not forgotten. He [sic] is always counted as one of the children. And as such a loss may alter, forever, the course of the parents' life and even of the parents' relationship to one another.*

In the context of organ donation, the mourning and memory of the child is again substantially altered. The child's death is ambiguous. Is my child really dead? is not an unusual question troubling the thoughts of donor parents (Pearson, Hickson et al. 1996). Even though the parents concede that the medical knowledge assured them that their child was dead, their final memories of their child before they made a choice to donate was otherwise. Their child looked alive. Their child was breathing; his or her heart was beating and she or he felt warm to touch. All the medical reasoning in the world about brain death cannot remove this experience, but only make the experience all the more ambiguous and uncertain.

That their child's death is intimately involved with a decision which they had to make can effect the parents' mourning. Existing in a society where the social mandate is life, to then be presented with an altruistic alternative as a way to curb this tragedy is morally questionable. The questions for all parents sharing this plight remain, what choices are available? Do we have a choice? Can we make such a decision now? In saying no are we denying life for others? In saying yes are we hastening our child's death? The choice is loaded with many questions that prohibit any easy answer and substantially complicate donor parents' grief.

What choice is available? A choice of 'no' is always marked by the realisation that the no may be associated with another person's death. What more the media typically portray this other person as a child or young person in great need (Binnie 1995; Carter 1995). Despite the person being a stranger, that their death is somehow connected to a choice that the parents are having to make cannot help but burden them with a guilt that is consequent on our being purveyors of a medical technology that claims to afford us greater choices. An irony that is sometimes morally overwhelming for donor parents (Robertson-Malt 1998). That medicine does provide us with choice is uncontestable, but that these choices are always liberating or easy to make is contestable.

Death studies and inquiries into the cultural reasonings of grief invariably argue that we cannot measure one bereavement against another (Aries 1975; Carey and Sorensen 1997; Clendinnen 1997). This is a valuable conclusion, but one not easily appreciated by a dominant reasoning that prefers the pragmatics of a well defined comparison rather than the messiness of the difference and uniqueness of each person's grief. Grief, like any human emotion, has been pathologised and theorised so that we have developed and built upon critera of assessment with which to manage 'it'. That grief can be somehow quantified (i.e. this person is in the acute stages of grief) however is problematic.

The term, 'Pathological Griever' is the unfortunate product of such reasoning and is a term that is found in the 'specialists' discussions about organ donor families who continue to talk and seek answers to questions about their experience, sometimes six to ten years after their loss (Douglass & Daly 1995; Robertson-Malt 1998). Such

unfortunate reasoning fails to realise that the families never 'get over' their loss they just learn to live with the grief. That the family's method of coping should be subject to some form of criteria as to determine whether it is appropriate, normal, is a reflection of our social obsession to manage death in the most clean and precise manner possible. A product of a reasoning that has compartmentalised our emotions like all other forms of our Being into neat, manageable boxes.

Following their child's death, part of the parent's grieving process and subsequent capacity to rebuild their lives around their grief is achieved through their being able to make sense, achieve some meaning from the death (Randol 1986; Gilbert 1996). Such meaning however seems awkwardly absent in a society that concedes the death of a child as an unnatural event. Similarly, the death their child experiences is a new death that defies all their enculturation of what or how death appears. The parents do not have any conceptualisations or rituals of practice to help them deal with such an event. There are no socially sanctioned rituals surrounding the mourning of death that is consequent of brain death and organ donation. Instead, the parents' experience and contingent grief has been uneasily placed amongst the rest. But that their experience is profoundly different and deserves an understanding that arises from an appreciation of these differences is, I would hope, compellingly obvious. That the parents will have an ongoing array of questions about their experience, simply because they are situated within a society that is still struggling with the meaning of brain death, needs to be accepted instead of dismissed and labeled as a sign of pathological grief.

Questions as simple, yet ethically and philosophically profound as, 'Is my child really dead when part of him/her lives in another?' are reasonable, given the nature of the death the parents have experienced. Yet such questions are too disconcerting for a profession that needs definite, certain answers in order to be successful in its support of parents. But certainty fails these questions. Consequently, these questions are often dismissed as inappropriate as they are considered the hubris of a person who has failed to accept the diagnosis of death as given by the neurological specialists. Many questions thereby

remain unanswered and for many of the parents there efforts to rebuild their lives is made a struggle (Pelletier 1993b; Sque and Payne 1996).

Recognising the public need to be educated about brain death has been a central focus of the national coordinators of the organ transplantation programme (Dye 1995). Yet to date, this education remains largely superficial and paternalistic. The information given to the public is pre-dominantly only of a 'needs to know' basis. For example, only in the last year has discussion of the appearance of the *heart beating* organ donor reached media review. Until this point in time, the public conceptualisation of organ donation has been commonly associated with that of *the non-heart beating* cadaver. In the latter instance, the person is dead in the traditional sense of the term. This perception makes organ donation a relatively easy choice for many as any concerns about body integrity can be outweighed by a more dominant social ethic to help another by partaking in this wonderful gift. "Why not!" is the persuading logic because clearly I will be dead!

The success of the transplantation programme, however, is premised on the availability of live (fresh) organs. Heart beating donation is therefore the most common practice (Spital 1996). Parents are relatively unaware that permission to donate their child's organs will occur while they can still feel the warmth of their child's flesh, and see the beat of their heart. All involved in the transplantation programme regret this situation because, as the coordinators concede, how can the family, in the midst of trying to comprehend their child's brain death, possibly accept this ambiguity of death while all their senses continue to see and feel life? (White 1996).

The dominant reasoning used to override all the possible failings or shortfalls of the transplantation practice is once again projected onto the altruistic implications of the gift of life. The specialists' support the parents through a framework of questions like, Will this gift of life become a sense of purpose for the parents? Does the parents' option to help another become a 'passage', a life rope attached to their loved one amidst this overwhelming sense of loss? Does the 'opportunity' for them to make something positive out of an otherwise negative event, make the death seem more tolerable? (Martinelli 1993; Sells 1994; Raper and Fisher 1995). All such questions tend to be

appeasing notions upheld by a society that attempts to transcend its fears of death by having a belief that life has a purpose.

The Moral Muddles Pervade until the Ambiguities Fade

So the debates rage and the uncertainties prevail and caught in the middle of all these debates and uncertainties are those being asked to consent. The parents, no matter how hard they try, find it difficult to realise or treat their child as an object, a biological entity devoid of the essence that is their being. To the parent, their child's body does not need to be animated by consciousness in order to represent their personhood. Every mark and contour of their child's body calls, evokes memories of the person their child is to them. Their child's person or self is embodied in the body, and the body and person are one. That the parents can see the heart continuing to beat and when they touch their child and feel the warmth of their skin and see the passage of breath, a cognitive dissonance (Sque and Payne 1996) is set in place that is at once compelling and psychologically crushing.

> *There's this 'just a shell' theory of how we ought to relate to dead bodies. You hear a lot of it from young clergy, old family friends, well intentioned in-laws—folk who are unsettled by the fresh grief of others. You hear it when you bring a mother and a father in for the first sight of their dead daughter, killed in a car wreck or left out to rot by some mannish violence. It is proffered as comfort in the teeth of what is a comfortless situation, consolation to the inconsolable. Right between the inhale and exhale of the bone-racking sob such hurts produce, some frightened and well-meaning ignoramus is bound to give out with, "It's OK, that's not her, it's just a shell'. I once saw a Episcopalian deacon nearly decked by the swift slap of the mother of a teenager, dead of leukemia, to whom he'd tendered this counsel. "I'll tell you when* 'it's' *"just a shell",' the woman said, 'for now and until I tell you otherwise,* she's *my daughter. She was asserting the longstanding right of the living to declare the dead dead* (Lynch 1997, p. 23).

In spite of any ease the medical profession may have in accepting the inevitability of this new death, to expect the same reactions of the parents is somewhat foolhardy. The old death is ritualised and firmly ingrained in our psyches from birth; ingrained to such a degree that these rituals establish expectations and norms of behaviour about how death should feel and be (in spite of our prediliction for death denial). Whereas this new death

defies all of these expectations and the fact that it is a consequence of medical technology makes this new death a unique occurrence of an intensive care environment where there is little time or room amidst the rush of routine to establish any new rituals of behaviour to ease its passage.

One way in which the public have attempted to develop an understanding and acceptance of this new death is by claiming that the patient has not one but two deaths. The professional practice (versus rhetoric or theory) in many ways supports this understanding. That the person does have two deaths is in practice quite true. Despite the introduction of a new (neurological) death, the old, cardio-pulmonary death, remains a working criteria (so long as the term irreversible is attached to the event). So, in the instance of the heart-beating donor, the patient is first diagnosed as having irreversible cessation of all functioning of the brain stem. This, as far as any medico-legal definition is concerned, marks the death of the 'person'. The body's life is then maintained until the heart is dissected from the body and at this point irreversible cessation of cardio-pulmonary function occurs.

As would be obvious from this discussion, the first death remains free of any ethico-legal implications of intent to take life. The second death, death of the body however, does not. From this situation the very act of organ harvesting can be considered implicit in ending the life of the donor's body. The Hippocratic oath of 'do no harm' is being transgressed by the surgical incision and removal of organs? Therefore despite the notion of two deaths appearing to be what is actually taking place, arguing the case of one death helps doctors to avoid the ethical slippery slope contingent of a two death position.

However, without the two death theory being an accepted understanding of what happens in practice, the ambiguities continue. How do we come to understand a body that continues to live once a diagnosis of death or brain death, has been given? Are we to understand that the living body which remains is nothing more than an unfortunate complication or 'side effect' of the technology and diagnosis? Are we to consider it as a *product* of a medical diagnosis that needs to be managed accordingly? Denial of the two death position results in the answers being yes.

When brain death is considered death, the easiest way to manage the life, is to deny it as a *life* per se and instead call *it* an object life: a life that is possible only because of the technology available. The life remaining is then explained or realised as a disembodied life; an artifical life orchestrated and controlled by the doctors and nurses accordingly. This line of reasoning however results in a reinforcement of the object notion of the body (the mind-body split). Indeed, the life being manipulated and carefully managed is not acknowledged as belonging to the donor, because the donor no longer has the prerequisit for ownership which is personhood (which in these circumstances is signatured by consciousness). If medicine was able to avoid this conundrum I am sure they would, yet in practice avoidance is what ultimately happens. Because of the ambiguity surrounding the whole experience it seems far easier to try and avoid the parent as the situation is pregnant with questions about this new death.

There seems no adequate nor appropriate way to deal with the body except to try and ignore its significance. The body's significance however, is repeatedly made evident to all present by the rush of activity that happens around the bedside once a consent to donate has been given. Following these events, every activity can be construed as emotionally and morally brutal. The living body, at this point in time, is made significant not for the donor or their family, but for the recipient. Such circumstances tend to situation imbue the surrounding environment with a tension that all present must somehow try and accomodate in the most sensitive manner possible (Pearson, Robertson-Malt & Walsh 1997).

How the family, nurses and doctors relate to the living body that is still present becomes a constant challenge. Calling *it* the donor's body or the heart-beating donor gives, by some strange unavoidable quirk of language, the body a personhood, a life. Such is the case that a common recommendation by transplant coordinators to the nurses caring for the heart-beating donor and their family is for them to refrain from using the term donor, or talking to the donor when engaged in care (Pearson, Hickson et al. 1996). Instead, the nurses are encouraged to refer to the donor, if needed, as the *cadaver*. This request however can cause great conflict for nurses who typically pride

their professionhood on their theoretical orientation and practical support of the patient as an embodied being.

Similarly, even though the rhetoric of nurses and doctors is that the heart beating donor is dead their clinical practice commonly displays behaviour that speaks otherwise. In an ethnography conducted by Pearson, Walsh and Robertson-Malt (1997) that sought to understand the common culture of the operating room with the event of organ harvesting, both nurses and doctors were noted to watch the clock for the exact time that the heart was removed from the donor. As if they were mentally recording the final or second death of the body. Likewise, phenomenological interviews with critical care nurses who care for heart-beating donors repeatedly convey the difficulty they can encounter when any authority or policy tries to force them to treat the donor as nothing more than a body, an object for use (Pearson, Hickson et al. 1996; Pelletier-Hibbert 1998). Not only do nurses feel such practices to be disrespectful to the patient (whether they understand them to be dead or alive) such distancing behaviour is also considered disrespectful to the family who are always present and watching them complete their cares. Preparing the donor for the family to spend time with, after the organ retrieval has occured when the ventilator and various other pieces of life support equipment have been removed, has become an important part of the nursing care of the donor family. Having the family witness their loved one's body, finally 'at rest', is realised by many nurses as a crucial event in their passage of attempting to accept the loss of their loved one (Pelletier-Hibbert 1998; Pearson, Robertson-Malt & Walsh 1997).

Such practices by both nurses and doctors contradict the rhetoric or theory of brain death as death per se. Subsequently, the old debate about whether death is a process or event has been reignited to try and explain away this ambiguity. In many ways the treatment of death as a process rather than a single defined event supports the doctors in their efforts to persuade the donor families to more readily accept the death of their loved one and consider the issue of transplantation (Kass 1992; Raper & Fisher 1995). By explaining to the family that their loved one is in the process of dying and that brain death confirmation is the begining of that process seems in many ways more

psychologically tolerable for the family than to ask them to accept or divide their loved one in two. When seen as a process, the death of their loved one's body is more readily realised as an inevitability, event that medical science has unfortunately or fortunately prolonged. There are however many problems with this position, as this perspective leaves the doctors conceding that life continues to be present and subject to manipulation and 'violation' by the transplantation process. Either way though, whether death is explained as an event or a process, that life continues to be present in some form for nurses and doctors to explain remains the case.

Conclusion

The principle question begging throughout all debates and discussions about the ambiguous state of a Being that has a dead brain but live body is, if anyone is comfortable in claiming that the body is merely an object for use? Once the 'person' no longer has any use of the body, symbolised by the death of the brain, can medical science use 'it', the body, for the benefit of another? Do nurses and doctors have the right to dismiss the families' notions of what is death and in doing so present them with a definition that is incongruent with their very experience? These pervasive uncertainties and perplexing ambiguities, borne from the practice of organ transplantation and its contingency with our cultural history of death and reasoning, has been the central theme of this explication of the parents' context. It is from this overarching context of a socio-cultural passion for certainty amidst death's constant uncertainty that a journey toward an understanding of these parents' experiences begins.

Chapter Four

The Process of Meaning Making

Our conversational practices are shaped within and shape the stories that we live amongst.` Apart from them I do not know who or what I am, none of us do ... We spin yarns, tell tall tales to sew the world together, make it whole... There are mutliple meanings in everything. Beyond words everything is indefinitely uncertain and yet before and beyond question. Telling it is a way of catching a handful of air, laying claim to primeval lands, fencing off a patch of desert. Words are our way of appropriating, laying claims, drawing bounds, insisting on particular cultivation. Reality is created in our conversational practices and spoken into some form of being in the conversation of our lives over and over again. Reality is moment by moment on the run. Moment by moment the extraordinary is seen through the patina of convenience we cover over all the unknown world so that it can become a story world. It is unknown world that is our quest, not just the repetition of familiar story worlds ... we are always on the edge, the frontier of what we may yet know. How do we reach by our words into the heart of the possible? There is no method and no frauds will do

(Miller Mair).

Introduction

The discussion in Chapter Two focused on the philosophical underpinnings of this research methodology and identified three critical tenets when contemplating an understanding of the parents' experience:

1. that meaning is made rather than found

2. that meaning is made in the conversational dialogue of our relationships with others

3. that these relationships are historically constituted and socially embedded and that although the meaning we create in these relationships are of the *here* and *now* we need to remain cognisant that they are formed and shaped by the *there* and *then.*

Although these tenets seem obvious and readily available for the development of a process of inquiry, a creative challenge exists for any person attempting to conduct

research that is predominately informed by the philosophical writings of Heidegger and Gadamer. Both Heidegger and Gadamer insist they are not writing a methodology nor providing a method of how to understand the truth of human being. Rather, their work is a philosophical treatise on human understanding. Their philosophical position(s) ultimately realise understanding to be the fundamental ontology of our everyday existence and not just an epistemological tool of human inquiry. For both philosophers, our very being is a never ending circle of understanding, questioning and interpretation called hermeneutics. Indeed, their philosophical orientation implies that understanding is a dynamic, inductive process where meaning and understanding are made in the event of a particular context of being and not just that which is found through the deductive seeking of some transcendental truth believed to exist outside of human experience. For Heidegger and Gadamer, human experience *itself* is the very process of understanding.

Nevertheless, despite Heidegger and Gadamer's ontological stance against the epistemological reduction of understanding to a single method, the history of hermeneutics is one that is method orientated. With its etymology arising from the name of the Athenean messenger of the Gods Hermes, hermeneutics has a long history of being realised as a process of interpretation that makes the uncertain more understandable; a technique that supports a desire to mine essential meaning(s) from text. It is therefore not surprising that hermeneutics is the name that has been given to the scholarly and methodical interpretation of biblical texts. And so, throughout the history of theology hermeneutics has been upheld as the process that supports the exegisis of biblical truths.

However for the purpose of research, the theoretical underpinnings of heremeneutics shifted from pure theology to philosophy and found favour in the philosophical works of *Scheilmarcher (1768-1834) and Dilthey (1833-1911).* From their legacy, hermeneutics has been developed as the principle method of the interpretive paradigm. In many ways hermeneutics has been hailed as *the* method for the human or social sciences as it works at substantiating the subjective person-centred inquires of the humanities while

questioning and disputing the impersonal, objective inquiry of the dominant scientific paradigm (Hekman 1983).

Debate about whether or not hermeneutics is primarily an epistemology or ontology has been central to its growth throughout its history of use. Despite the differences of opinion which maintains such debate, the majority agree that the dialectic circle of question and answer, interpretation and understanding is the central framework and significance of hermeneutics as a form of human inquiry. Whether as ontology or epistemology, hermeneutics is realised as a circular dance between situated or partial (individual) understandings and the shared or collective reasonings of a society and its culture. Understanding (interpretation) is realised to happen when these two positions of meaning merge and give rise to new meanings.

Difference in opinion about hermeneutics as ontology or epistemology are primarily concerned about whether or not hermeneutics is *just* a method (a tool) we use to understand the world (epistemology), or whether hermeneneutics is far more universal than this and therefore more likened to a metaphor for human experience itself (ontology). In support of the latter position Gadamer (1975 p. xxx), with reference to Heidegger maintains that:

> *Heidegger's temporal analytics of Dasein has, I think, shown convincingly that understanding is not just one of the various possible behaviours of the subject but the mode of being of Dasein itself, and hence embraces the whole of its experience of the world.*

To treat hermeneutics as just an epistemological tool is, according to Gadamer, to conceive of it too narrowly (Hekman 1983). For Gadamer hermeneutics no longer means to provide rules for understanding, but to lay bare the ontological structure of the process of understanding (Hogan 1976) which according to Heidegger is Dasein (a process of becoming).

Nevertheless, a lack of any well defined method in the treatise of Gadamer and Heidegger does not support, as many postmodernists wish, a thesis of *no method.* Instead, the absence of a specified method in Heidegger's work supports his hesitance to endorse the dualistic debates of subject/object; fact/value that have plagued the

epistemological efforts of metaphysics for centuries. For Heidegger (1962), the history of metaphysics reveals a legacy of how a method can become the position of ultimate judgment. Our inquiries have become method dominated. Methods claim authority according to how well they help us in our efforts to correspond or mirror the truths of reality.

Given this valuing of method, the absence of an appropriate method, or the inproper use of this method, is considered by many who adhere to this perspective to result in a superficial and false view of reality. The research method is considered to provide a *bridge* between the subjective interpretation of the objective truth or the corridor between internal and external realities. The method has become the bridge that needs to be traversed before any true understanding of the world is possible. Heidegger's preference for considering life, being itself, to be the process of understanding encourages a displacement of this authority of a single method for a plurality of methods; many of which develop out of the inquiry itself and according to the questions being asked. Hermeneutics, as a method of investigation, is endlessly open to extension. Instead of one method achieving authority over our meaning making the question/answer dialogue of our living sets in place the parameters of meaning making. Critical reflection and contemplation of this meaning making will in turn reveal a pattern, a method for possible re-use.

Since our primary way of being in the world is to seek meaning and purpose we have, throughout the centuries, divined a multiplicity of ways to try and achieve some sense of meaning and significance about our experiences. Our histories of meaning making encourage within us choices and criteria that pattern the way we share in meaning making with others. Recollection of our meaning making will always reveal a pattern, a method of how this meaning is made possible. We then re-use this criteria according to how successful it is in helping us to achieve some sense of certainty about our place in the world. Others go further in their efforts and attempt to achieve some understanding of how certain they are of their certainty. Either way, the questioning is ongoing.

Traditionally, the effort of inquiry has been to try and establish rules that sequence the events of this process toward understanding in the hope that the same outcomes—and possibly certainty—will be achieved (or should I say maintained). Yet because the establishment of all methods is essentially a recollective act that can reveal many patterns of meaning making, the glorification of one method and the positioning of this method as an *a priori* in understanding the world is to Heidegger (1962) illusory and ultimately constraining of the potential for human understanding in every situation. For Heidegger, *how* the event of understanding happens is more important than the *what* of understanding as the what is only linear or uni-dimensional. For both Heidegger (1977) and Gadamer (1976) the how of this event is multifaceted and thereby requires an approach to understanding that values this temporalness and plurality rather than attempting to normalise and reduce it into some pre-existing template of reasoning.

Missing from many of the debates about the authority of a particular method(s) is the acknowledgement that all methods are realised retrospectively, at least intitially. All great scientific breakthroughs are typically random and then made to appear orderly by a retrospective gathering of the process that achieved the *breakthrough* in understanding (Harvey 1988; Capra 1997). Even something as simple as a cooking recipe follows a similar process. Chefs, in search of a new taste sensation experiment with a combination of aromas and flavours. In finding a pleasing combination they attempt to recount their steps in order to write a recipe so that others can share in the pleasures. Human experience is however situated, multifaceted and temporal and hence continuously changing. Consequently, any process of trying to understand such experience needs also to be understood as situated and temporal.

Amidst this plurality of methods, the best or highest moral endeavour we can uphold in our search for meaning is to listen, acknowledge and attempt to understand the meaning that other's make of their experiences—to converse with them. The primary effort of inquiry becomes one of attempting to see the significance in each person's choice of meaning making and to try and understand their criteria of truth. From this perspective the emphasis of inquiry becomes the establishment of dynamic relationships of

questioning and conversation which establishs a forum to see another's partial position of understanding the world.

Such an approach is in opposition to the monologue enforcement of single truths through the domination of established methods. The future cannot be made to occur by the sheer force of our convictions as to its possibilities. As Shotter (1990, p. 12) explains:

> *... if we are to act in such a way, we must not act solely out of our own inner scripts, plans, or ideas, but instead be sensitive in some way to the opportunities and barriers, the enablements and constraints 'afforded' to us by our circumstances, in order to act 'into' them. Such a form of knowledge cannot be formulated in terms of facts or theoretical principles, for it is a form of practical knowledge, relevent only in particular concrete situations; but it is not practical knowledge in the technical sense of a craft or skill, for it is knowledge which only has its being in relations to others.*

Any method of hermeneutic phenomenology is upheld by Sorrell (1994, p.5) as a carefully cultivated thoughtfulness and conversation rather than a technique to be learned and implemented.

The pragmatic move for research guided by the treatises of Heidegger and Gadamer is to realise life as textual. We use our socially given linguistic domain to understand ourselves, others, and the world as meaningful (Polkinghorne 1988, p. 135) and it is through this shared language that we continue to make meaning. The most immediate way we share and attempt to understand another's experience is through their languaged descriptions, their recollective accounts of their life events, which can be recorded and translated into a working text[19] for analysis.

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[19] the text is understood as the participants expression of their experience which even though fixed in writteness continues to engage in open-ended dialogue. As Gadamer (1975, p. 368) encourages the so called subject matter of a text needs to remain open. In this sense Gadamer is dependent on Heidegger's distinction between the past as over and done with (Vergangenheit) and the past as still effective (Dagewessen) and as continuing to open up possibilities for the future, possibilities realised in dialogue (Hogan 1976). Gadamer (1975) suggests that the making of meaning begins when one is sufficiently open to allow the text to question them. To say that a text strikes us in the form of a particular question is to say that it speaks like a partner communicating to us in dialogue (Hogan 1976, p.9).

Understanding comes when history is seen as the source of meaning (Hogan 1976). To interpret another's description of their experience requires an appreciation of their experience as embedded in a historical and social context of shared meaning. The *text* therefore becomes a historical horizon against which various questions are raised and where answers and meanings are continuously remade. Through dialogue, the interpreter makes the written word speak anew (Hogan 1976) and bringing into dialogue the 'subject' matter of a text is what Gadamer (1975, p. 371) considers to be *'the authentic hermeneutic task '*

As each parent describes their experience to me they are in a process of meaning making. This meaning making is temporal (fluid not fixed) as it happens from within the totality of involvements of their present, particular situation of relating to me and other aspects of their life. The meaning they make, although constituted by their lived experience, can never be the meaning they had when actually living the phenomenon in question. Their understanding has undergone a process of historical transformation. Each parents' interpretation is fluid and changing as the particularity of their circumstances (relationships) change. The parents therefore have no single meaning for their experience but rather a multiplicity of partial meanings that are always situated and momentary in nature. Likewise, language itself as Carr and Kemmis (1983, p. 182) encourage, '... *has a history, and to understand any supposed truth or any truth claims requires setting it in the framework by which language came to mean, and to allow us to mean, the particular thing being claimed'*. Any method suited to accepting this notion of meaning as a fluid, temporal event of a particular socio-historical dialectic needs to be inductive in orientation and only realised retrospectively since the process of inquiry will shift and change according to the passage of meaning making that occurs.

Many nursing scholars have acknowledged this lack of method and the need to respect the temporal nature of meaning making that dominates the philosophical tenets of hermeneutic phenomenology and social constructionism (Lumby 1994; Running 1994). In attending to these issues while grappling with the demands to present a method of inquiry many have explicated their research methods as consisting of a series of

interdependent phases of question and answer. I conceded the wisdom of such an approach and so follow their lead. In recalling my process of analysis, this dynamic process of recursive dialogue between myself and each participant moved through a series of four distinct, but open ended phases:

1. Phase 1: Dissatisfaction

2. Phase 2: Seeking to Relate, to Share Understandings Through Dialogue.

3. Phase 3: The Fusion of Meaning Through Dialogue (to understand is to hear).

4. Phase 4: Generating Meaning Together.

Although each phase shares in common the circular dialectic of hermeneutics each phase is unique and differs according to the questions asked. The questions refocus and generate the dialectic of meaning making that occurs in that particular phase of inquiry:

> *... the dialectic of question and answer is there all along in advance of the dialectic of interpretation. It is the dialectic that lends understanding as the determinate quality of an event* (Gadamer 1975, p. 447).

The diagram in Appendix I attempts to convey more clearly the circular, dialogical process underpinning the phases of analysis. Each phase makes clear Gadamer's (1975, p. 361) belief that rather than engaging *in* dialogue the dialogue *engages us* . Over time I moved through these series of phases (30 months in total) and my interpretations and understandings of each parent's experience also moved, changed and evolved. This recursive process of question and answer (between the particular and the shared) continued throughout the three years until I reached a point—an event that Heidegger (1962, p. 343) calls *resolution*—where I believed my understanding of the parents' experiences was as rich and complex as their conversational descriptions encouraged. Contrary to popular interpretations of Heidegger (Crotty 1997) this point of resoluteness was not achieved because I felt I had *discovered/uncovered* the essence of their experiences. Instead, this position was primarily an issue of research pragmatics. Ultimately, my understanding of the parents' experiences could be ongoing and so I had

to reach a point in my interpretations where I determined that my understanding of their experiences qualified sharing with others.

This point of resolution occured when I anticipated that my understandings of the parents' experiences could effect positive change in practice if shared with others, with the emphasis being on shared. Through this very text my interpretations will become part of the shared dialogue about donor parents' experiences. From this sharing of information a new dimension of the conversation occurs which in turn creates an opportunity for further, different meanings to be made. It is through this process of shared, ongoing dialogue that I believe significant, valued change in practice and policy can happen (Gadamer 1976; Lumby, 1994). Each person who reads my interpretations will join in the recursive dialogue about donor parents' experiences, but from their own particular situated relationships, and in doing so they will generate through their conversations with others different, interpretations and understandings.

Phase 1: Dissatisfaction

For the pragmatics of a research method, a beginning of my interpretation of the parents experience needs to be identified. On reflection, this 'beginning' occured with the inception of an inchoate yet compelling question: *What is the experience like for a parent consenting to the organ donation of the brain dead, heart-beating child ?* This question did not simply appear from nowhere. Rather, this question arose from within a totality of other questions and their contextual relationship with my life experience (foreconception, forestructure). Hence, although my interpretations can appear to begin with this question, there really is no true end or beginning to the ontological circle of question, interpretation, understanding and question. In hermeneutics as ontology, the question and answer are two aspects of the one totality called experience. As Heidegger's (1962) notion of preconception and historicity as well as Gadamer's (1975) concept of prejudice suggests, *we understand because we understand.* In being so, my ability to question the parents in the first place arises from my capacity to share and relate to them through a framework (language) of shared meaning. Understanding is truly historical through and through.

Nevertheless, this question placed me within a process of meaning making where I realised that my potential understanding was limited only by the question I chose to ask. Each question I asked generated a thousand others. Questioning my present understandings and interpretations became the constant energy in my effort to generate an understanding of the parents' experiences. The questions created a necessary tension between what I knew (collective/shared) and what I anticipated could still be realised or understood (particular/partial). Each question nurtured in me a want and effort to join with each parent in a conversation where we could push the boundaries of what is already realised about their experience toward new dimensions of meaning and understanding. This constant effort to question my present understandings of the parents' experience is very important. Without this questioning, my understanding becomes superficial as it fails to relate to the changing context of each parent's (and my own) meaning making—which is always in the process of becoming (made and remade).

My questions were embedded in anticipations (preconceptions) of what this experience could be like for the parents. In each conversation (dialectic), I helped to fuse these preconceptions with the parents' history of meaning. Each questions arose from a constant internal dialogue between my assumptions of the socio-historical complexity about death and uncertainty (as discussed in Chapter Three) and other more personal foresights gleaned from being a nurse who has cared for heart-beating donors and attempted to support their family through the experience.

I have vivid recollections of these occasions of care being innundated with similar questions and imaginations of how the families must be feeling and what they maybe thinking or anticipating. I often questioned how I would personally cope in the same circumstances, and marvelled at their strength and apparent fortitude to cope with their sudden, unexpected loss. Many questions about how the parents even begin to accept what is taking place often dominated my thoughts during these times of care. All these questions are, however, only a glimmer of what is happening for the parents. Conceding that there is so much more to be known about their experience—knowledge that could only be furnished by the parents' descriptions—fuelled a dissatisfaction with my

present understandings. I became commited to question and seek further understandings that were directly informed by donor parents.

Phase 2: Seeking to Relate, to Share Understandings through Dialogue

As the first phase of the research process is marked by a question, so too is the second, third and fourth phase. Each phase however is dominated by a different set of questions. The type of questions dominating this phase of the research process are primarily driven by research pragmatics, such as: *Who will be involved in the study?*

Attending to questions of this nature is common to the process of all research. Many research projects are consumed by a rigorous process of trying to determine the exact criteria of selection that will reduce the research bias and therefore achieve the most accurate reflection of the phenomenon's reality. However, given the methodological position unperpinning this thesis, one or one hundred parents could have been invited to converse with me about their experience. Having no assumption that there is some essential nature to be uncovered about the parents' experience, the number of parents involved in the study would not improve nor clarify my understanding of how it feels to be a parent consenting to the donation of your heart-beating, brain dead child's organs. The number of participants is irrelevent as I am not searching for a truth or essence, but rather attempting to make situated, partial meanings that arise from and return to the socio-historical web of shared meaning about their experience. Multiple descriptions do not bring me closer nor afford me a clearer glimpse of a deeper truth about the parents experiences. Having a larger number of parents' descriptions to interpret will not necessarily make my understandings more powerful or significant.

One thing that multiple descriptions do however provide in this context is an awareness that this research is not concerned with a phenomenon that has only happened to one parent. Every day parents are having to confront and grapple with the complexities of this experience. Similarly, the questions and conversations that are generated during my interpretation within and across each parent's description substantiate an appreciation of our thoughts and understandings as arising from and returning to a socially

constructed and historically embedded context of shared meanings. Our language, the place where meaning and understanding arise, that paradoxical place of commonality and difference, makes these shared meanings apparent. From the particular/partial (individual) we generate or add to the shared experiences and from the shared we generate the particular. Without reflection and appreciation for the particular we run the risk of succumbing to broad generalisations that do more to dilute understandings than ignite meaning. Each parent is therefore understood to have a unique interpretation and relationship with this history of shared meaning and will consequently describe their experience(s) differently. Each individual description then adds another dimension to our shared understandings of their experience.

In deference to my stated position however, three criteria for participant selection were established. These criteria were driven primarily by an ethic or moral wish to minimise the distress the parents might incur from being involved in the study and having to recollect, in detail, their experiences rather than driven by a misguided desire to achieve a *representative sample* of donor parents. Notions of representative populations and samples of participants are illusory when practicing from a methodological perspective which realises human experience to be situated and temporal. Such a stance perceives human experience to be forever changing as the multiplicity of variables that compose each event are momentary, unpredictable and not controllable. Consequently, the very notion of a *sample* of subjects that are representative of a population or the experience in question is untenable and any claims to have such representation are viewed as problematic.

The first criterion of participant selection was the most obvious and seemingly essential one of the participant needing to have lived the experience of consenting to the donation of their brain dead, heart-beating child's organs. The remaining selection criteria, as mentioned, were established from an ethical stance of wanting to minimise the parents' distress. Given the emotionally vexed nature of the experience to be recounted, the parents do not simply speak about their experience as if retelling a story about some walk in the park. The loss of their child is often impressed in every cell and fibre of their

body. Recounting their experience can leave many parents feeling as if the event is reoccuring. A full sensory replay of the event, with all the associated smells, sight, sound and touch can occur and leave some parents in a state of uncontrollable crying, anger, helplessness and fear. Working with the belief that the parents never 'get over' their experience, but simply learn to live with the loss resulted in the establishment of a second criterion which was the need for a six month reprieve between having lost their child and participating in the study. However, in establishing this waiting period as a necessary criterion of selection I did realise that it may ultimately make no difference to the parents' experience of participation. As mentioned, their memory of the experience can be replete with sensory cues which the passage of time offers little in desensitising.

A final criterion of *voluntary participation* was regarded as the ultimate ethical standard governing participant involvement. While voluntary participation is considered a universal mandate for research involving human beings, the parents' freedom of choice about participation was realised as the most comprehensive means of addressing the emotional risks of their involvement. Their freedom of choice to participate and withdraw, at anytime, from the study was determined to be the primary way that the parents could maintain agency over what they felt capable of contributing to the study.

My concerns about the emotional labour for each parent was also counterbalanced by an equally strong belief in the possibility that the parents could benefit emotionally from being involved in the study. Numerous scholars suggest that the act of retelling a painful experience, although emotionally harrowing at the time, can often be therapeutic (Brison 1997; Lumby 1992; Parker 1995). Through attentive listening—which is an integral feature of this whole process of inquiry—each parent can experience a sense of being heard with an obvious intent to understand, which can support many with their efforts to survive their loss. New understandings about themselves and their experience can be achieved and given recognition through this process of shared meaning. Hence, recounting their experiences with me can be seen as part of the parents' ongoing effort to understand their lives as now lived.

With such issues in mind the moral onus on me as a researcher became one of making sure that each parent was aware of all the possible risks associated with their participation in the study. First the voluntary participation of each parent's involvement in the study was established by their responding to a national call for interest in the form of a advertisment placed in one of five leading Australian weekend papers: *The Weekend Australian*, *The Courier Mail* (Queensland), *The Sydney Morning Herald* (NSW), *The Star* (Tasmania); *The Age* (Victoria). The advertisment attempted to explain clearly the main aims and objectives of the national project: "*The Ambiguity of the Gift of Life*": *Exploring the Experiences of Donor Families and Health Workers and the Public Discourse on Organ Donation,* and encourage interested families to make contact to talk about their experience (differentiating between heart-beating and non-heart beating donors) and possible involvement in the study. Providing the parents with the opportunity through numerous phone conversation, to ask as many questions as possible, was seen as an important means of helping them to make an informed choice about their wish to be involved in the study.

It was during these phone conversations that I was introduced to a new level of questioning. The depth of emotion and pain, clearly evident in each person's story, transcended many of my preconceptions about their experience. Comments like: *My child was five and hit by a car while trying to cross the road to play in the park,* or, *I never anticipated that this would happen to me, really what parent would want to?* intensified my thoughts, anticipations and questions about the parents' emotions and the complexity of decisions they had to contemplate during their experience. Each new question made conversation with my preconceptions about the social and institutional constructs of health, medicine and parenthood and how they interrelate in the event of each parent's experience. During these intitial conversations with the parents my understandings of their stories ranged from bitter disappointment, despair and anger about what they went through to a gratitude at having the opportunity to help another and make something good arise out of the worst possible life event as a parent.

If after our initial phone conversation the families were still willing to be involved in the study I posted them a plain language statement (Appendix III) and consent form. The time between the first conversation and receipt and return of the consent form was considered to be a valuable *time out* period or *breathing space* for the families to reconsider any issues they may have as well as seek clarification and/or possible withdrawal from the study. Each consent form was signed with each family understanding that they could withdraw from the study at any time without fear of retribution. Once the consent was signed and returned I contacted each family to arrange a time and place for an interview. From these phone conversations twenty family members volunteered for the larger study with five parents from this group, Ellen, Pip, Thomas, Phedra and Andrew, also agreeing for their stories to become the focus of this present thesis.

Over the next two and a half years I came to know each parent's story intimately. A précis of each parent's story follows:

- Ellen, who is a nurse and mother of five children shared with me her story of consenting to the organ donation of her brain dead, heart-beating five year old baby boy, Owen. Ellen's story is replete with guilt for not being with her baby boy when he died. Ellen tells the story of Owen having two deaths for which she was absent on both occasions. The first death happened when Owen was hit by a car while Ellen was away from home on a walking trip. The second death occured during the operation for organ retrieval. Although Ellen remained at Owen's bedside throughout the diagnosis of brain death and preparation for organ donation, she was not allowed to be present for the operation. Ellen's life is now dominated by a constant sadness from feeling that she left her boy alone and while alone he died. This is a sadness from which Ellen anticipates no reprieve.

- Pip is a mother of two who shared with me her tears, anger and pain of consenting to the organ donation of her brain dead, heart-beating seven year old boy, Hamish's organs. Pip recounts holding her 'baby' boy while he lay mortally wounded on the road, waiting for the ambulance to arrive. Twenty four hours later, with Hamish's

blood still on her clothes and hands, Pip returns to a home that will never be the same. Despite every detail of the past twenty four hours seared in her memory Pip is still, eight years later, unable to understand what happened that day. Pip has spent the past eight years trying to understand what she and her family went through during that twenty four hour period, but feels as if her every effort has been thwarted by a bureaucracy, too big and impartial to care.

- Thomas recounts the story of his son, Brett, who died during an operation that was meant to be the final operation of a life time filled with surgery to repair a congenital abnormality of his spine. Thomas recalls how easy it was to consent to the donation of his child's organs as he was standing in the unit where he had stood so many times in the past—where he had spent the first few months of Brett's life, nine years ago—and saw then how valuable such a *gift of life* could be.

- Phedra talks to me about a life, her life as a parent, cut short in its prime. Phedra tells the story of how she lost her daughter only weeks after she had left home to study interstate. With her daughter's independence and potential only beginning to take flight Phedra tells of her struggle to then give this life potential a second chance to someone in need.

- Andrew moves through a difficult conversation about the pain and anguish of losing his baby girl, Angelica, who was the focus of his future hopes and dreams. Andrew and Joyce were late to parenthood as they struggled for years with infertility programmes. Finally they were blessed with the birth of a beautiful girl. Angelica was Andrew's pride and joy. Angelica's life however had not been easy. Born with severe temporal lobe epilepsy, Andrew and Joyce had battled for years to find a drug or treatment that would help control her seizures. In the last year of Angelica's life they had found a drug that appeared to be helping. So life seemed good. The day before the fatal car accident, Andrew had rejoiced in his daughter's achievements at school. The next day, however, this joy proves a painful memory that makes the loss of Angelica all the more unbearable.

Phase Three: The Fusion of Meaning through Dialogue (to understand is to hear)

The third phase of the process toward understanding the parents' experiences regards my joining in conversation with them about their experience. The only question that governed this phase was an interview prompt of: *Can you describe, in detail, your experience of consenting to the donation of your child's organs.* All the meaning making of this analysis takes place within the recursive dialectic of question and answer that happens within these initial personal conversations, and then after in the retelling and interpretation of these conversations as text. That these conversational interviews with the parents are not contrived, but instead given the necessary space and time to achieve full freedom of expression proved to be the most important part of this phase of the study.

An ethic of autonomy and moral freedom drives the entire process of analysis for this thesis. Such a right, maintains Belenky, Clinchy, Goldberg and Tarule (1986, p. 34) helps to protect each participant, *'... from being managed and manipulated'*. Belenky adds that *'... the moral principle of respect for persons is most fully honoured when power is shared not only in the application ... but in the generation of knowledge'*. This ethic is made of particular significance during this phase of meaning making as it is during this phase that I actually ask the parents to openly share with me a full description of their experience.

In keeping with the philosophical tenets that underpin this process of analysis, understanding is realised to be the product of our conversations. Hence, the sharing of knowledge in this process extends not only to an appreciation of the indigenous knower as the primary person where meaning can be sourced but also to a recognition of their co-authorship of the dialogues and subsequent interpretations being made. Therefore, the author of this product is neither the parent nor myself, but both. Consequently, the meaning made in each conversation is unique as it is constituitive of the merging and interplay of our histories of meaning which we both bring to the conversation. As Gadamer (1975) explains, a fusion of horizons occurs within our dialogues which results

not in the discovery of truth about the parents' experiences but rather the creation of new meaning that is contingent of our shared meaning.

It was during this phase that I interviewed each parent. Each interview was conducted in the privacy of the parent's home and recorded on tape. A focused, non-structured interview technique was used to gain access to the parents' descriptions of their experiences. The interviews were focused in that parents were asked to talk about their experience of consenting to donation, but non-structured in that there were no preset questions which guided the conversation. This style of interview supports the methodological stance as it treats the person who has lived the experience as the *indigenous knower* from whom further understandings can be generated. The interviews always commenced with a casual conversation of general greetings and getting to know one another. It was hoped that during this time the parents could develop a space of comfort from where they felt confident to share with me the recollection of their experience. Through these preliminary conversations we would together arrive at a point in our conversation where the orientating question: *Can you tell me about your experience* felt appropriate to introduce. In this way the interviews were relaxed and open to all potential emotions and questions.

To each interview I brought many foresights and preconceptions about their experiences which allowed for a space of shared meaning and understanding to occur. These foresights and preconceptions were not called upon as a means of directing or coaxing each conversation toward their particular certification. Instead, once the orientating question was placed into the conversation the remaining questions driving the dialogue between us arose from the immediacy of our conversation and where it was being led by the parent at the time. During the interview, whenever an extended period of silence occured, which generally indicated that the parents had exhausted their description, another question was offered for reflection. Such questioning had no specific order and was principally directed by the parent's response to the previous question asked. Sometimes the style of questioning assisted to refocus or redirect the interview when it

appeared to be heading on a tangent of no apparent value and so far removed from the experience at hand.

This atmosphere of free conversation and shared meaning is likened to Gadamer's (1976) notion of play. For Gadamer, knowledge and understanding do not arise from preset rules of how the conversation should be structured and presented. Instead, the rules of a conversation arise from a mediation between the players and a genuine intent of each player to share and relate to one another. There is a humility, a willingness on each player's behalf, to become lost in the significance of the game (conversation) made possible by the other's presence. The richness and depth of each conversation is therefore the product of this open relationship of free conversation rather than a consequence of a particular player's (ie. the researcher's) preset authority of choice or arbitration.

Running (1994, p. 138) calls these relationships *covenental* relationships of inquiry as apposed to the *contractual* relationships that tend to dominate the methods of traditional science. According to Running (1994) the covenental relationship is unlike the predefined and emotionally neutral stance of contractual relationships. Instead of the objectification so apparent in the contractual relationships the convenental relationship is a spontaneous, dynamic relationship constituitive of the shared meanings of the people embedded in each situation. Hence, acceptance of each parent's self-determined authorship of their descriptions about their experience was an essential ingredient of our relationship and one that supported them in their freedom of expression.

Mutuality not neutrality was an important orientation of this inquiry that helped to support the parents in the generation of rich, complex descriptions of their experience. During our time together, the parents and I questioned the possible meanings that their experience had for them. During and after each interview I was impressed with the intricate complexities of each parent's experience which were then recorded as field notes to become part of the evolving text for interpretation. Their use of words and vocal emphasis, their pause and silences, helped to construct salient themes that ranged through a mutliplicity of emotions such as sadness, anger, helplessness and guilt. Such

impressions add to the *forestructure* of (my history of coming to understand) the parent's experience and so influence each of my subsequent interpretations.

Phase Four: Generating Meaning Together

Phase four of this process of interpretation is concerned with the pragmatics of coming to understand an experience when an understanding rests within a constant flux of questions and answers such as, *What is being told (made) in the parents descriptions of their experience* ?

Textual analysis of the parents descriptions dominated this phase of the process of analysis. Each interview, from the previous phase, was taped and lasted on average two hours. These tapes were transcribed and each transcription became a *text* for interpretation[20]. Initially this phase of analysis commenced as a thematic analysis for the larger study and was completed on a computer using a basic word processing package. The analysis was structured as follows:

- Each parent's transcript was labelled and managed as a separate document. Once completed each transcript was quickly read in an attempt to gain a cursory impression of the overall story that this collection of people were sharing. I engaged in this process several times and made notes about various feelings and questions that arose during each reading in a separate document called, *General Notes*. This document remained open throughout subsequent readings to which I would add other reflections and comments as necessary. Numerous patterns, plots, themes and theories presented over the years and were recorded in this document. They all spoke *about* the parents' experiences but never *for* their experience.

- The document, *General Notes* became the journal for this analysis. I liken this journal to being an example of what Koch (1994) regards as the 'decision trail' needed as a

[20] Each document was saved under the Microsoft format of *Text Only with Line Breaks*. Saving each transcript in this format results in each page and line of text being numbered. This system of numbering provides an accurate referencing system which can then be called upon whenever a section of transcript is used within the body of the thesis (e.g. p. 1: 2-22).

means of reflecting on the 'integrity' or 'believability' of an interpretive research process. Before reading each text I would re-read the journal and become re-engaged with the passage of interpretation that the texts were undergoing. I continually questioned this passage of meaning making and made comments about this questioning in the document, *General Notes*. Hence, this document (General Notes) became a space for reflection of my pre-understandings or prejudices about the text(s). This process of reflection upon my prejudice was not to be ignored as biased and somehow negative. Rather, such reflections were valued as they provided a necessary space that encouraged a critical reflection of my evolving intepretations. As a research method, hermeneutics gains its depth and scope for understanding through being open to working with the never ending potential (the figurative and suggestive powers) of language to express our way of being in the world. The rigour of this method therefore rests in this constant reflexive questioning of our present, evolving understandings of experiences (of the world) set up through the journal's critique. The journal helped to maintain this rigour.

- Once I had completed the overview I concentrated on each individual story. Again I re-read each text completely and attempted to identify the central themes of the story being told. Next I slowly re-read each line of the text while constantly questioning each part (word and sentence), with the whole. The order or sequence of each text remained unchanged but gradually the text was broken into a series of sententious phrases—with corresponding pieces of text from their stories used to try and exemplify the meaning being made.

- These sententious phrases were bolded in order to clearly delineate them from the main text. Once the text had been sectioned as such the text was re-read and the phrases were refined by a constant reflexive questioning of:

1. *Does this interpretation fit the context not only of this particular section of the text, but also the text as a whole?*

2. *Is this interpretation succinct, in harmony, faithful with the overall context of the text?*

3. *Is there a different way that the interpretation could be told to convey the meaning more justly?*

Again, notes were made in the accompanying document *General Notes* about all answers and concerns which arose during this questioning.

- Once this process was completed for all the parents' descriptions, the main text was removed from between the bolded phrases. The phrases were then grouped into a separate document called: *Themes*. Each story's collection of themes are shown in the Appendix: 'Themes'. These documents then became the text with which further dialogue was made. A hard copy was made of each document and I spent time reading and re-reading these themes in order to find commonalities between the parents' descriptions which I then grouped together.

For two and a half years I conversed with each text and intimately came to know, their particular character and story. From this nurtured familiarity I slowly began to translate each parent's description of their experience into a story; a story that made uniform the story *I heard* through their descriptions. This retelling of each parent's story therefore is a reconstruction that has been guided by the various foresights and foreconceptions (my history of meaning) that I have developed about each theme and its significance to my understanding of each parent's experience.

Gadamer (1979) encourages that since this process of retelling is central to our understanding of one another a more appropriate metaphor for the hermeneutic process of understanding is *translation.* Gadamer suggests that it is in the effort of trying to interpret another's interpretation that a common horizon of meaning is made. This effort is a conversational encounter of two different language worlds that when fused in dialogue create new meaning. This joining in conversation, this fusion that takes place between the horizon of the text and that of the reader, is according to Gadamer (1979) an ontological encounter. In this merger, meaning is made and this fusion takes place in the language of story.

As text, each parent's story became the *other* in the dialogue of my effort to understand their experience of consenting to the organ donation of their brain dead, heart-beating child. The subtleties inherent in each story's simplicity teased me into deeper questions, and fewer answers. Fortunately I never ceased to question, and while several themes became common to these interwining discussions, each time they returned they resonated with new overtones and new undertones. Union, bonding, blending, fusion are all terms that have been used to try and relate what happens during this long process of constant dialogue with a text. For me, Seamon (1993, p. 230) aptly uses the term symphysis as it is a Greek term that means 'growing together'. Through the passage of time I grew to appreciate many different dimensions of the parents' descriptions. Each parent's story provided me with a window of opportunity to further understand this complex human experience.

In spending time reading, listening and questioning the stories that this group of parents shared I began to build a tapestry of meaning. The way the tapestry is woven reflects the context of meaning making that I shared with each parent and so is a complex web of past, present and future meanings. Each piece of thread in the tapestry represents an interpretation of a parent's story. Alone, each piece of thread is not the tapestry. Nor could the tapestry be without each piece of thread, something would be missing. Instead, the thread and tapestry are interdependent or mutually dependent.

Over the years I constantly questioned each part (emerging theme) against the whole (not only of each story, but the story of my understanding of this group of parents). Each answer generated another question and each question became substance for other answers. From this hermeneutical perspective of mutal respect of the parts with the whole, an understanding of the parents' experiences unfolded (which is discussed in Chapter Six).

An important issue that needed to be realised and valued during this phase of the process of understanding was how the written word constantly struggles to capture the totality in flux of understandings being made. What became obvious to me during this phase was that my interpretations and understandings of each text were never something

that the text *is* in its collection of words, syntax or the correct semantic representation of the words with their 'corresponding' reality. Rather, the meaning I gained was borne through the many conversations I had with the text while forever cognisant of the ongoing possibilities of meaning, inherent in future readings. As Gadamer (1975, p. 361) explains:

> *... the genuine dialogue is never the one we wanted to engage in ... one word calls another ... All this announces the fact that dialogue has a mind of its own, and that the language used to dialogue carries a truth of its own in it; that is it unconceals and lets something emerge that is there to stay.*

Consequently, meaning about the parents' experience is 'shown' or heard in the dialogical movement between the textual description of their experience and the reader. Each story's meaning is constituitive of the words spoken and written, and so much more.

Dialogue is therefore realised as the motion or play of words found in the telling of each story; and the meaning of the text grows in this telling and re-telling. Each time a story is revisited or retold the dialogue's meaning originates in the ties that are constantly being undone and re-positioned within the context of the present retelling. It is here that language as performance is made obvious. The text and interpretations are not used to lay down truths, but are there to guide one towards an understanding: an understanding which is our situated knowing. Each word plays its joyful game with the others while always hinting, glimpsing at something more. The meaning is what is *heard*, or what we listen to in the retelling of each story made possible through the descriptions each parent provides. The meaning being made in this play (performance) of dialogue can never be completely captured, but only realised partially, as it is forever (as are we) in the process of *being* retold.

Conclusion

An ethical imperative that underpins this whole process of questioning is to respect the other as irreducible and to realise meaning and understanding as shared rather than appropriated. Although an understanding of the parents' experience evolved during this

phase of analysis this evolution was not a hierarchial process where I built upon a foundation of acceptable understandings of various parts of the experience in relation to the whole. Rather, the evolution of understanding was like a web, a web of meaning making which the writing that accompanied this meaning making reflected/captured. Each question I asked the text afforded an understanding which led not to one, but to a multitude of other questions and dimensions of understanding. Understanding the parents' experiences therefore does not arise from a reduction of their text into disparite pieces of meaning. Understanding happens between the spaces of each story's retelling. Thus, to talk of the themes of interpretation that I made through this process of analysis: **Unprepared, Uncertainty, Watching and Waiting and Aloneness**, does not refer to particular parts of the text but rather to the text understood from another dimension (partially and temporally). The next section of this thesis is an explication of this interplay between the parts and the whole, the discursive movement between the commonalities and individual stories of the interpretive process. In presenting my understandings in this way it is hoped that the interdependence of the parts (themes) with the whole (stories) is realised and from this dialogical interplay a glimpse of understanding the parents' experience is made possible. I also hope that through this process an appreciation for understanding, made through reflection on lived experience rather than rhetoric, may also be realised.

Chapter Five

Understandings—Themes and Stories: Parts and Wholes

> *I want to see and say, hear and say, ordinary life. It is not a theory that I want to exemplify but a way of speaking which raises possibilities of life where previously they were hidden or absent. It is ... for the frightened, the lost, and the alone, that I am involved within. The loud and brash, successful and powerful are beyond my ken. They are likely to ignore those I seek to know. There is a bias towards the poor of a certain kind in what I have to say. I have to try to speak from within their worlds from within my own ... it is a passionate, moving attentiveness that I seek, that I believe and lives its right to say, to see, to touch, to express, to share (There are so many times when we cannot afford a primly, pedantic fearfulness that must wait on proof and only values what is filtered through a particular method). If this is even partly to be possible, I need real belief in feel and flow, recognizing and following understandings that come through hints and pores.*
>
> (Miller Mair)

Introduction

As the previous chapter discussed, the hermeneutic analysis of the parents' descriptions of their experience resulted in the evolution of two independent yet synergistic scopes of meaning: the parts versus the whole or, more specifically, the themes versus the stories. In order to help further an understanding of the parents experiences this chapter intends to show the dynamic interplay between these two scopes of meaning.

Since a methodological tenet of this thesis is that meaning/understanding is made/heard in the performance of language or in the telling of a story, the dominant part of this section is the retelling of the parents' stories. In presenting these stories for you to dialogue with and develop some meaning from I have woven throughout their retelling the themes of meaning that each story shares in common with the other which is a process that makes this chapter an extremely long yet compelling discussion. This length, however, was unavoidable. Because each theme is a dimension of each parent's story they are interdependent and so in their explication and discussion their meanings readily cascade one into the other. This union makes any attempt to separated them into neat and tidy

subheadings problematic. Despite their commonalities though, each story needs to be realised as a complex interplay of the four identified themes which makes them as different as they are common. Each story embodies a different meaning of the various themes. Even our cultural definitions of **unprepared, uncertainty, watching, waiting** and **loneliness** remain superficial and shallow in comparison to the meaning they exhibit when realised within the context of each parent's story.

Throughout my analysis I came to appreciate how particular stories were more suited to particular themes. Each theme will therefore be introduced in light of its particular emphasis in a particular story. However, even though this marrying of theme and story provides a general layout for the following discussion, this process does not exclude a particular theme from being discussed within the context of another story.

Weaving Together the Themes and Stories

To begin this discussion I commence with a review of the theme *being-unprepared.* **Unprepared** is the first theme to be discussed as I came to understand it as the first and constant state of being that each parent lives in their experience of consenting to the donation of their heart-beating, brain-dead child's organs.

This notion of being unprepared relates to the sudden and acute nature of the parents' tragedy and how this sudden shock tends to set the mood for the rest of their experience. This sense of being unprepared remains with the parents throughout their experience. Many parents say now that it is because they were so unprepared for what happened to their child that they continue to labour the pain of their loss today.

Being unprepared is the actualization of a collection of circumstances that we can all relate to and is primarily experienced when a situation proves not to be as we expected. Although possibly aware of what might or could happen in a situation, being unprepared means for many that they did not anticipate the experience would happen in the way it has. Depending on the nature of the circumstance we are 'thrown into', this sense of being unprepared can readily cascade into other emotions such as shock, bewilderment, disorientation, confusion and guilt. Amidst the routine of our daily lives,

being unprepared for the circumstances unfolding before us can leave many feeling disorientated and troubled, as they are left feeling that they are not prepared to cope with the situation.

That we can all suffer this sense of being unprepared belies a fundamental belief that our futures are predictable, hence controlled through diligent forethought and preparation. Hidden within this belief is a corresponding expectation or responsibility to prepare ourselves accordingly for *the* future. Guilt therefore is a common consequence of being *caught* unprepared, as we tend to punish ourselves for not knowing or anticipating better.

Within the context of this research, being unprepared is almost an inevitable and somewhat *expected* response to their child's death. Death of a child is always untimely as it does not correlate with the parents' future expectations and assumptions of how their lives should unfold. Children represent the youth and future of a society and so are *usually* expected to survive/outlive their parents. Parents take for granted the cultural assumption (or preference) that death is for the 'diseased and infirm'—both of which are traits rarely given to children. The donor parents therefore lived with an assumption that they would die before their child. They chose never to anticipate their child's death as they would always attempt to anticipate any risks from which they would protect them accordingly. Their child's death was a sudden, unexpected event and Ellen, Thomas, Phedra, Andrew and Pip's shock and despair when hearing the news of their child's accident cogently indicates just how unprepared and overtly random this event seemed for them:

> I heard sirens and I had a phone call ... to say there was a bad accident and Angelica was badly hurt ... And you immediately rang me and said these same words and I was quite incredulous (Andrew & Joyce/ p. 1: 7-10).

Each parents' story conveys how threatening this event was to their assumed future; how they felt the event radically transform their lives as once known and cherished; and how they were lost with what to do next or expect. Being so unprepared, each parent

recounts an experience that is racked by a constant vacuous questioning of: 'Why is this happening to me? Why here? Why now? Why?'

> I was in a state of shock. So I went in and sat with him and it was just sort of to be there. And it was all pretty unreal you know... its almost like you have been put into another life; like you have been taken out of the what you were doing sort of hours before and just put into this situation ... its just too much to comprehend (Ellen/p. 4: 21; p. 5. 1-4).

Pip recalls, almost tasting the memory, the physical feeling of her life being irrevocably transformed by the sight of her baby boy mortally wounded and laying on the road:

> ... I was running and I just lost everything halfway down the driveway and I looked ... I couldn't see properly ... and suddenly I saw him just lying there and he was dead. Once I could see his face, it didn't sort of show it. I thought, `What the hell does this mean?' And I ran staight to Hamish and I got to him and this unbelievable force hit me, it was like a brick wall. I heard it and felt it, it was like it hit me. It was like bang crash. This unbelievable force hit me. And I don't know whether that was actually going into shock or whether it was Hamish dying, I don't know (p. 2: 22-24; p. 3: 1-11).

Belief in the risk modification of our futures is arguably a legacy of our social faith in science and technology (More & More 1994; Dewar & Morse 1995; Dollimore 1998). Our nebulous yet unconscious faith in science to control our world and keep us safe is evident throughout the parents' stories in the way that although each parent was overwhelmed by the sudden threat that the accident placed upon their futures their fears were temporarily usurped by a faith they had in medicine to prevent the mortal threat of the accident. Each parent had a somewhat unquestioned expectation that if they could not protect their child, medicine would. Consequently, the shock and bewilderment they experience from being unprepared for the accident is only compounded when the doctors appear to be as helpless as they are with their efforts to control the circumstances at hand. The parents are cognitively unprepared for the doctors inability to offer them any hope in preventing their child's death. At every turn the parents' expectations are thwarted by circumstances beyond their control and so they are left feeling bewildered, helpless and in total despair of what to do:

> ... when my husband left, he left at 10 o'clock, um I just kept a vigilance, sat beside Owen, beside his bed. At that stage, I didn't really know what was going on. I knew that he was on the life support, I knew that he was very sick but I didn't know what his prognosis was, what his future was. And at that stage, I hadn't seen a doctor. I just went in and the nursing staff were just treating him and you just let them do it, because you knew that they had to care for him. I stayed there until about two or three in the morning (Ellen/ p. 5: 5-11).

So unexpected, and therefore intellectually intolerable, is this state of helplessness for Pip that devining a miracle becomes a prefered reality than having to accept the lack of future being offered:

> ... he [the doctor] said, 'Well it's what you call a critical head injury'. I said to him, 'Is he going to be alright?' he said, 'well I must say just at the moment, there is really nothing we can do.' He said, 'it would have to be a miracle' ... and I looked straight at him and said, 'Okay, we'll perform a miracle, we'll pray'(Pip/p. 11: 1-8).

Being so bewildered with what was taking place left relatively simple things, such as lack of familiarity with the intensive care environment, to further complicate the parents' growing sense of uncertainty and confusion. Unprepared for the environment, many of the parents struggled to make the unfamiliar familiar. Often left to do this alone the parents' quickly learned that their tragedy is just one among many.

Although managing emergencies is a routine event of the intensive care environment, this emergency is not routine for the parents:

> ... we went into a casualty and there was a sea of faces, a sea of people... it was all bizzare. I went up to the desk and I thought now do I wait in line, what do I do?... They were all so busy (Pip/ p. 7:20-25; p. 8: 2-4).

The initial shock and threat of their child's circumstance leaves each parent stunned and bewildered, uncertain of what to do or who to speak to for help. The parents however quickly learn that time and attention are ingredients most in demand in the intensive care environment. Time and attention are therefore scarcely available for their abysmal questions and concerns:

> ... you couldn't stop it ... there was absolutely no control whatsoever. We were just totally out of control from that moment on (Daniel/ p. 18:16).

The events of their tragedies continue to unfold before their eyes but at a pace that denies them any ease of assimilation. Although present and watching everything take place their lack of familiarity with the place and routine leaves the parents feeling as though they are floundering in space and time. They struggle just to acknowledge the implications of what is happening and so are rarely ready for the final diagnosis when it confronts them. Again unprepared for this information—words that say their child has no hope of recovery—the parents are overwhelmed as they feel their whole world collapse with the passage of this one sentence:

> ... and the doctor came over and said, 'Look Mr Hughes I have to tell you'—I don't know his exact words but—'I have to tell you that I consider from all the gauges and everything here, that your son is brain dead.' Oh and then it just hit me like a brick wall (Thomas/p. 6:5-8).

The parent's feel their 'now' being consumed by disbelief and shock as they suddenly realise that the last conversation they had with their child, was the last. Concomitant with this overwhelming sense of shock and lack of preparation, the parents become *uncertain* about everything.

Feeling *alone and uncertain* are consequent emotions of not being able to relate or connect with the people or environment we find ourselves in. As already realised we gain meaning about our world through our relationships. If however we are unable to engage in these relationships to any meaningful degree then a sense of isolation and uncertainty can evolve. The environment and circumstances fail to make sense. The parents circumstance can provoke a multitude of issues that impede their ability to relate to others during this period, with grief being the more obvious example. Grief has become an isolating emotion in our society as people often prefer to avoid the person in grief as they tend to sense a relative futility in any words they have to offer (Bowlby 1980; Charnock 1985; Brison 1997). Isolated by their grief, loneliness soon *becomes-the parents*.

Loneliness is a state of being that we experience when we have no one to share our experiences with or relate them to. Loneliness is therefore implicit in the parents' lack of familiarity or certainty about the diagnosis of brain death. Their confusion or inability to accept what is taking place or understand what they are being told typically takes place amidst people who appear so certain, so clear about what needs to be done and when. Subsquently, the parents feel alone in their struggle to comprehend what everyone else seems to realise as fact.

Compounding the parents' uncertainty and loneliness is their relative lack of understanding or familiarity with what or how to ask the necessary questions—or how should they begin to relate to others in order to have their questions answered and concerns resolved. For some parents, a vicious cycle unfolds as their uncertainty fuels their inability to ask questions that could help them better prepare for the eventual outcome. Often attempting to transcend the pain of the present circumstances through finding solace in a hope that things may somehow change becomes the most comforting response. However, sometimes an overwhelming need for hope, accentuated by a looming fear that potential answers to their questions may remove this needed hope, can further distances some parents from reaching out and relating their needs to others. The following story of Pip's experience is replete with this sense of being unprepared and how her lack of familiarity and preparation for what was taking place feeds her uncertainty and eventual sense of loneliness and isolation.

Pip's Story

'Hamish, open your eyes!'

'Mummy's here Hamish. Can you hear me?'

'If you can hear me Hamish, squeeze my hand.'

The entirety of Pip's concentration is focused on her hand as she waits for her little boy to squeeze it. And he does. But his eyes remain closed. Pip will never see Hamish's eyes open again.

Behind her, Pip can hear her eldest boy Damien, crying, wandering on the road in circles. Wandering in circles as if in his motion he will find a way to rewind the madness of this event that is happening to his family.

Holding on to the safety of her little boy whom she cradles in her lap, Pip also attempts to manage the safety of her eldest boy.

'Damien darling, run and get mummy some blankets ?'

'We need to keep Hamish warm until the ambulance arrives.'

'So can you help mummy and run inside and get some blankets'. Damien turns and runs toward the house.

Pip's husband Daniel, is standing behind her. He too is overwhelmed by the sight of his baby boy laying on the asphalt—motionless, helpless and bleeding. But unlike Damien who has been thrown by this sight into circles of hysteria, Daniel has been struck dumb. It is as if his tears and urine, laying at his feet are swallowing his motion. He stands statue like, watching everything happen before him but incapable of stopping a thing. The force of his disbelief holds him trapped in another time and space; another dimension that has left him absent of the capacity to move his body or direct his thoughts. A dimension of torture so cruel as he is unable to do anything but watch his life fall apart before him. Daniel feels as if he has been frozen in this space of torture to witness a punishment—his punishment: the taking of his life as once known.

Within this triangle of family pain is a stranger. Pip can see a young man wandering in distress. She cannot however place his face but soon realises who he must be when he walks towards Daniel, begging his forgiveness.

'I know who you are', thinks Pip.

'You're the owner of this car that stands beside me, as motionless as it has left my son.'

Pip wants to yell at this stranger, 'How could you not see my little boy!'

'He was only playing, riding his bike like he always has, every afternoon after school. And this place of play has always been so safe.'

'I never really questioned his safety on this quiet country road where he is now laying.'

Pip's anger and distress grows as she realises Hamish also had no fear; and that Hamish wouldn't have seen the car coming before it hit him.

'Why are you here?' is the screaming question that races through Pip's mind.

'Where were you going?'

'You don't belong here.'

'I never anticipated or expected you.'

'Never.'

But not a sound breaks from Pip's mouth as every word she speaks is reserved for her little boy, laying before her.

'Hold on Hamish my baby.'

'Hold on.'

'I can hear the ambulance coming baby.'

'Everything will soon be okay.'

'Help is coming Hamish.'

'Just hold on for mummy.'

'I need you Hamish.'

'Just hold on a little longer.'

'Squeeze my hand again Hamish. 'But Pip feels nothing. Nor has Hamish squeezed her hand the last three times she has asked.

The ambulance arrives and the crew approach Pip and move her to one side. Pip feels her hold on Hamish release as she lets go so that others can help him. The ambulance crew quickly surround Hamish and hide him from view. Pip struggles to see, hear what is happening. Pip wants to tell them that Hamish has responded to her, but her words seem to fall silent—uncertain of being heard.

Lifting Hamish from the road, the crew place him in the back of the ambulance. Needing to stay close to her son Pip walks to the open doors of the ambulance—assuming rite of passage. She is stopped.

'But he needs me', Pip laments to the officer who halts her efforts.

'He needs me close by.'

'We are sorry Mrs Aires, but there's not enough room.'

'You are going to have to meet us at the hospital.'

'It will be okay.'

'Just follow us.'

Not wasting any time Pip turns and gathers her family and follows the ambulance close behind. Pip is drawn by the flashing red light and siren as they command her every direction.

The crowd of people surrounding Hamish grows as the seconds from his arrival in the emergency department pass. With her hands and clothes covered with Hamish's blood, Pip stands at a distance, watching, hoping she can catch a glimpse of her son or hear from someone that everything is going to be alright. Help is happening now she thinks to herself. Hamish is going to be okay now. Yes, he is going to be okay, Hamish is being helped.

A nurse approaches Pip and moves her to a seat. Daniel too is being positioned, like a fragile doll, out of harm's way. Daniel appears mute. He hasn't spoken for the past hour since hearing a bang and the screech of car breaks and running to the road to find the unimaginable. The nurse starts to wipe the blood from Pip's hands. Crying for her to stop, Pip pulls her hands in close to her body. Pip needs to keep this part of her little boy close by. 'Don't take that away from me', cries Pip, 'please stop'.

Unable to sit and just watch what is happening Pip jumps from the seat and runs towards the family doctor appearing from the crowd of people that surround Hamish. 'Tell me what's happening', she begs. 'Tell me John. I need to know now or I will go crazy'. John gathers her hands in his and pauses carefully. Pip looks into his face and can tell that he is the bearer of bad news. 'Pip, Hamish is in a semi-coma. He needs to be air lifted to a bigger hospital where they can operate.' Pip begins to release a wail that has been threatening to escape from deep within her pain. 'This can't be happening,' she cries. 'I thought he would be safe here. I thought everything was going to be okay, now that he is here.'

'No, Pip. Hamish is in a critical condition. It looks as if he may have some brain damage. Pip, I can't say what is going to happen. I don't know if he is going to be okay.'

The crowd shifts and Hamish is being carried outside to the pad where a helicopter has landed to take him away. He lays still. He doesn't open his eyes to see Pip standing there, waiting for him to get better. Once again Pip moves with the crowd and attempts to follow the stretcher that is carrying Hamish to the helicopter. She is stopped again. 'There is not enough room for you to go Mrs Aires. You will have to drive to the hospital.'

'No', screams Pip. 'Hamish needs me and I must go with him. Its over three hours drive to the hospital and I can't be away from him for that long. I want. I must be with my son. 'But Pip's words fail to achieve any authority with those who are listening. So while fighting the grip that halts her every move Pip watches as the crew rush Hamish to the helicopter and it rises into the air and disappears from sight.

For three hours Pip and Daniel sit in the back of a car, silent. Pip's parents are in the front of the car. They too are silent as they judge every attempt at conversation too painful. Daniel, still unable to speak, aimlessly stares out the window. Pip's mind is with Hamish but is tormented by the distance that prevents her from touching him, talking to him. She is with him, but there is no physical link that allows her to comfort him with a soothing touch that tells him everything is going to be alright. He is going to be okay, resigns Pip as she is unable to entertain any other outcome as that would mean the end of her life; a life that she had grown to assume would always be complete; a life, that until this morning, had given her such pleasure.

Arriving at the hospital, Pip exits the car before it is parked. With the speed of her movements trying to keep pace with the urgency of her need to be with her child, Pip races into an emergency waiting room that is thick with people waiting. But Pip's need creates a panic inside of her that is uncontainable when made to wait. Pip feels that her baby is waiting for her to arrive yet nobody is waiting to help her. Unable to stand in a queue and wait to be told where her son has been taken, Pip races to the front of the line and begs for someone to help. With her blood stained appearance signalling to the crowd that she is in the midst of an emergency she is given the space for her demands. But the staff meet Pip's need with a degee of control that baffles and distances her.

'Hamish Aires has been taken to intensive care, bed 16.'

'Thankyou', says Pip, 'but I don't know where intensive care is!'

'Here's a map Mrs Aires. Its quite self explanatory. You can take that lift over there. Thank you.'

Pip's emergency is managed and then promptly dismissed for the next emergency that is waiting in line.

Whilst studying the map Pip turns and walks across the corridor towards the lift. But Pip's mind, which is with Hamish, is unable to decipher the 'self explanatory' map that she is holding. The lack of direction fuels Pip's despair as she is again left waiting to see

Hamish by circumstances beyond her control. Knowing that her son is somewhere in the building Pip begins to call his name, calling out loud for anyone to help her find Hamish. Pip calls in vain until a nurse, witnessing her distress, attempts to help.

'Your little boy's in intensive care.' 'Okay, say's the nurse can you run'? Come with me I'll take you there'. And together they run through what seems to Pip like a never ending maize of corridors. Finally arriving at the entrance to intensive care Pip bursts through the doors, unable to heed another direction that tells her to wait in the form of a sign of 'Do Not Enter' in red print on the doors to the unit. Pip catches sight of Hamish as soon as she enters the unit and begins moving towards him. Two nurses proceeded to question her presence, but the doctor, standing at the end of Hamish's bed, gives her a welcoming nod and Pip's access is granted.

Hamish's head has been shaved and he has something in his mouth that is different from when she last saw him. Unable to touch Hamish until she knows he is okay, Pip asks the doctor to tell her, tell her everything. 'If you don't tell me everything', says Pip, 'I won't cope. So please tell me everything'.

'Well', says the doctor, 'its what you call a critical head injury'.

Yes, thinks Pip, that is why he came to this hospital. I want to know how he is know that he has been here for at least three hours. Hasn't the operation helped? Hasn't anything changed? Is Hamish not getting better now he is here? 'I understand', says Pip, 'but is he going to be alright?'

'Well', hesitates the doctor, 'I must say that at this moment there is really nothing we can do. It would have to be a miracle for things to get better'.

With hope being the only thing that Pip is able to contemplate Pip looks directly into the doctors eyes and says, 'Okay then lets pray. Let's pray for a miracle if that is what is needed at this point in time. We will perform a miracle for my baby boy'.

Pip however feels alone in her prayers. The doctor leaves and Pip approaches the bed where Hamish lays, as if asleep.

Pip waits by Hamish for the doctor to return and for a crowd of people to surround his bed and begin performing the miracle; begin exhausting every opportunity, every chance to make her son better. But no-one comes. The frantic rush to help her son seems to have dissipated and Pip begins to question why: Why are they waiting? What are they waiting for? Why aren't they in the operating room doing something, anything. Pip however seems to question in vain as Hamish lay silent and she stands beside him, waiting.

Unable to tolerate the lack of activity, or effort to help Hamish, Pip pleads with the doctor to phone a friend, a neurologist, for a second opinion. Recognising Pip's need the doctor talks to this friend and explains what is happening. After the doctor finishes talking Pip takes the call and listens while her friend attempts to reassure her that everything that can be done is being done to help Hamish. But with these words of reassurance still fresh in her mind Pip continues her struggle to communicate or trust that the doctor is trying everything humanly possible to help her child. Absent of any further recourse Pip is left with nothing else to do but wait. Pip sits by her son's side and watches the care fall into the hours as they quickly pass.

Time passes and still Pip is left waiting for her son to be cared for. Nothing seems to happen to Hamish unless Pip asks. Concerned with the large gash in Hamish's cheek, Pip asks the nurse if the doctor is going to repair it with some stitches. The nurse beckons the doctor and asks the same. Saying nothing to Pip the doctor approaches Hamish and pulls the wound apart with his hands. As if he were pulling her cheek apart, Pip begins to sob hysterically. The doctor asks the nurse to remove Pip from the bedside and the curtains are drawn as if to conceal his activities from further question. Half and hour later Pip is allowed to return to the bedside. But again Pip is shocked by the apparent lack of care that is being shown towards her son. Whilst she was gone the doctor had sown the laceration on Hamish's cheek closed. But instead of the small carefull stitching Pip anticipated the stitching seemed careless and crude. Large blanket-like stitches pull the edges of the wound closed. Her boy will be scarred for life with these stitches. Pip stared at the stitches in disbelief until she summised that nobody

would put such stitches in a little boy unless they believed he wasn't going to survive. Blood however was weeping from the wound and Pip asked the nurse if she could clean the blood away. Taking a dry cloth from the locker beside the bed the nurse passed one quick wipe across the swollen wound, leaving a smear of blood from one side of Hamish's face to the other. This ruthful action seared Pip's being. Pip's distrust and despair at the lack of care and concern for Hamish was sealed by this smear. Pip's last sight of Hamish, before leaving the hospital is a sight that contains this smear of disinterest—a smear of no care.

The place becomes more cold and uncaring as the hours pass. The staff seem to distance themselves from Pip and her pain. They only seem to come near her to look at the charts and briefly write something in the notes that rest on the desk at the end of Hamish's bed. It's hot and Pip is thirsty, but she is offered nothing to drink nor does she feel safe to leave Hamish to buy a drink from the canteen. Receiving no concern from the staff, Pip feels as if she is imposing on their tolerance when she asks to use their toilet. With two other family members present they take turns in sharing the comfort of the one chair that is positioned at the head of Hamish's bed. Other chairs could easily fit in the available space, but none are offered. Always close by the bedside Pip watches carefully everything that is being done to Hamish. No-one offers to tell Pip or Hamish what they are doing and Hamish's name becomes conspicuously absent from all conversations. Distressed by this lack of communication Pip asks the nurses to use his name.

'His name is Hamish', she said, 'Please talk to him and tell him what you are doing'.

But even Pip felt excluded from conversation. Determined to care for her son Pip becomes Hamish's voice and eyes. She asks the nurses what they intend to do and proceeds to explain their actions to Hamish.

Twelve hours after Pip first arrived in the unit the nurse approaches to tell her that the doctor wishes to talk in private. Fearing the worse Pip again begins to panic and search for Daniel. With an assertiveness that suprises both Pip and the nurse Pip states she

cannot talk to anyone about anything without Daniel being present. Daniel however remains in a state of limbo and is incapable moving on his own let alone making any decisions. Nevertheless Pip does not wish to be alone for these conversations and demands that Daniel is present. Unable to move unless moved by someone else Daniel is found sitting outside in a cement courtyard with the social worker. Being told what is happening the social worker moves Daniel inside to the meeting room. This room is air conditioned and furnished with several armchairs and a lounge. The comfort of this room stands in stark contrast to the discomfort at the bedside. But this comfort is only a shallow physical comfort. It soon becomes obvious to Pip that this room is a place of great emotional pain as it is a place where death is heralded. A place she would gladly trade for the discomfort, yet potential hopes of life at the bedside with Hamish. As if unable to find any 'kind' way to present the news the doctor proceeds in a very slow, precise and calculated manner to tell Pip and Daniel that he believes Hamish is brain dead. These words mean nothing to Pip as she cannot believe the doctor could say such a thing when Hamish's life is so obvious.

Pip's distrust and distance from the staff extends into a chasmic impasse. 'Pip', the doctor says firmly, 'I told you when you first arrived twelve hours ago that there is no hope, that Hamish is going to die'.

'But he is not dead', says Pip, 'and yet you insist on treating him and talking about him as if he were. I can see him breathing and he has twitched; he has moved. I have seen him move'.

'Yes Pip you can see signs of life but Hamish is what we call brain dead which means that he is never going to wake up again; he is never going to talk to you. Hamish cannot breathe without that machine. Pip, we have done one set of tests to prove that Hamish is brain dead and we need to do another. And we don't do the second test unless we are already convinced that he is dead. In six hours time Pip that second set of tests will need to be done and Pip you need to prepare yourself for the outcome.'

Pip felt Hamish's life under threat and rushed back into the unit to be with him. But his bed was gone from where she had left him. Before Pip could release the scream that was threatening the hushed tones of the unit a nurse takes her by the arm and instructs her that Hamish has been moved into a single bed room at the end of the unit. We thought you would like some privacy. The kind gesture was lost on Pip who could see nothing else except the threat that was looming against her son and her motherhood.

Even though the room had changed and there was now three chairs around the bed instead of one, Hamish looked the same. Nothing had changed. Yet Pip had been told that everything had changed. Pip had been told that her little boy is dead. That he is dead according to everyone in the unit who has the sense to realise the facts. Pip however cannot see these facts. Holding Hamish's hand and feeling the warmth of his skin Pip wonders why nobody but her valued this life that she sees, this rhythm of breath and heart beat. Pip couldn't explain or understand these signatures of life as anything other than life itself. And that life is so precious to her that she is angered by anyone who tries to tell her otherwise. Pip again becomes alone and confused. She doesn't know what to do or who to trust.

The new room has a clock, and Pip witnesses the passing of every second in the remaining six hours. Yet the more she wills this time to stand still the faster time seems to move through its hours. Five and a half hours later the doctor instructs Pip that it is time for the second set of tests to be done. Frantically fighting for hope and determined to not waste any moment of hope Pip refuses to let the doctor proceed until the full six hours are complete. But the final half hour is gone before Pip realises and the nurse is again asking her to wait outside. The curtains are drawn and the tests are finalised. Unable to see for herself Pip has to accept the doctor's word that again the tests proved Hamish to be brain dead. As the announcement of her son's death is being made Pip finds herself glancing at the clock on the wall and realising the time of ten past twelve is the same time of day Hamish was born. Everything seems so out of place. The order of Pip's life, her family's life, is being radically transformed by these words and she is loosing the direction that only yesterday seemed so real. 'What does this mean', says

Pip. 'I don't understand what this all means or what is meant to happen now'. Looking at Pip the doctor says, 'Pip I now have something very difficult to say to you'. Pip wonders what could possibly be more difficult than what he has just said. 'You have two choices. The first is the opportunity to help someone else Pip. Pip you can decide to help another little boy or girl who is desperately fighting to have a relatively normal life. You and your family, Pip, can make Hamish's death help these children. You can donate some of his organs. The alternative Pip is to switch the machines off.'

The former choice, helping children in need, sounds so noble to Pip. Caught in the majesty of this thought Pip finds herself asking what can she give. 'What organs would we be able to give?' The doctor proceeds to list the organs that can be given and with the mention of each organ Pip find herself thinking about the poor people in need. There is a moments pause between the doctor completing the list and Pip shrugging her shoulders as if to try and lift the haze that has fallen over her thoughts. She replies, 'All I suppose!'

'I suppose you can, ah, will need all of them!' With the swiftness of the decision made, the doctor gives Pip a paper to sign. With her thoughts barely able to direct her hand to the signing of her name Pip hands the paper back to the doctor which on receipt provokes a statement from him that sounds a mortal blow to her motherhood. 'Pip, your son is no longer yours, he now becomes the property of the state.'

'Oh my God', says Pip 'what have I done! What does he mean property of the state? Nobody owns Hamish! I don't even own Hamish', thinks Pip. 'Hamish is his own little person. Nobody owns anybody. Oh my God what have I done!'

Again Pip feels her trust has been violated. I didn't sign my son away. I didn't sign my son to belong to anybody but himself. How could they be doing this to me? They didn't say that I would be giving Hamish to anyone. They told me Hamish was dead.

Daniel too signed the consent but to this day he cannot remember doing so.

Pip returns to the bedside expecting some apparent change in Hamish but again there is none. Blood still smeared across his face, his heart beating and chest rising with every breath, everything's the same. Unable to comprehend anything that is happening Pip is approached by the nurse and told the police are here to witness Hamish's death.

'But he's already dead', exclaims Pip.

'Yes', says the nurse, 'But you have to tell the police that this is your son. Your son died a violent death and the police need to witness the death in case of a coroner's inquest'.

Yes it has been violent, thinks Pip. One emotional attack after another. Pip doubts though that the police will be able to witness the real scars from this violent death. Pip has witnessed this death for the past twenty four hours and has learned that although Hamish looks asleep the scars of his death surround him. I am the scar thinks Pip. There is a hole in the middle of my soul that is swollen and raw and threatens to swallow me. But you can't see it can you. You can't feel or touch it, can you!

What happens now? Again Pip waits for something to happen, waits for the staff to turn the machine off. But nothing happens. Pip asks for direction and she is told by the doctor there is nothing else to do but say goodbye and leave. Pip is surprised by what she believes is their first sign of compassion.

'They are waiting for us to leave before they turn the machine off. How nice and considerate of them to realise how painful it would be for me to watch them switch the machines off before Hamish goes to surgery.' In the months to follow however this belief of compassion will turn into a sense of violation and anger as Pip learns that compassion wasn't behind the staffs motive at all. Instead, their concern was for someone else. Hamish would remain on the ventilator until his heart is taken.

Appreciating the staff's concern, Pip begins to determine how to leave. But she thinks, 'Leave, how do I do that?'

'How do I even begin to say goodbye to my little boy?'

Pip finds she cannot say goodbye to Hamish. Instead she tells him that she will see him soon and tries to act as if she is just leaving for the night and that she will be back in the morning. Pip scans the room and unit and tries to determine how she will leave. First she considers, I need to get to that door of this room. Once at the door I then need to summon the courage to walk away from the room and to that door leading to the car park. Pip does this while all the time fighting the guilt and pain that accompanies her every move. Pip doesn't look back. She is numb, oblivious to all that surrounds her. Once outside in the car park Pip can see the car and starts moving towards it. But her legs collapse beneath her and she dissolves into the ground. Pip's fall releases from her a wailing lament of, 'Please don't let him hear me leave. Please don't let him see me leaving.' Pip's lament continues as two friends, walking beside her, pick her up and carry her to the car. In the car Pip crawls to the floor, again trying to hide from Hamish the fact she is leaving. Pip feels as if her heart is being dissolved by tears that will not stop. She can feel the motion of the car as it moves her further away from her son. The car's journey leaves her son behind, alone and with no-one to protect him and she is not coming back.

Daniel and Pip's journey home is awash with tears. Their home is in blackness. The rooms are cold and Pip's mother gives her and Daniel a sedative and carefully places them in bed. Laying in the darkness Pip feels the whole bed move with the pounding of her heart. She turns to Daniel and says now we have to sleep. Right now it's time to sleep and she enters what proves to be a legacy of broken dreams and sleepless nights.

As a nurse listening to each parent's story, it is possible to not only hear problems about the care they received but also identify possible solutions. While the stories convey a sense of being unprepared and the incumbent torment suffered as a consequence of their loneliness and uncertainty each story also points toward possible ways that could minimise these feelings. For example, being able to trust the support and guidance given by the staff seems central to the parent's capacity to cope. Unlike Pip, parents who found they could accept the finality when the diagnosis of brain death

was made felt this was so because the staff continously prepared them for that outcome. Conversely, any indication that what is said or done may not be the whole story can result in parents feeling angry and deceived and continually questioning what else have they not been told. As Pip recalls;

> ... the lack of information and the guilt, there is nothing that anybody can do about it now ... I have just got to live with that forever...that we abandoned our son. Not through choice but through people telling us what to do. And if you think about it for any length of time, about what we left him to, it's mind blowing. And then you think about it and make an effort to find out what happened ... and find out that all this other stuff happened. It make you even more angry (p. 45: 7-14).

Being unprepared for an experience that totally transforms their lives, many parents are left feeling helpless and alone. Each parent found their sense of helplessness unbearable but some individuals, such as Thomas, were able to break this silence with the help and compassion of staff who appeared to understand his need to know and be a part of every decision that was being made about his son. For Thomas, the nurses and doctors welcomed him to join all events and efforts made to help his son. Each time the care changed or a new intervention was attempted the staff would show Thomas or try to explain to him why:

> ... we had a terrific set of people around us. They involved us and that's probably what made it so acceptable ... the doctor got very involved with me and he said, 'look we've got to, I can give him these drugs' and [the intracranial pressure] would go down to 70 and he'd quickly up the dosage and this battle see sawed for about and hour and a half. He said, 'Look we aren't winning here.' 'The next stage', he said, I can do the set of drugs one more time, but if it doesn't work I'm afraid that you're going to have to be realisitc and think about the worst, because we can only go so far with keeping the medication up to keep the swelling down.' So we went through the whole see-saw again (p. 5: 1-10).

The meaning and significance of the differences between Thomas and Pip's experiences—the difference in their *being* lonely and uncertain can only be realised through the retelling of Thomas' story.

Thomas' Story

Leaning foward Thomas kisses Brett on the cheek.

'Good night son.'

'I love you.'

'I will see you in the morning, sleep tight.'

Brett smiles, quietly rolls over and waits for sleep to arrive. Walking from the room, Thomas stops himself from turning back to say, 'Don't worry, everything will be alright', as he has already said this at least ten times today. Thomas also knows that everything may not be okay and each time he finds himself saying that it will, he is reminded of an alternate possibility. The operation planned for Brett in the morning has only been performed nine times before, so the risks are high. Brett and the family have decided that the risks are worth taking as Brett's capacity to participate in all the sporting activities he so loves is diminishing with each month's passing. Brett, born with a congenital abnormality of his vetebral collumn, has already had six operations in his twelve year life. The eve of each previous operation has always been full of anxiety for Thomas and his wife Emma; yet they have learned, from watching Brett, to take each moment as it comes and to treat each operation as an opportunity, never a possible defeat. Thomas is always amazed at how brave his little boy is in the face of each operation and at how little he complains of the pain that he must obviously be in, twenty four hours a day. Four years ago Thomas had hoped that that operation would be the last; but in the last year Brett has undergone a growth spurt which has placed undue pressure on his spine and is now threatening him with paraplegia. So, as the days pass Thomas watches as his son looses the energy and mobility that typically animates his slight frame. In many ways then, Thomas embraces the potential held in this operation for his son as he realises there is little else to do.

Next morning breakfast is unusually quiet as everyone is anxious about the day's future, and all other conversation seems meaningless. Though having been through this process

six times before there is a sense of familiarity about the events taking place and the family seem to prefer to flow with this familiarity than move with the alternate insecurity of uncertainty. So routine was the day made, that Thomas kisses Brett goodbye while saying, 'I will see you this afternoon'.

'I will be waiting for you in the intensive care to wake up', says Thomas.

Giving Emma a kiss Thomas whispers to her, 'Ring me when Brett goes into the operation.'

'I will see you at the hospital at about four o'clock, and don't worry, everything will be okay.'

Having spent the morning being prepared for the operation Brett lays on a bed waiting for the theatre team. Sleepy from the premedication, he listens to his mum as she talks about the beach holiday they have planned for the Easter break. The family will be there in three weeks time and all the tension and worry of now promises to be but a memory. Brett has invited his best friend Samuel on the holiday and is looking forward to the fun they will have together, playing and exploring through the rock pools and sand dunes. With the theatre team now ready these happy thoughts are put to one side as Emma kisses and squeezes her boy tight.

'Bye, Bye mummy', says Brett.

'I will be waiting right here for you to come back', replies Emma.

'I love you.'

Taking a deep breath as she watches her little boy wave goodbye, Emma turns and prepares herself for a long wait. Deciding to take a walk outside to phone Thomas, Emma walks past the entrance to the neo-natal intensive care unit. By the sight of these once familiar doors Emma is taken back to the many nights and days that she and Thomas spent in there, waiting for Brett to recover. She remembers how ill the little children were and all the worried parents who stood close by, waiting for their child to

recover. These memories rest heavy on Emma's mind and so she quickly lightens them by the promise that this will be the last operation. She releases a sigh of relief as she thinks about how Brett will soon be able to leave this struggle behind.

The hours pass and Emma returns to the unit to wait. She makes casual conversation with the staff as she is familiar with many of them as they have cared for Brett before. Emma is comforted by their concern and genuine interest with Brett's progress over the years. They too celebrate the fact that this operation promises to be his last and they make sure that Emma is comfortable while she waits. Six hours later Emma sees Brett's anaethetist, John, enter the unit. He looks at her, but fails to offer the smile she has been waiting to see. She watches as he talks to David, the doctor in charge, and continues to watch, anxiously, as they both turn and walk towards her. Emma begins to feel uncomfortable as their manner portends to her that something is wrong. Greeting Emma with a smile that quickly fades, John begins to tell her that there has been some complications.

Complication. This is the one word that Emma has always feared she would hear one day while waiting for Brett to return from an operation. She rejoiced its absence in each passing event. She thought that this time too she would be lucky. But no. No, that word had arrived and Emma didn't know where or how to begin to cope with its presence now it was there.

'Emma', continued John, 'Brett has failed to wake up as we had hoped he would'.

'During the operation the main artery, the aorta, tore and we had to quickly transfer him onto a heart-lung bypass machine.' Emma watches in stunned silence as John struggles with his difficult task.

'We tried to maintain Brett's blood pressure while the bypass equipment was being primed but his blood pressure dropped before we were ready to transfer him; so we believe that there must have been at least an eight to ten minute period where Brett was without blood to his brain.'

Emma remains silent, hoping that there soon will be a 'But' in this monologue of pain to give her some hope.

'But', continues John, 'he's a young boy Emma, and we believe that he can recover from this complication, but we will have to wait'.

Appreciative of the But, Emma is concerned about the wait.'What are we waiting for?' asks Emma. 'I don't understand why he isn't waking up.'

'We don't really know either', said John, 'but the next twelve hours are critical'.

'When the brain is starved of oxygen Emma', says David, 'the blood vessels in the brain can start to break down and that can lead to bleeding in the brain'.

'If Brett does develop bleeding in the brain then we will have to try and control the rise in pressure that can result as this rising pressure can cause serious complications.'

Emma finds herself saying thank you as John leaves. Saying thank you to someone who has said nothing to help her but everything that threatens to destroy her. Emma reflects on the tragic irony in saying thank you to someone who is leaving her shaking and confused and with nothing to do but wait and cry.

One hour later Thomas arrives at the hospital to find Emma crying and saying, 'Brett's not waking up! He's in a coma and on a heart-lung machine'.

Thomas struggles to comprehend what Emma is saying. All day he expected to arrive and see Brett awake and waiting to see him but no, this is proving to be nothing like what he expected. Before he is able to catch his thoughts to ask Emma for details the doors to the recovery room swing open and a chorus of beeping infusion sets, monitors, nurses and doctors accompany a bed where Brett lay. Thomas struggles to see Brett's face but his sight is fractured by the myrid of wires and tubes that surrounded it. Thomas and Emma stand silently in the background and watch as one group of people hand their care over to another. Slowly the crowd ebbs and the nurse, Mary, beckons for Thomas and Emma to join her.

'You sit there Emma and hold Brett's hand.'

'I need you to talk to him and tell him that you and Thomas are here and that everything is going to be alright.'

'Thomas', instructed Mary, 'I would like you to massage Brett's legs and arms'.

'He's still cold from the operation and that can help.'

'So would you like to do that while I just continue fiddling with this equipment and writing down a few observations?'

Together Thomas, Emma and Mary work as a team to help Brett through the next twelve hours. Over the next three hours Thomas and Emma share conversation with Brett; telling him about anything and everything their troubled minds can muster. While watching Thomas and Emma quietly the significance of this boy's life is revealed to Mary. Mary listens to their life stories and shares the mourning of their potential loss. Quietly moving in the background, still listening to the stories Mary explains the 'why' and 'what for' of each change of infusion, replacement of equipment and silencing of alarms.

At 10 p.m. Mary encourages Thomas and Emma to give themselves and Brett some rest so as to gain some needed strength and endurance for the next day. Emma, having been at the hospital all day, is encouraged by Thomas to go home. Their daughter Jessica is at home and needs someone to explain to her what is happening and bring her to see Brett in the morning. Thomas stays and is encouraged to take some rest in the parent's room.

'I will contact you if he wakes', says Mary.

Exhausted by his fears Thomas takes this opportunity to rest, confident that Brett is stable and safe.

At 1 a.m. Thomas is woken by a phone call. 'Thomas', says David, 'I need you to come to the unit.'

Thomas feels his heart lighten as he races the corridors toward the unit. Brett is okay, he thinks. He has woken and want's me there. Everything will be fine. As Thomas rushes into the unit though his lite heart is quickly burdened by David who greets him with a, 'Sorry Thomas, but the pressure in Brett's skull is fluctuating and we need to start some medications to try and control that'.

'Thomas', continues David while pointing at the monitors, 'we need to keep Brett's pressures above 70 millimeters of mercury and below 100'.

'I hope this medication will do this Thomas', warns David, ' because there are not many options left'.

Finding nothing to say, Thomas watches as David and Mary battle the see-saw of Brett's blood pressure. Grounded by David's conversations Thomas finds himself the rest of the time floating in a haize of hopes whilst mesmerised by the monitors and their green lumescent numbers rising and falling—tossing his hopes to despair. Suddenly, Thomas is once again grounded by the sound of David's voice saying, Thomas we aren't winning here'.

'This medication is not helping.'

Though journeying every inch of this battle with David, Thomas has nothing to say—no piece of advice or magic potion to offer his son's conquistador. He follows David's every lead, but is lost in this situation as to know which way to go, which way to turn. Feeling totally helpless, Thomas places all his faith, potential for hope, in the choices David makes.

'I can try another set of drugs, but if they don't work I'm afraid Thomas', says David, 'you're going to have to be realistic and think about the worst possible outcome'.

'We can only go so far with the medication to keep the swelling down, after that, we have lost the battle.'

Thomas watches as the last line of defense for his son's life advances and wages war against an unyielding pressure. As Thomas stands by and watches all effort seem useless he feels someone embrace his shoulder, as if in an attempt to help him stand against this threat of his child's death that is bearing upon him from all sides. Thomas feels himself let go into the support of this embrace and sob for some release. Thomas finds himself sobbing for the situation to be different and for the situation to be as he had planned—just another operation that Brett needed to go through. Yes, it was the last operation for Brett, yet Thomas had hoped that this operation would offer nothing but hope, enhance Brett's life and not like this: devoid of all hope and threatening to end Brett's life that has barely begun.

Thomas watches the green numbers continue to rise. He watches as the battle to save his son's life is lost. The social worker, Christine, who is embracing Thomas begins to cry. She is sharing in Thomas' pain, and Thomas is comforted by her honesty of emotion. David then approaches Thomas and says, 'I am sorry Thomas, but nothing seems to be working and I am afraid that everything indicates to me and my peers that Brett is brain dead. We now need to perform a series of test to make certain that this is the correct diagnosis'.

Christine's embrace was no longer strong enough to stop the weight of Brett's death from forces Thomas knees to buckle beneath him. Feeling as though his life breath has been squeezed from every cell in his body, Thomas finds himself breathless. Slowly standing Thomas walks to the bedside and looks into Brett's face.

'I can't see death?', questions Thomas to Mary.

'Brett looks as if he is asleep'!

'I know', says Mary as she stands next to Thomas cleaning Brett's face; 'but the pressure inside his skull is too high. Brett will never wake again Thomas, 'because his brain is dead'.

Thomas watches Mary as she cleans Brett's face. He sees no life in Brett's eyes when Mary lifts each eye lid to cleanse inside. All Thomas can see is a glazed stare. Brett's eyes have no spark or vitality, no life. 'My son has gone Mary, hasn't he', cries Thomas. 'Brett has gone'.

'Yes', replies Mary with a voice that has become worn brittle with sadness. 'Brett has gone.'

Thomas can hear the sadness in Mary's voice and can see tears welling in her eyes. Mary holds her arms out as if to welcome Thomas' pain. Thomas welcomes Mary's embrace as it helps to fill some space in this sadness of his that seems so vast and endless.

'I need to ring Emma', says Thomas and Mary walks him to a phone at the nurses' station.

'Emma', whispers Thomas, 'we have lost Brett, come now'.

Unable to say anymore Thomas replaces the receiver and returns to Brett. He waits. Once Emma has arrived and spent time alone with Brett and Thomas, David tells them that he wants to do the first test.

'This is what is called an EEG', explains David as he carefully watches Thomas' response to see if he understands, 'and its purpose is to look at the electrical activity in the brain'. Thomas and Emma watch as Mary and David place a cap and electrodes on Brett's head. Once the electrodes are connected to the machine Thomas, Emma, David and Mary watch as all but one of the ten electrodes record a straight line.

'What does this mean?', says Emma. 'Where is that movement coming from if Brett's brain is meant to be dead?'

'Well', said David, 'I cannot explain that so we will need to do another test to be certain that there is no activity in Brett's brain'.

'We will need to take Brett for a cerebral angiogram.'

'This test looks at the blood supply to the brain. We believe that because of the high pressures inside Brett's skull the blood supply is not getting to his brain.'

Listening to this conversation Emma feels as if they are talking about a stranger; as if these words cannot be associated with the little boy she was talking to and caressing this morning. The little boy who waved her goodbye with such bravery and reassurance. Brett is wheeled away for this procedure and returns half an hour later with David saying that the results show that there is no blood flow to Brett's brain and that clearly he is brain dead.

Emma however is still concerned about seeing movement on the EEG and David decides to conduct another test to see if that movement is still present. Once again Thomas and Emma watch as the electrodes are placed on Brett's skull and the recording is made. This time there is no movement of the stylets, no recording of brain activity.

'Emma and Thomas', says David, 'there are a series of basic reflex tests that I also need to do, but these are quite distressing and you wouldn't want to see these being done'.

'So', continues David, 'I think you should wait outside for a moment and we will come and speak to you when we have finished.'

Mary guides Thomas and Emma to the staff lounge room where they can be alone.

Now, with the tests indicating that Brett is brain dead, Emma feels all the hope that she has been holding onto dissipate. Defeated by an opponent she had no ability to control Emma sobs in Thomas' arms. As Emma's pain meets with Thomas' he pulls her close to his heart and begins to sob with her.

Ten minutes later Mary enters the room. After sitting for a moment and trying to empathise with their sadness she tells them that David, Professor Carter (Brett's surgeon) Professor Thompson (Director of Pediatrics) and Christine the social worker would like to come and talk to them. Attempting some degree of composure Thomas and Emma acknowledge each person as they enter the room and gather a chair to sit. Once the group have spent a moment conveying their sadness and condolences to

Thomas and Emma Professor Thompson says, 'Mr and Mrs Hughes we formally have to advise you that your son is brain dead and that we are deeply sorry'.

With the word 'formally' making Brett's death seem more final, Thomas and Emma are again overwhelmed with tears. And again they are not alone in their sadness. Professor Carter who has been a Cardio-Thoracic surgeon for thirty years begins to cry. Brett is the second child he has lost and Thomas can feel his sense of failure and regret. Thomas however receives Professor Carter's tears as a sign of strength and appreciates his willingness to share his emotions so open and honestly.

As the minutes pass and the doctors wait to answer any questions that Thomas and Emma may have Thomas, while looking at Emma, says they would like to donate some of Brett's organs. Surprise at the frankness on Thomas's behalf the two professors ask if he is sure, 'Are you sure that is what you really want to do'?

In harmony and with a clarity that conveys their determination Thomas and Emma's reply, 'Yes, we are sure'.

'Well', stumbles David in a manner that fails to hide is surpirse, 'If that is what you really want then we can arrange for the transplant co-ordinator to speak to you; and if after speaking to him you still wish to follow through with donation we will support you in whatever way possible throughout the whole process'.

The transplant co-ordinator is however busy elsewhere and is unable to see Thomas and Emma for another six hours. So they wait and take this time to phone relatives and have them come to the hospital and say their goodbyes to Brett. The staff room is kept vacant for the family as a retreat when not at the bedside with Brett and the family move freely between this space and Brett's bed, talking to Brett, crying but most of all, waiting. Throughout the wait Thomas is comforted by Christine's (the social workers) constant but silent presence. Saying little but sharing a lot, Christine is welcomed by the family to join in their discussions about Brett; to share the family's tears and laughs, sadness and pain.

The next six hours pass quickly and the relatives slowly leave the family to have their private time with Brett. The transplant co-ordinator arrives and carefully explains the details of the procedure and what Thomas and Emma should expect. With a conversation that lasts an hour Thomas hears little but few sentences as they break into his silence:

'When the organs are removed, says the co-ordinator something is put in their place.'

'No empty cavities are left.'

'Great care is taken in removing the organs because that is the most important stage for the success of the transplant.'

'There is no disfigurement to Brett.'

'The better the condition of the organs the greater the success for the recipient.'

'You will have your chance to say goodbye afterwards.' 'Brett will be taken to a quiet room where and you can take him off the bed if you like hold him and say your goodbyes.'

On hearing this Thomas becomes uncomfortable as he imagines holding Brett lifeless and dead. For a reasons he couldn't identify this thought of holding his dead son seems wrong—too macabre.

'Have you decided what organs of Brett's you would like to give?'

'Well, says Thomas, 'His kidneys, heart and lungs'.

The transplant co-ordinator begins to read a list of possible organs. Though the mention of each organ cuts further into Emma's pain and sense of loss, she nods quietly to each, until he says Corneas.

'No, I'm sorry. No I can't give Brett's eyes.' Each time Emma closes her eyes she can see Brett smiling at her, looking through her with his bright blue eyes.

'No', she struggled, 'you can't have Brett's eyes'.

'I think you have given more than enough', consoles the transplant co-ordinator, 'Please don't be sorry; you have given more than enough'.

'We now have to wait', said the co-ordinator, 'for the various tranplantation teams throughout the country to respond to the gift, and that can take some time.'

'I suggest that you try and get some rest and I will call you once everything has been arranged.'

Tired but unable to rest, Thomas spends the next six hours watching the nurses care for Brett. He watches as they continue to massage his legs, hands and feet and talk to him about everything they are doing. Thomas also caresses Brett's hands and face and tells him how much he loves him and is going to miss him. As time passes Thomas finds himself wanting to lift Brett off the bed and cradle him in his arms. No longer at odds with this formerly macabre thought Thomas instead silently longs for the time when he can hold his boy, one last time.

Although at first appreciating the time to say their goodbyes, the waiting begins to make the loss more overt. As each hour passes the waiting becomes more harrowing. Fatigued from no sleep and exhausted by their sadness Thomas and Emma become increasingly burdened by the wait. Each hour becomes a wait for this waiting to end. As Thomas watches he can see the nurses struggle to keep Brett alive for the transplantation. Brett's hands and feet become puffy and discoloured and Thomas can see on the monitor Brett's heart beat missing every third beat. As this starts to happen Thomas watches as the doctors and nurses again try and juggle Brett's medication in an effort to keep him going, just a little longer. Seeing this struggle Thomas is again convinced that Brett is dying and there is nothing anyone can do to stop this from happening.

Finally the surgical teams arrive and Thomas and Emma walk with the nurses as they wheel Brett to theatre. As they walk past people in the corridor Thomas wonders if they can tell, can realise what is happening. There is nothing to indicate that his son is

dead and Thomas wonders whether this will be the same after the operation. Challenged by this thought Thomas asks the nurses pushing the bed, 'How are you going to wheel Brett back from theatre? Are you going to have a sheet over his head or something?'

'No, says the nurse, Brett will be wheeled back in exactly the same way as he is being wheeled down.'

'He will be treated like any other person returning from theatre'. Thomas is comforted by this thought.

For the next two hours Thomas and Emma wait to be told that the operation is over and they can now hold their boy. Unable to think about what is happening to Brett while they wait Thomas and Emma instead talk about who Brett is helping and if they will ever meet these people, some day. Finally told that Brett is now ready, Thomas and Emma are lead to a small room. Brett has changed. Laying on a bed, surrounded by clean white crisp sheets he looks peaceful. No longer struggling with life. There are no tubes in his mouth nor needles in his arms. Someone has placed him in pyjamas; they are unfamiliar to Emma. Two chairs rest next to the bed—a signal to Thomas and Emma where they should sit. At the bedside Thomas leans forward and kisses Brett on the cheek. Placing one arm under Brett's shoulders and the other under his knees, Thomas lifts his baby boy off the bed and sits. With his lips pressed close to Bretts forehead Thomas whispers 'I love you'. Not hesitating this time Thomas adds 'Don't worry, everything is going to be okay' and again, 'Everything's going to be okay'.

Emma and Thomas spend the next hour and a half taking turns holding Brett and saying their goodbyes. Seeing the toll of the wait and struggle in Brett's eyes, Thomas finds himself saying sorry and wishing that everything had happened faster. Brett's eyes have begun to sink in their sockets and Emma too is disturbed by how the wait has drained her boy.

Three days later, Emma and Thomas' sadness is momentarily lifted by a phone call from the transplant co-ordinator saying, 'I'm happy to tell you that a gentleman received your son's kidney and that a little girl received Brett's heart and lungs'. Continuing with

the news he adds, 'The first thing the little girl said when she opened her eyes after the operation is, 'I haven't got cold feet anymore.' Before completing the conversation the transplant co-ordinator reminds Thomas that he can write to the recipients if he likes but that the letters need to remain anonymous and be directed through him. Four days later Thomas takes this opportunity and writes a letter to both the families saying, 'I'm happy to hear that everything was a success and that our gift has been worthwhile in that it has saved you the pain and suffering that we have gone through in losing our son and that we wish you all the best'.

Two years pass and Thomas continues to wait to receive news from the recipients. Needing to have some communication with the recipients Thomas attempts another letter; this time a Christmas card saying, 'Having heard further that you are now completely self reliant and everythings going well, we wish you the very best and would be very interested to hear from you if you feel so inclined'.

Two months later Thomas and Emma receive a thank you letter from the gentleman. Seven months later they receive a letter from the little girl's family. Always subconsciously waiting for the letters to arrive, Thomas received the letters and after finding somewhere quiet to sit opened them. Reading the words of thank you from the recipients filled Thomas with a sense of resolution that the effort both he and Emma have been through is appreciated and respected. He cries in silence.

One year after Brett's death Thomas sits waiting in a coffee shop in an inner city mall. A tall dark haired gentleman approaches his table and with a gentle enquiring voice asks, 'Are you Thomas Hughes?' Smiling at the man as if welcoming an old friend back into his life Thomas replies, 'Yes, I am Brett's father'. Unable to contain their tears of joy the two men embrace each other and struggle to know where to begin saying what they have been waiting to say and hearing what they have been waiting to hear.

Although Thomas shares the themes of unprepared, watching and waiting, uncertainty and loneliness with Pip, Ellen, Andrew and Phedra, they are expressed in a different

tone and therefore achieve a different understanding and meaning in the context of his story. The quality of relationships Thomas had with the staff, the willingness of the staff to involve him and his family in every aspect of his son's death, seemed to afford him a clarity and acceptance which is sadly missing in Pip's experience. As Thomas explains:

> ... the fact that we were involved, we were never restricted and it was a come and go for the entire family right from the word go. We never had to come to grips with what brain death was because we lived what brain death was. And that was the big difference. The fact that there were no barriers there ... we were part of the whole system (Thomas/p. 14: 16-20).

Thomas' experience is an experience of sharing and support. An experience that celebrates how important honesty and sincerity is in our relationships and about how such openness can help us with our ability to cope during times of incredible loss. Thomas' story shows how honest, open, supportive relationships can afford us the necessary strength in clarity and direction to make choices that when first presented appear insurmountable.

The truth and sincerity of the information given to each parent seems to be formative in their long term acceptance of the donation. Although Thomas shared with each parent a sense of being unprepared as well as the overwhelming shock of the final diagnosis he felt more able to accept the death of brain death as he had developed a trust in the honesty of the staff's support and information. Thomas' acceptance and trust was further nurtured through being present during the brain death testing. Actually witnessing the absent response of life helped Thomas and his family to assimilate the information they were receiving and so more readily accept Brett's death when finally told. When finally given the diagnosis, although overwhelmed by its implications, it seemed to simply confirm for Thomas what he already expected or anticipated.

Such honesty however, such openess of relationships is difficult to achieve under the current policies of practice. The preferential practice in transplantation for beating-heart donors has made covert many of the staff's activities at the bedside prior to consent being given (Pearson, Hickson et al. 1996). Rarely are nursing staff able to discuss

notions of brain death or organ donation with the family before the doctors have confirmed and explained the details of the diagnosis. The parents are often unaware that staff are commonly engaged in care that is simply maintaining the viability of their child's organs until they are able to make a decision about donation. Such policies create situations that make dishonesty implicit in the very relationships needed between the parents and nurses.

Pip recounts the feelings she had when she later realised that attempts to salvage Hamish's organs had commenced prior to her giving consent:

> ... I was sitting in her [bereavement counsellor] room uncontrollable crying having realised the fact ... that they had actually started proceedings for organ donation before they had actually asked us. And the realisation of that was most devastating ... it's all just fears and realisations that they had just conned and deceived me while I sat their with my child (Pip/ p. 47: 24; p. 48: 1-3:19).

Although there is no malice in the actions of care undertaken by the nurses this does not in turn dismiss a needed appreciation of the meaning that such practices have for the waiting, uncertain parents. For Pip, the eventual realisation of the intention of these practices cascaded into a series of other issues that left her and her family feeling completely violated and abused at a time when they needed more than anything to trust in the staff's guidance. At every opportunity and twist Pip recounts an experience of not being aware of the full implications of a beating heart transplantation. Pip felt totally unprepared. That Hamish would go to theatre with his heart still beating and return dead was an inconceiveable thought for Pip. This thought: the thought that Hamish was alive while the rest of his organs were being taken, is for Pip the greatest violation of her trust. They tricked me out of protecting my child has become Pip's eternal lament.

Pip is tortured by this thought as she believes she would never have agreed to the operation had she known that Hamish would go into that operation alive and return completely dead:

> ... we were told that there would be no autopsy ... then it was only when we had come into contact with other donor families who said ... 'Oh but an autopsy is automatically carried out on donors' ...

> 'No', we said, 'no that's not right. You've got it wrong'. And then we were so concerned about it we rang the coroner and asked if we could have the autopsy reports ... and he said sure I'll post it to you ... this was three years later ... its the grossest violation ... to think that there are possibly hundreds of families, not only donor families but hundreds of bereaved families that have no idea. And they just live in this situation of no information (Pip/ p. 32: 13; p. 33: 3-5; p. 34: 3-8).

This violation of trust would later ignite in Pip and Daniel a need to uncover more untruths; a need to uncover other violations that happened to their son that because of their shock and uncertainty they unwittingly allowed to happen. Pip and Daniel's life has now become this search. A search for complete honesty. They join other parents in their campaign for the right of donor families to complete honesty about the implication of the decisions they make while living their experience.

Parents who were not as involved as Thomas was in every detail of the testing for brain death of their child, continue to question in the aftermath the 'properness' of the brain death process. Andrew's wife Joyce explains that although she does not deny Angelica's death, actually seeing the tests performed would have helped her feel more certain about the diagnosis and the decision both she and Andrew made. With such evidence in hand they believe they would not have had to rely so much on blind faith in the doctors word. Bearing witness to the tests they now anticipate they could have better determined the truth of their situation:

> ... I think I feel comfortable with my daughter's death ... But I would have in some ways liked to have been there when they did the things on her ... wouldn't that have helped me accept the fact that she was brain dead? I mean if you take her off life support and there is no response, there's no response! (Joyce/ p. 9: 14-21).

Being totally accepting of the doctors diagnosis and the belief that their child is dead does not however appease the emotional challenge—the cognitive incongruence—many parents feel when confronted with the overt life they continue to witness while waiting (Pearson, Hickson et al. 1996; Sque and Payne 1996). It often fails to make sense. Caught in a relentless process the parents force themselves to accomodate this incongruence with a belief that, given time, they will come to understand what has

happened. The parent's thereby depend on the staff for direction. They need to know what to expect and what is going to happen next in order to help them cope with a process that is moving too fast for them to understand. For me, Ellen's story speaks of this struggle to cope and comprehend what is happening. Ellen depended on the staff for guidance. Ellen's inability to openly relate her emotions and needs to the staff however has left her feeling misguided and guilty about the decision she made to leave her son during a time which she now believes he needed her most.

Ellen's Story

Life felt wonderful to Ellen as she walked through the forest in the morning sunshine. She felt an independence that had been in abeyance for the past ten years. A mother of four children James 12, Jessica 10, Madeline 8 and Owen 5, Ellen's life had been happily dedicated to their needs and little else. Recently separated from her husband Ellen's independence was now acsessible, as David chose to care for their children on the weekends. So, enjoying the warmth of the sun and freshness of the forest air Ellen found herself relaxing as she wandered through it enjoying the stillness and solitude that the surroundings offered.

Aged forty two Ellen had found the last two years with Owen, her youngest child, particularly challenging as he was an active child, so full of life, yet she loved him. She loved all her children and therefore felt slightly uncomfortable about not leaving a contact number with her husband when she set out for her day in the forest. This discomfort however was readily placated by her faith that her children were safe and in good hands and that nothing would become so urgent that David could not manage until she returned from her day out with friends.

And at David's house everything was okay. James, Jessica and Madeline were playing on the gym set and Owen was being treated to a read of his favourite book by his daddy. With his little face furrowed in a frown of concern about the book's repetitive question of where the little puppy could be, Owen would, before his father could turn the page,

know that the puppy was in the park. With the book finished and daddy called to the phone, Owen decided to look for the puppy.

Owen knew that the park where the puppy could be was just down the street and across the road. With his father busy on the phone and his brother and sisters playing in the back garden, no-one could remind Owen not to wander out the front gate on his own. So, as Ellen wandered through the bush, captivated by the sights and sounds that she saw, Owen also wandered to the park; caught up in the play of finding the little puppy. But as Ellen was mindful of where she walked and the hidden dangers of which she needed to take care, Owen was too embroiled in play to see the car that hit him as he wandered across the road in search of the puppy in the park.

Although James was also caught in play with his sisters he heard the potential for tragedy in the screech of car breaks and ran to see what was happening. Seeing a car stopped in the middle of a busy road James also saw a little boy, fallen, in front of the car and ran inside to tell his father, never thinking for a moment that it could be his baby brother, Owen, laying silent on the asphalt. In full flight to help the people in the accident, David ran towards the crowd asking if they needed an ambulance. Heeding the crowds needs he ran back inside and called an ambulance, telling the operator that a little boy has fallen out of a car and help is needed urgently.

David tells his children to keep safe behind the front fence and runs toward the crowd to offer help. Standing at the edge of the crowd David notices Mrs Edwards, his next door neighbour, crouched over a small child—attempting resuscitation. As she lifts her head to scan the crowd, in search of help, David glimpses the incomprehensible, little Owen's face. The sight freezes David to the spot. Consumed with disbelief he begins to tremble. A scream wrestles from deep within his soul to move. Yet it is as if his body is incapable of responding to this call in any other way but to shake from toe to temple.

The ambulance crew arrive and Owen is surround by another circle of strangers. Still nobody in the crowd is aware that the child's father is standing within their midst, frozen to the spot. By this time David, already fallen where his tears have shed, is

comforted by Mrs Edwards who tells the approaching police officer that he is Owen's father. With his son now in the back of an ambulance that is attempting to pull away from the crowd, David is being told by a policeman that he needs to get to the hospital and that he shouldn't drive but instead have a friend take him. So, although just moments ago David's body seemed incapable of responding to any of his own commands, the command of a stranger propels him into action as he sets about calling a friend for transport and asking Mrs Edwards to watch over his children. Before leaving the house David phones Ellen.

'Hello this is Ellen, I am sorry I am unable to come to the phone right now but if you leave your name and number I will contact you as soon as possible,' Ellen's unsuspecting voice mail message answers. David waits for the tone and with his voice trembling with the weight of the words saying, 'Ellen, Owen's been in a road accident. He's hurt real bad. Come to St Thomas Hospital as soon as possible'.

Then David, eager to get to the hospital, quickly replaces the receiver and tells James to phone his mother in an hours time.

Four hours later Ellen, arriving home, enjoys how heavy with fatigue her body feels from the day's walk. She feels relaxed. Telling her friend to get a cool drink from the fridge, Ellen walks to the answering machine, to check for messages. Her body fatigue and heaviness soon turns to dread as she listens to David's voice, then a policeman and finally her eldest son James all heralding the same message: that her baby boy has been badly hurt in her absence.

Feeling her life rapidly change from a tranquil shade of yellow happiness and contentment to a brittle grey of sadness and pain, Ellen struggles to know where to begin. Taking command of her first need—the need to know how her son is—Ellen phones the hospital. As the conversation progresses though Ellen feels this control of her needs slipping away. The doctor she is speaking to tells her that Owen has critical head injuries and has been air lifted to the childrens hospital in the city, at least a two hour drive away, and that she should travel there immediately.

David waits for Ellen at the doors to the intensive care unit. Words seem futile and devoid of all sense. All conversations of meaning to Ellen and David have turned into those which instruct and direct their every action. David tells Ellen that a social worker is waiting to see them before they enter the unit. The closer Ellen gets to seeing her child the more brittle words become. All words become fuel for her pain. Ellen and David are told by the social worker that Owen's condition is critical and to expect the worst. Owen has suffered major brain damage from the accident and has just returned from emergency surgery to try and release the pressure that is building up inside his skull. But, although Owen has received all the treatment his condition warrants, there appears no real room for hope.

Suddenly, the energy that had carried Ellen from the phone call to this conversation seems to dissipate as her knees collapse and she raises her hands to her face. Weeping the words, 'please don't let my little boy die', Ellen is again lost as to what she is going, or needs to do.

Attempting command of the situation, Ellen identifies her greatest need is to be close by her child. Taken into the intensive care unit Ellen's sense of control is again challenged as she is confronted by strangers working with a maze of wires and tubing that tempt to hide her child's small frame from view. Feeling as though she is the stranger, Ellen begins to question her right to be here; as although she is a nurse, Ellen is unfamiliar with the equipment and how it all works to help support her son's life. However, as Ellen moves through the barriers of unfamiliarity and sees her son's face, touches his warm hand, she realises that what she needs to do is simply sit by his side, and watch over his life. Still unable to comprehend what is taking place, nor decide what to do, Ellen just waits and watches other people care for her child—making sure that her little boy is safe.

David leaves to take care of the other children, with the promise that Ellen will phone him on the hour. As the hours pass, Ellen sits and watches her child breathe and his heart beat. With the knowing eye of a mother Ellen, from time to time, scans her little boys body and is lost amidst the difference between the minor degree of physical injury that she can see and the critical prognosis she is told. She wonders however how much

damage is concealed beneath the bright white bandage around his head. His head is wrapped in a bright white bandage. His little face has tell-tale signs, somehow his face looks different. It lacks the gentle smile that it usually assumes while he sleeps. His little eyes are swollen and blackened around the edges, and his cheek and nose are grazed.

The hours stagger by and Ellen waits with her child, in silence. Still uncertain of where her child's life is heading Ellen is approached by a nurse who encourages her to get some rest, to leave Owen's side, because tomorrow is going to be full of many decisions that rest will help her make. So Ellen, still unable to think about doing anything but stay by her child follows the nurse as she leads her to a room across the hall. Yet this space and distance that is meant to give Ellen comfort and rest is full of dis-ease. This space of rest is full of torment. Everything seems so unreal as Ellen lays on the bed knowing that across the hall her little boy is struggling for his life. Ellen weeps in this space for her child and how helpless she feels in being unable to change the situation. In this space Ellen feels lost in her efforts to keep her child safe. Ellen aches as she realises she has no choice but to leave her child's future in the hands of the doctors and nurses. So, Ellen weeps whilst fighting sleep.

As the tears flow Ellen thinks back to a conversation she had with a close friend who came to visit her early this evening. The friend, also a nurse, warned Ellen that the doctors may approach her about organ donation. Unable to comprehend it at the time Ellen now realises in this thought some way to regain control of her son's future. A way to turn this terrible situation around— achieve something positive out of all this pain. With this thought ebbing the flow of tears Ellen leaves the room and returns to her child. However nothing has changed. The machines continue to beep in their rhythmic monotone and Owen's condition is still the same. Owen is even laying in the same position which she left him in, some two hours before. The only thing that has changed is the nurse taking care of Owen.

At seven o'clock in the morning David returns to the unit with the children. Before leaving the night before David and Ellen decided that in order to cope with what is happening, the whole family needs to be together. Once again the social worker wants to

talk with the family and prepare them for the coming events. It is a different social worker this morning to the one the night before and she spends most of her time reassuring the family that everyone is here to support them through the coming events; and that to get through this experience they will all need to work together as a team. This conversation is double edged as although Ellen is comforted by these kind intentions she is also struck with sadness; as although she has not yet officially spoken to any doctors she is now convinced that Owen is going to die. Finished with her instructions, the social worker leads Ellen and her family into the unit. Madeline, Ellen's youngest daughter, is frightened by the machines, strange faces and hushed voices and clings closely to her mother's side. Too afraid to get close to Owen, Madeline remains at her mother's side and watches, confused, by all the care he is receiving. James however climbs onto the bed and holds Owen's hand. Jessica, following James, sits at the end of the bed stroking Owen's foot, while all the time watching his face to see if he notices. Liam, the nurse, attempts to answer each and every question that Jessica and James find about the fluid in the bags, the bandage around Owen's head, the tube in his mouth that leads to that machine, and about when their baby brother is going to open his eyes and get better.

At ten o'clock the social worker approaches Ellen about a meeting the doctor and nurses caring for Owen wish to have with the family. The social worker leads Ellen and her family to a small room where the doctor and nurse are seated. Directing his conversation at the whole family, the doctor starts to explain that given Owen's present condition and the results of various clinical tests to date he believes, with great regret, that Owen is brain dead. He proceeds to try and explain what he means by brain death, but all the explanations fail to make sense to Ellen, despite her nursing background. Ellen glances around the room at her family and sees the dismay and confusion on their faces. This term brain death just doesn't make sense. How could he be dead when she, the whole family, can see Owen breathing. Unable to wait until the family can arrange their confusion into questions, the doctor proceeds to tell them the day's plans. 'We need to confirm this diagnosis with a brain scan that looks at the blood flow to and through the brain. Owen needs to go down stairs in an hour's time to have this test. If this test is

positive, continued the doctor, if the test shows that there is no blood flow to Owen's brain then you will need to accept that your son, brother, is dead'. With Ellen still trying to determine what questions need to be asked the meeting ends. The question though come easier, fast and furious, at the bedside. The next hour at the bedside, before the test, is spent with Liam attempting to unravel the maze of questions that flood the family's mind.

Slowly learning that Owen's chances of survival are poor, Ellen tells Liam that her family have decided to offer some of Owen's organs for donation. The words however come suddenly and without warning as Ellen is determined that this is one decision over which the family will maintain complete control. Ellen dreads the thought of being asked to donate Owen's organs and doubts if she could donate under such a request. Liam acknowledges Ellen's request with care and compassion and tells her he will notify the doctor about her family's decision.

Owen's condition remains unchanged as he is taken and returned from the cerebral angiogram. Ellen is told the test is positive—an irony as the outcome promises to be negative—but still Ellen fails to see any evidence of Owen's death. She only hears it in the doctor's words. Numb and struggling with the lack of death's presence, Ellen forces herself to trust the doctor's words and let go of the signs of Owen's life, to which she has held faith. These signs were tormenting her, teasing her needs; but she needs to let go before Owen can go. Ellen tries to release these hopes to give room for something good to challenge the pain that is threatening to swallow her whole. The transplant coordinator arrives and tells Ellen and her family what they need to do. Suddenly time passes quickly and things, begin to change rapidly. Ellen and David are told they need to sign a consent that lists exactly which of Owen's organs they want to give. Everything is now changing quickly as Ellen feels she is being swept on top of a wave that is too powerful for her to control. Instead she will have to ride this wave to the end, hoping that everything will be okay. Although Ellen feels as if she can balance on the crest of a wave, she can see the edge and how far she could fall. The water is cold—it gives her no comfort and her family seem to be lost in its wake. The directions/instructions are too

many and so ordered and calculated. They fall starkly upon the mess of Ellen's life. Ellen soon finds she is no longer floating on top of the wave, but swimming, caught in its current. Struggling to stay afloat. The wave however stops suddenly and unexpectedly as Ellen is told she can now say her goodbyes to Owen and that she will be notified if the operation has been a success; notified if they are able to find a suitable recipient for the organs her family have donated.

The control Ellen felt she had regained in directing the request to consent is rapidly lost as Owen is removed from her touch in preparation for the operation. Ellen and family, unable to know what to do, leave the hospital as directed and wait for the phone call. Once again though Ellen feels uncomfortable, tormented by this distance from her child. Ellen needs to be by her child's side; stay with him until he goes to theatre; wait for him to return from theatre and travel with him on his long journey back home from the hospital where he can rest, finally. The tears flow until Ellen returns to the hospital early the next morning. Yet again a different social worker greets Ellen and tries to explain to her how different Owen will look this time, compared to when she last saw him. Again the social worker leads Ellen to her son. She is right, Owen has changed. He is cold to touch and he isn't breathing. Owen is dead. Sobbing with pain, Ellen lifts Owen off the table and cradles him in her arms. Rocking back and forwards Ellen apologises to Owen for leaving him. She wonders where he has been since the operation and if anyone has been with him? Or has Owen been alone, as she fears? Conscious of her every move being watched and waited upon by the social worker Ellen begins to feel awkward for the social worker's space and time. Feeling that she should leave, Ellen gains some strength to lay Owen back upon the table and say goodbye. But Ellen doesn't want to leave. Ellen wants, needs, to stay with him always, but she cannot.

Four weeks later Ellen receives a letter from the Red Cross telling her that three people are doing well from her gift. Comforted by this thought Ellen signs a piece of paper indicating her wish to have communication with the recipients and constant progress reports from the transplant coordinators about the recipients' health. Ellen however continues her wait to hear and she grows dispondant as she begins to feel forgotten.

Ellen does not regret the donation but becomes disenchanted by the lack of concern and compassion for her needs now that everything is over; now that Owen has gone.

Ellen's story reads like a confession of guilt that she has harboured for being misdirected in the last hours of Owen's life. Ellen begins her story like an act of confession about not being present, nor contactable, when her little boy was injured. As if confessing to being 'caught out' in failing to be a responsible parent, Ellen retells her story. She tells of her absence from the initial accident and how her experience then becomes one that is dominated by an effort to try and regain her presence, her responsibility in her child's life. Ellen finds herself struggling throughout her experience to regain responsibility for his safety. But every circumstance Ellen encountered seemed to reinforce her absence—reinforce her torment and distance from being able to protect her child against danger.

Ellen's story speaks of a parental bond that is not broken with her son's death but, if anything, passages a new stage of renegotiation. The hospital routines and policies of practice, however unwittingly, place barriers around this parental bond. While in the care of nursing staff, trusting their guidance, Ellen made some irrevocable decisions that have since impinged upon her capacity to live with her child's death. Nowadays Ellen is angered by the thought that hospital routines and policies were allowed to take priority over her being with Owen. Instead of her last moments with Owen being substance for memories that will help her passage her grief they were coaxed into some neat and tidy event to be managed accordingly; a circumstance which Ellen eternally regrets having lack of control over:

> I think throughout ... I felt that I wasn't able to say I'm Owen's mother and I just want some time on my own with him, as his mother. I guess, you know his father, his father could feel the same or brother and sister could feel the same. And that should have been the way, that everyone had their time with him, that special time. When I look back, you know, yeah we were all together but I don't feel I had a special time with him by myself. And that we were going through a process. And I realise that there's formalities that you have to go through as such, but you know there has to be, I don't know whether there has to be, I mean I don't you know,

> maybe it's better just to let things happen as they happen. And maybe allow the family to make more decisions, in their own way yeah. I mean and I think I would have liked to have been asked whether I wanted to remain with Owen until he went to theatre. We weren't asked. It was almost like, 'Well you say goodbye to your son now and we'll do these other things later'. I would have liked, I mean I might not have wanted to, but I felt that I needed to be asked, you know, 'would you like to stay with Owen? Because I can remember going back to my friend's place that night and lying there and thinking Owen's on his own now, he's on his own, you know. He's got nobody there, no family you know. And I found that really devastating. I mean you know, just to have somebody with him and you know just to sit with him until he went to theatre and maybe when he came back. I mean that's a possibility you know ... You know I found that you know, distressing. I felt as though I'd left him at the hospital and the next day when we went back and we saw Owen in the special viewing room, you know I went, we came back to ... that day, that was the Tuesday. And I felt as though I left him there and then we had to come back and we had to make the funeral arrangements, you know. And you know, I'm not quite sure where he was when we left him. Whether they left him, where they were going to put him. They didn't show us you know. And they didn't, they didn't ask us if we wanted to stay with him you know. He was just left. And er I don't think, I can't remember, I think it was, it wouldn't have been until the Wednesday that I went to the funeral directors here and we would have made arrangements for Owen's body to be brought back you know. I don't know, maybe somebody could've stayed there or you know just, been in the car when he was brought back and just be with him. You know his body (Ellen/ p. 13:18-21; p. 14:1- 21; p. 15:11-13).

Ellen's experience therefore is one of torment. Ellen lives with the constant question of could more have been done for her son? Ellen is not alone in having these feelings. Each parent suffers these thoughts. Ellen however, has no grace from such thoughts. Left with this guilt Ellen questions the relationship she had with the staff during her experience. Unprepared and unfamiliar with everything Ellen just watched and waited to be involved, to be supported and guided. Left to wait, Ellen is now left feeling that her trust in the staff to guide her should have received greater respect as she had no one else to trust. Ellen constantly asks was she right to agree that Owen was dead when she, to this day, still cannot understand the diagnosis of brain death; when she still struggles to comprehend how they diagnosed her child dead when he still seemed so alive:

> ... I wanted to go through the issue of brain death, because I just wanted it explained to me over and over again. But you know I couldn't, I couldn't grasp that ... physically he looked so well and yet you know, yeah and what, if he had survived what would he be like and things like that. Like you create all these sort of scenarios

> in your mind. Because what you're looking for is life rather than death in what we try to provide because we don't want him to die. And you just look at all different scenarios, you know. Was there a possibility you could have done something else, that could have maybe reversed his brain damage you know. But we all know that brain damage you know is not reversible. But you just go over and over it in your mind. Yes but that's what a lot of the questions centred around I guess. And then we looked at the X-rays and you see that from the neck up, there's no life at all. There's no blood circulating or anything you know. It's really hard to comprehend, it's just so hard to comprehend. To actually see that and to comprehend that you know, your child has died (Ellen/ p. 16: 19-21; p. 17:1-15).

Ellen now reasons that life support is 'life' support and was she right to sign that 'life' away. Ellen cannot seem to remove the fear that maybe she was not right in doing this. Ellen fights the *shoulds haves*; should not a parent protect their child's life to the bitter end; and should she have insisted on more time to try and understand what was taking place? Ellen fights the fear and guilt that in signing the consent form she once again abbregated her responsibility as a parent to protect her child from danger. A sense of parental failure and guilt therefore pervades Ellen's memories and meaning making of her experience. Ellen has struggled with this sense of guilt ever since she heard David's voice on the phone two years ago. Such fears are difficult to battle when she feels forgotten and left waiting to hear if the struggle has been worthwhile:

> I said that I wanted, I said that I wanted to be kept informed as to how the recipients are going and they've not rejected. And you know that I wanted to be informed in the way of letters. But it was really, it was very very poor. I feel very disappointed um I feel very disappointed that we haven't had more communication with the Red Cross and that we haven't. I don't know that they, that they don't just, I said that I didn't mind this, you know I didn't mind being told. And I just felt that from the day we walked away from the hospital, that we weren't taken care of ... the organ donation coordinator was present. And he talked to us so well, I felt that he was genuinely interested in us ... While we were there but it was almost like the minute we went away, we were sort of forgotten (Ellen/ p. 15:17-21; p. 16:1-8).

Ellen believed that offering to donate rather than waiting to be asked would help her to regain some control over her child's future, despite this future's premature end. Once Ellen signed the papers however she was told that she could say her goodbyes. In signing the papers Ellen now feels she helped to sign away her connection, her ability to

remain by her child's side until he died. The consent thereby did not give her more control but rather forced her away, further extinguished her time with her son. Ellen also lives with the realisation that in consenting, her child underwent an operation from which he returned 'completely' dead. This second death however was a concept she could barely fathom in the hours prior to the donation. So, Ellen only realised the magnitude of the decisions she made when she returned to the hospital the next day to see her son after his operation. On her return she was again presented with the reality that in her absence Owen had journeyed another incredible change; a change for which Ellen feels she should have been present. Owen had died once in her absence and she had unwittingly allowed it to happen again. Feeling as if she should have known better, that she could have stayed with her son, has remained to burden Ellen's grief and so make her guilt in these ensuing years all the more difficult to bear.

The parents dependence on the staff for guidance is repleat throughout their stories and no more so than in Ellen's. All the parents described feelings of never knowing what to do, where to go or what to anticipate. The majority of parents felt as if they were waiting in limbo, uncertain of what to expect or anticipate next. The staff constantly try to prepare them for what is going to happen but, for many, no amount of preparation could be enough. With the staff hesitating to predict what will occur with certainty, the parents often felt trapped between hopes that things may change and an anticipated certainty of their child's death.

Consequently, each parent's dominant mode of *being* during this experience is that of ***watching and waiting***—removed from the action and events that are taking place, yet irrevocably transformed by what they are witnessing. An isolating experience for which they are totally unprepared. A dominant need of each parent during their experience is therefore to try and stop their loss by attempting to help and protect their child. However, the parents uncertainty and lack of familiarity with the environment and policies of care leaves them unable to readily engage in their child's care. They find themselves in an environment where another's capacity to help is given priority over their parental role; and so their ability to control the situation is rapidly diffused by an

environment that has defined roles and regulations to determine who is in control. Subsequently, they feel separated and distanced from their child and all efforts to control their pending loss.

Left with no choice but to watch others attempt to help their child the parents feel removed and distant from what is taking place. Such circumstances can induce overwhelming feelings of helplessness as the parents' experience the dilemma of having to watch their future hopes and dreams fall apart while uncertain of if or when it will all happen. Their waiting is difficult to endure as they stand passive witnesses to events that irrevocably transform their lives.

The theme *loneliness* equates with the parents' sense of isolation and powerlessness over their actions, the environment and choices made. With their principle position being that of witness the parents have no real choice but to wait for the death of their child to come—wait for the diagnosis to be made. Even the potential power to be gained from the choice to consent is absent by the very way in which it is presented. Typically presented as *'... this is the opportunity to make something good out of something bad'*, tends to deny the parent a choice they can publicly honor.

The parents' experience as witness (watching and waiting) is well portrayed in Phedra's story since an integral component of the witness experience is a *felt* distance that we are unable to transgress when watching a situation and waiting for it to end. Phedra's experience commences with an overt example of this distance as her daughter's accident and hospitalisation occured hundreds of miles from her home. Phedra speaks of a parental bond that connects her with her daughter in spite of the distance between them. However in this circumstance, this physical distance between them is acutely felt by Phedra once her daughter is injured and circumstances delay her being present with her daughter. Her ability to relate to her daughter despite the distance subsequently becomes a torment for Phedra as she now feels their separation more acutely. Throughout Phedra's experience this sense of separation and distance represents itself in various ways, all of which firmly entrench in her a sense of bearing witness to events beyond her control.

For example, the very act of watching another person both paradoxically connects and distances us from this person. Being able to watch a person perform a particular task we are immediately reminded of an existential space that separates us. Not only do we observe them but we can also observe ourselves observing them. We therefore become the silent witness of our own actions. An experience which is enhanced the more our wishes and wants differ from the practices we are actually engage in. Despite this sense of separation however, other people are an obvious part of our world as they are connected to us through space and time; connected to us through our awareness of them. Our sense of connection with these people is enhanced the more we are able to relate to them. Our sense of isolation and distance therefore is inflated if we are aware of their presence but prevented in some way from interacting with them.

Phedra's inability to control the circumstances she was 'thrown' into or understand what was taking place left her feeling distanced from the activities and alone and uncertain in her grief. Unable to communicate with her child Phedra had nothing else to do but anticipate the permanent nature of the physical separation and distance that death would bring to their relationship.

Phedra's story

Phedra sat by the warmth of the fire, late one Sunday winter's evening. Her mother sat opposite listening as Phedra spoke about her daughter and how happy she was that they are finally relating so well. Christine had phoned that morning with the surprise news that she was coming home for the Easter break. Some friends were giving her a lift into Boarder Town where she had booked a flight to Brisbane. She would arrive home in a couple of days and Phedra was so looking forward to her arrival. Christine had left home just recently to work as a social worker in an Aboriginal community in far North Queensland. Christine's teenage years had been particularly difficult for Phedra as she and Christine seemed to be forever in opposition. Phedra had longed for the happy, trouble free daughter she once knew. Lately though, and maybe because Christine was finding her independence, their relationship was blossoming as they seemed to enjoy listening and sharing each others stories about life's complexities and mysteries. Instead

of disappointment and frustration, so typical of the years gone by, Phedra was now excited for Christine: the future she had envisaged and the new found relationship they were nurturing. Phedra's mother rejoiced in her happiness and relaxed, as Phedra did, into reading the night's hours away.

Relaxed and full of comfort, Phedra answers the phone that rings through their peace. Surprised to be receiving a phone call from the police at 10 o'clock at night, Phedra listens to the constable, uncertain of what to expect. Suddenly the peace is broken and Phedra's mother is startled from her fictions with the sound of her daughter sobbing, 'No, No, No'. Running across the room to help Phedra brace herself against what she is being told, she listens as Phedra searches for answers, 'But is Christine okay?'

'I'm sorry Mrs Wilkinson, replies the constable, 'but I'm unable to give you any details.'

'I can give you the hospital phone number, and you can speak to the doctors.'

Once he had recited the phone number, and without asking Phedra if she is alone, or if she needs any more help, the constable ends their conversation. Phedra stands by the phone, bewildered by the news and the absence of the messenger who just delivered it. 'Am I dreaming ?', is Phedra's question to herself as she feels as if the tranquility of her life has been ambushed by a person unwilling to wait or listen to her questions.

Phedra questions, 'How this is all possible, how can this be happening ?'

Yet, Phedra's dismay is transposed into certainty with the sound of her mother's voice asking, 'What's happened Phedra?' 'What's happened to Christine?'

'She's been in an accident mum', weeps Phedra, 'but I don't know, I don't know how bad, or if she is okay'.

'He wouldn't tell me anything.'

'I've got to ring the hospital mum'.

But with her hand's shaking and mind racing too fast to deliberate the phone number Phedra watches as her mother takes control of the situation for her.

'Yes, Mrs Wilkinson', replies the doctor caring for Christine, 'Thank you for ringing'.

'Look, your daughter has had a serious car accident, and we are in the process of trying to stablise her in intensive care'.

'Is she awake?', stammers Phedra in a voice that denies her the controlled, collected manner she is trying so hard to convey.

'No', states the doctor, 'Christine is unconscious at the moment'.

'She is fully ventilated, and we need to do more tests.'

'Is she going to be okay?' pleads Phedra.

'Well, Mrs Wilkinson, at the moment I am unable to say, but given time, we never can tell'.

'Are you able to get to the hospital?', asks the doctor.

'I'm making arrangements to leave tonight', replies Phedra.

'Well, we can talk some more when you get here Mrs Wilkinson.'

The conversation ends with Phedra feeling that everything is under control. The lack of any clear answers about Chrisine's future, leaves Phedra choosing hope instead of despair.

Phedra's husband arrives home to her crying and on the phone, in conversation with an airport offical who is telling her that unfortunately the airport is closed tonight due to bad weather. Phedra's mother informs John as to what is happening and he waits for Phedra to tell him the plans.

'Christine's been in a bad car accident', cries Phedra to John, 'But we can't get to her until tomorrow afternoon at the earliest'.

'The doctor says that she is stable at the moment, but he wants us there as soon as possible.'

Before Phedra could finish telling John everything she was feeling, the phone rings.

'Mrs Wilkinson, this is Mackay base hospital again, can you recall how long ago Christine had a tetanus shot?'

Uncomfortable with not remembering this finer detail of her daughter's health, Phedra stumbles, 'I think she must of had one in her last year at school, about four years ago, but I'm not sure'.

Phedra explains to the doctor the difficulty they are having in getting to the hospital and he asks her not to worry, or rush, just to arrive when she can. Again Phedra finds herself comforted by the doctors words as she sets about trying to pack and organise her journey.

Yet the phone rings again and Phedra finds herself rushing to anwer its call. The phone has become the ligature that traverses the distance between her child and self and she feels a slave to its every command. Phedra determines to sleep on the floor by the phone tonight in an effort not to miss a call.

Once more the doctor is needing some information that only she can give.

However momentarily comforted by the way this information holds her close to her child, Phedra aches with how these telephone conversations also reaffirm the distance that exists between she and her child.

'Mrs Wilkinson', enquires the doctor, 'is your daughter an asthmatic'?

'No', replies Phedra quizzically as she feels uneasy at not being able to place the importance of this question in the puzzle she is attempting to assemble about her daughter's condition.

The conversations continue back and forth throughout the night as the phone seems to ring every hour; but still Phedra is no clearer about her daughter's condition. At four in the morning Phedra, resting on the lounge room floor next to the phone, sits upright suddenly. Her mother, startled by this sudden move asks her what is the matter.

'Mum', cries Phedra, 'I can hear Christine. She's calling me, she's telling me she's in pain'.

Desperate to know what is happening Phedra phones the hospital and asks if everything is okay.

'Mrs Wilkinson', says a nurse, 'We've had to transfer Christine out of the hospital to another specialist centre for a CAT scan'.

'Oh, what does that mean'? inquires Phedra.

'Has Christine got brain damage'?

'I'm unable to say Mrs Wilkinson, but all the information will be available to you from the doctor when you arrive'.

'Has she woken yet'? begs Phedra.

'No', replies the nurse, 'I'm afraid not, Christine is still fully sedated and ventilated'.

Still, treating no news as good news, Phedra determines not to worry as she tells herself that Christine has simply bumped her head and they are just doing some tests—like the doctor said they needed to do in order to make sure that everything is okay. Yet, Christine's voice, clear and strong, calling to Phedra and telling her of her pain threatens to de-rail this belief, this need, that Phedra has for everything to be okay.

The next day, with the travel behind them, Phedra and John stand at the doors to the intensive care unit where Christine lays waiting. But the sign on the unit doors instructs them to wait until they are called to enter. Standing in the middle of the corridor, exhausted and with their luggage surrounding them, Phedra and John wait. Eager to enter

the unit, Phedra is also scared, fearful of what she will see. Again, Christine's call to her in the middle of the night has left her uneasy that things may not be good. An hour passes when Phedra and John are invited into the unit to see their daughter.

The quiet of the corridor contrasts with the rush of activity and equipment in the space they are entering. Yet all this chaos fades as Phedra catches sight of Christine in a bed, up against a wall, down the far end of the unit. Walking towards the bed Phedra feels as if she has been placed into one of the dramas she has watched so many times on TV. Phedra stands at the end of the bed looking at all the pieces of equipment that are arranged around Christine's bed and at the wires, drips and tubes that seem to extend from every crevice of her child's body to give the equipment some purpose. The nurse leaves Phedra and John with some space and time to be with their daughter. They stand at the end of the bed, alone and uncertain of what to do. John is the first to break free of this inertia as he walks to the side of the bed. Phedra follows and stands on the opposite side of the bed carefully watching John's every move. John leans forward and whispers in Christine's ear, 'come on Christine sweetie, you can make it, come on, we're here now'.

Phedra too leans forward but is made silent by an overwhelming feeling that her daughter is dead. Being so close Phedra could feel that her daughter was dying, and this thought readily joined with the memory of Christine calling her last night. She was dying last night, when she was calling me, thought Phedra, and I wasn't with her. Grief sticken and drained by this realisation Phedra feels propelled to leave her daughter's bedside. Phedra needed to escape this space of pain, escape this space that was confronting her with her daughter's death.

Phedra found herself running out of the unit and down the corridor. She did not know where she was running to, only what she was running from. Phedra kept running until she was outside the perimeter of the hospital. Unfamiliar with every aspect of this place she was in, she walked with no aim but to maintain space from the death she had just confronted. Lost and having wandered for two hours, Phedra happened upon a florist shop where she finds herself buying a single red rose for Christine. Wanting to give this

symbol of life and purity to Christine Phedra returns to the unit and places the rose at her daughter's bedside. John had remained by the bedside, becoming familiar with all the equipment and his daughter's condition.

Sitting next to John, exhausted and lost admidst her tears, Phedra watches as the doctor approaches her. After introducing himself the doctor proceeds to ask if they would consider organ donation. His words seemed so out of place. Even though Phedra intuited that Christine was dead, she hadn't been officially told this by any of the staff so it felt wrong that he could be asking her this question now. Confused, Phedra continues to listen as he stumbles to explain what brain stem death means. Without waiting for questions the doctor states he will leave them to think about what he has said and before leaving he hands Phedra a piece of paper. Feeling as if she has been ambushed for the second time in the past twenty four hours by a stranger who doesn't wait to see if she is okay Phedra looks down at what he has left her. The piece of paper is a two page pamphlet about organ donation. Phedra reads the words on the pages but finds that they too leave her as vacant about understanding what is happening as his conversation has.

Phedra, now uncomfortable with sitting, moves to the bedside and takes hold of Christine's hand. Her hand is warm and this warmth comforts Phedra. Phedra wants to keep this warmth, even though this seems silly to her since she knows Christine is dead. Confused, Phedra becomes concerned when she feels a draft from an airconditioner or fan blowing across Christine's body.

'Could you please turn that fan or air condioner off ?', asks Phedra of the nurse who is sitting at the end of the bed, watching her every move.

'Of course Mrs Wilkinson', responds the nurse, 'I'll see what I can do for you'.

The nurse returns to the bedside to measure Christine's urine that has collected in a plastic bag which hangs at the base of her bed. Phedra too looks at the blood stained urine and tries to imagine what sort of internal organ damage is causing this bleeding. The nurse then quietly moves to the opposite side of the bed and lifts the sheets to expose

Chrisitne's tummy. Horrified with seeing a tape measure wrapped around Christine's tummy Phedra questions the nurse why its there.

'We need to keep a close eye on how much fluid Christine is receiving and loosing.' But these words don't appease Phedra's discomfort as she watches every part of her daughter's body being measured and monitored.

Having finished all the measuring and monitoring, Phedra watches the nurse as she cleans Christine's face with a warm, moist cloth. Phedra finds herself being soothed by the gentle movements of the cloth as it caresses every curve of her daughter's face. She imagines how warm and comforting this must feel for Christine. Watching as the nurse opens and cleanses each of Christine's eyes Phedra sees nothing. Again Phedra sees no life, just an absent, vacant stare and she is forced back from the bedside to sit next to her husband. Here she can see everything that is happening but cannot so clearly see the death. At this distance, with the alarms and monitors recording every heart beat and breath, Christine looks alive.

'Have you thought about the doctor's questions ?' asks John.

'Yes', says Phedra, 'I think that even though Christine didn't talk to us about how she felt about organ donation, she loved helping people in whatever way she could and so she would want to help these people too'.

John agreed and together they approached the nurse to tell the doctor of their decision. A couple of minutes later the doctor presents John with a piece of paper to indicate which organs he wants to give and to consent to this gift. Heart, liver, kidneys and corneas were consented and signed away within minutes.

The consent seems to ignite a flurry of activity as Phedra watches syringes of blood and tubes of fluid and swabs being taken, labeled, and rushed from her daughter to be tested. It all seems so unreal to Phedra as she stands silently watching her daughter again being quantified and analysed before her very eyes. Phedra stands holding Christine's hand, still confused and emotionally defeated by death's presence but illusive absence in the

warmth of Christine's hands and colour of her skin. Watching as everyone else takes life from her child Phedra asks the nurse to give her a pair of scissors so she too can take a sample of this life. Phedra wants a lock of Christine's hair; and it too is placed in a receptacle—a yellow government issued envelope—that is just as innocuous as the specimen jars and swabs that have taken everything else. How quickly it seems to Phedra that something so special as her daughter's life is reduced to nothing more than a piece of hair.

Waiting at the bedside, uncertain of what is going to happen next, Phedra is asked to leave as two doctors are waiting to do some tests on Christine. Phedra turns to see the doctors waiting and is disturbed by their casual dress. One in a pair of shorts and sandals and the other with a sun hat perched atop his head appears to Phedra as if they belonged on a golf course. Their lack of formality made Phedra question whether they were really doctors and if she should trust anything they had to say. But Phedra felt as if she was excluded from the conversations taking place. All information seemed to be sought from and given to John while Phedra was left in the background to watch everything taking place. Slowly, but surely she was becoming sceptical of what was happening. Everything seemed to be out of order. Shouldn't they have done these tests before they told her that Christine was dead? Nothing was making sense except the thought that maybe this was all just for show: that ultimately all the tests and decisions had already been made before they arrived, and so this was all just for her and John's benefit. Everything seemed so superficial, so unreal and out of order that it seemed like play acting to Phedra.

With the tests complete, Phedra watched as the doctors walked to John to tell him that there is nothing more they can do, that they were sorry but that was it! Despite the stabbing pain of these words Phedra could not cry. Instead she felt numb and exhausted of all emotion. She was in shock and could do nothing but stand still, feeling her heart pounding in her chest, sending her blood roaring in bounding thumps through her head. She felt as if she would explode any minute as she was too late to stop the fuse from igniting. Phedra watched as Christine was wheeled in front of her and taken to theatre.

Everything seemed to be moving around in front of Phedra as she felt helpless, unable to stop or control anything that was taking place. Amidst this mania a woman, the transplant co-ordinator, approached Phedra and placing her arms around Phedra's shoulders, held her close.

'I want to hold my daughter', said Phedra, 'I want to see her after the operation'.

This woman that seemed too young to Phedra to be doing such a job, just listened to Phedra's grief and assured her that she could have some private time with Christine after the operation. In the meantime she wanted Phedra and John to rest. So, while Christine was having surgery the transplant coordinator lead John and Phedra to a quiet, private place where they could rest in comfort while waiting for the operation to finish.

Phedra waited, but could not rest. Made mute by their grief, Phedra and John sat in a room kept all the more unfamiliar by their silence. They waited four hours, hours that seemed like an eternity, before the phone message came telling them that the operation had finished and that they were welcome to come and see Christine. The co-ordinator led them to what seemed like a deserted ward. Phedra, knowing that her child's death lay waiting for her to witness, was struck by the irony of passing a nurse carrying a new born baby in the corridor as she walked towards her dead daughter. That baby's parents are waiting, expecting to see life, thought Phedra whilst I walk expecting to see my child's death. Phedra however was not slow in her passage towards her child as the future moments promised her some time holding and caressing her child; a nearness that she craved while Christine was laying in the intensive care unit surrounded by all the tubes and pieces of equipment. Phedra found herself longing for the chance to hold her child and say goodbye unhindered by the surrounding staff and equipment.

Entering the quietness of the ward, Phedra quickly sights Christine laying on a bed, just like she was in intensive care, surrounded by clean white sheets and with her long hair cascading off the head of the bed. Someone had brushed Christine's hair as it shone in the light, looking so healthy and strong. Phedra stood stroking Christine's brow, pleased with how peaceful and still she now looked. Bending forward Phedra kisses Christine's

cheek and encircles her arms around her rested quite frame. Holding her tight Phedra can still feel Christine's warmth. There was no cold, pale death waiting as Phedra anticipated, just silence and peace. Wanting to see her daughter's eyes Phedra stops herself as she is scared of what she may see knowing they had taken Christine's corneas. With her head resting on Christine's chest Phedra could see a long piece of plaster covering a scar that ran down the centre of Christine's chest and quickly stopped the thoughts that began to explain to her what lay beneath that plaster bandage and why.

Unable to say goodbye Phedra instead rests for a while with her face feeling the warmth of her child's body. Repeating softly as if performing a prayer to the gods Phedra chants, 'I love you Christine, I love you'.

This closeness in touch is however cut short with John urging Phedra to, 'Hurry up', as he didn't want to be present when rigormortis came to confirm death's dominion over his daughter. With no-one present to reassure John and Phedra that this would not happen in the hour or two that they wanted to spend with their daughter they left the ward having spent only ten minutes in attempting their goodbyes with Christine.

Falling into bed at 1 a.m. in the morning Phedra and John are woken at 6 a.m. by a policeman banging on their door. The policeman hands Phedra a yellow envelope that has some pieces of Christine's jewellery inside. The rings are bent and misshaped. Looking at the rings Phedra remembers seeing them on Christine's swollen hands and wondered how they were able to prise them off her fingers. One ring, a silver floral ring, was Christine's favourite. Phedra places this ring on her finger while making a promise to Christine that she will never remove it.

Two weeks later Phedra is at home trying to regain some sense of purpose and order to her daily life. Yet she finds this so hard as she desperately needs to talk to someone but can find no one able to listen to her pain. John keeps his pain silent and so avoids Phedra as her pain is too loud, too tumultuous for him to bear. Phedra feels a chasm developing between her and John that threatens to divide them forever. Six months later Phedra leaves John and their marriage dissolves. Phedra's days are spent searching for

people to listen and understand her pain. She still does not understand what the doctors meant by brain death and feels herself starting to question whether she did the right thing.

As the weeks pass since Christine's death and donation Phedra waits to hear from the recipients as the only information she has received so far is a letter from the transplant co-ordinator telling her that five people have been helped by her family's gift. Expecting this gratitude and appreciation from the transplant coordinator Phedra is not however expecting the silence and lack of thanks from the recipients. Yes the transplant coordinator says to her that the recipients are immensely grateful, yet Phedra wants and waits to hear this from them instead. Disappointed and frustrated by this silence which is all the more complicated by the lack of freedom she has to communicate directly with the recipients Phedra longs for a change in these formalites and the opportunity to talk and meet one of the recipients that Christine's death has helped. These formalities prevent Phedra from establishing a relationship with the recipients, a relationship that she needs as it is a relationship that has been randomly initiated by Christine's death and her loss. The restrictions placed on Phedra in trying to develop these relationships leave her feeling lost and angry, mourning the loss of not one relationship but two; the loss of her daughter plus the loss of potential for a new relationship that her daughter's death has surreptitiously left her.

As the months pass and still no communication with the recipients Phedra finds herself growing increasingly depressed and doubtful of how right was she to give her daughter's life in this way. Unable to find answers at home, Phedra makes a pilgrimage back to the place where her daughter spent the last year of her life. Phedra wants to meet Christine's friends and search for anything that may tell her she made the right decision. Phedra spends three weeks with Christine's friends and lover. During this time she is reaffirmed of a special quality of Christine's, which was her wish to help all those who needless suffered. Christine's friends reassure Phedra that she made the right decision in consenting to donate Christine's organs. Before returning home Phedra, together with Christine's lover and some of her close friends, perform a ceremony to scatter

Christine's ashes. In the quiet of a warm summers afternoon and with the freedom and depth of the wide open spaces of the ocean they journey together on a sailing boat and scatter Christine's ashes at sunset. Watching as Christine's ashes rise and flow forth from the confined space of the urn Phedra feels a release and freedom from the sadness and guilt that has been haunting her since Christine's death.

Returning home Phedra is greeted by two letters. One letter is from a young woman who received one of Christine's kidneys. Unable to find the words to express her appreciation she instead tells how she begins each day thanking both Christine and her parents for her new life. Overwhelmed with tears of joy Phedra opens the next letter. This letter is from a gentleman, a man who calls himself a family man. He too wants to thank Phedra for this gift of life and apologises for the delay in what he states, 'is the hardest, yet most needed letter he has ever had to write'. Receiving this news and recognition of Christine's life and what it has meant to people in need reaffirmed Phedra's new found freedom and belief that she had fulfilled one last wish for Christine. Reading these letters Phedra felt she could no longer wish for Christine's life to return because for this to happen, four or five people would have to die. Instead, Phedra finds her life is now dominated by a wish to help other parents, families who have been through this experience. She is involved in parent bereavement support groups and volunteers to speak and represent donor families at various community meetings. Now, Phedra's daily effort is to try and prevent other parents and donor families from suffering in silence the way she has.

Phedra's story displays in many poignant ways how we do not have to be physically separate from a person to feel distant and alone. As if suspended from actively engaging in the decisions being made Phedra watched as her daughter's death unfolded and her life irrevocably changed. Living the loss of Christine soon builds distance between Phedra and her husband with the way in which they chose to experience their loss. Whereas Phedra's husband wished to remain removed, simply witnessing and not engaging with his emotions of loss, Phedra found her capacity to cope was dependent on

communicating and relating her sadness and loss to others. Unable to standby and witness each other's experience and management of loss Phedra and her husband soon separated.

Each parent shared with Phedra this sense of separation and distance as they watched and waited for their tragedy to end. As if too overwhelmed and bewildered to relate to what was happening the parents stood removed, yet present to everything that took place. While waiting—watching everyone else care for their child— distanced and unable to do the same, the parents felt increasingly alone. Dissociated from any direct care of their child the parents felt isolated in their grief: *cocooned* or trapped in their feelings of being unable to move or make decisions about their immediate future. The metaphor cocooned seems apt in these circumstances because, like the underlying paradoxes that their children faced, a cocoon has a double reality.

While being a space for death of the old, a cocoon is also understood as a space of safety, a space where new life can be created. Although momentarily imprisoning, a cocoon promises the possiblity of an eventual change: a release or realising of something different. Organ donation holds a similar promise for donor parents. Phedra embraced this promise as it proved fundamental in her capacity to accept the death of her daughter. Although death had distanced Phedra from Christine, organ donation held a promise of transcending this separation. This transcendence is often anticipated to be found in the new life of the recipients. Each parent held onto the hope that their child's death had not been in vain and that their 'gift of life' was appreciated or valued by someone. Through their child's life being given to someone in need their child's *life potential* can continue to be present in this world.

All efforts made by staff and anyone involved in the organ donation process to help the parents transgress their role of witness and actually help them get closer to their child are therefore treasured as special moments—moments of immense compassion and giving amidst an otherwise unceasing loss and sense of loneliness and uncertainty. Andrew and Joyce's story demonstrates how amidst incredible feelings of isolation and despair, simple moments of 'credible' compassion and care can make the experience

seem almost bearable. Their story however also makes explicit how this care and compassion can be tarnished by a lack of support and concern for their needs once the gift has been given.

Andrew's Story

'Daddy can you pin this badge onto my jumper?'

The pride in Angelica's eyes matches that in Andrew's heart as he takes the badge from his daughter's outstretched hand and with the care and precision to mark the honour of his duty, pins it to her jumper.

'I'm so proud of you', says Andrew into the beaming smile of Angelica's face.

'You have been practicing your reading and look what you have got to show for all your hard work, a fine badge saying *Young Readers Achievement.*

After giving Angelica a hug and kiss Andrew continues to help her finish getting ready for school. The Johnston's will be beeping their car horn any minute to let Angelica know they have arrived to take her to school and she does not like to keep the Johnston's waiting.

Waving goodbye to Angelica, Andrew returns to the house and prepares himself for work. Joyce, his wife, is already at work as her day finishes at 3 p.m. so she can be home to greet Angelica after her day at school. Angelica however won't be coming home from school today. On her morning journey to school a truck driver, with the morning sun in his eye's and unfamiliar with the road ahead, will not stop at the *Give Way* sign where Mrs Johnston's is using her 'right of way'. Instead of stopping as Mrs Johnston assumes he will, the driver continues driving his truck through the intersection and into the side of the car where Angelica is sitting—where she has always sat on her journey to school each morning.

Soon the sound of sirens runs through the corridors of the nursing home where Joyce is working, only two blocks from Angelica's school. Mrs Green, a resident whom Joyce is

caring for, makes comment to Joyce that she hopes the sirens aren't for the school. Momentarily caught by the dread of such a thought, Joyce agrees and then continues on with her morning routine, allowing this thought to cautiously subside into being a noncontendable fear.

One hour later Joyce's rountine is broken by the Director of Nursing, Patricia, asking Joyce to meet her in her office. Uncertain of why she has been summoned Joyce knocks on Patricia's door and enters.

'Thank you for coming' says Patricia with a warmth that is a little disconcerting for Joyce. 'I know, that this must seem strange to you Joyce, but I have some bad news'.

Still uncertain but now fearful, Joyce sits in the chair that Patricia directs her toward.

'Joyce', repeats Patricia, 'there has been a bad accident and Angelica has been taken to the Children's hospital'.

The blood rushes from Joyce's face as she panics at what she has just heard.

'Where, when, how?', cries Joyce.

Patricia cannot answer any of these questions and instead continues to try and instruct Joyce about what is happening, 'Joyce we need to get you to the hospital where you can see Angelica'.

'Yes', replies Joyce, 'I need to get to the hospital'.

'We have arranged a taxi for you Joyce and it's waiting outside.'

As Joyce is rushed to the hospital by taxi, Andrew is also racing against the traffic, trying to get to the hospital to see if his little girl is okay. Unlike Joyce, Andrew is calm. Many times in the history of Angelica's six year life has Andrew rushed to hospital. Angelica's severe temporal lobe epilepsy has been cause for most of her acute admissions to hospital, but she has always pulled through. In fact things had been so good for the past year that Angelica's schooling is no longer suffering. *The Young*

Readers Achievement Award is proof of that. Andrew is not scared as he anticipates he will arrive at the hospital to see his daughter; watch as her incredible will and determination pull her through another of her many crises.

This time however Andrew arrives in the emergency department to find Joyce waiting amongst a crowd of people also waiting. Surprised that she isn't with Angelica, Andrew embraces Joyce and her tears.

'What's happening'?, asks Andrew.

'I don't know'! replies Joyce. 'Angelica's been in a bad accident and I haven't been allowed to see her yet'.

'Why on earth won't they let you see her'?, asks Andrew.

'They say they need to stabilise her and that I wouldn't cope with what I would see', cries Joyce.

'But you're a nurse for goodness sake!' stammers Andrew, 'Don't they realise that?'

'Yes, they have all that information from the admission forms I have been filling out for the past two hours, but they still won't let me see her.'

Becoming concerned Andrew begins to pace, like a caged lion, back and forth across the waiting room floor. Looking in towards the treatment area Andrew spots Angelica, or what he recognises are Angelica's legs on a bed that is surrounded by people.

Next, the same bed begins to move. Surrounded by what looks to Andrew like the entire staff and equipment of the unit, Angelica's is being wheeled passed him toward another section of the hospital.

Joyce jumps from her seat and runs toward Andrew who is standing, now shaking with what he has just witnessed. 'It looks bad Joyce', laments Andrew, 'doesn't it?'

Shaking her head and lost about what to do or think, Joyce is approached by the nurse who has been asking her for details about Angelica's medical history.

'Mrs Daniels', says the nurse in a voice that seems too quiet and controlled to Joyce and Andrew in the midst of their chaos, 'Angelica has been taken to the Radiology Department for a CAT scan and from there she will be taken to the intensive care unit. I can take you to a waiting room near the intensive care unit where you can wait to see Angelica once she has returned from the tests and been settled into the unit.'

'What's happening?' begs Andrew. 'Is Angelica going to be okay? Are all these tests just to make sure that she is okay, to check her epilepsy ?'

'I'm sorry, replies the nurse, 'but I am unable to tell you exactly what is happening. I think that it's best if you wait for the doctor to explain all the details to you'.

Joyce and Andrew follow the nurse as she leads them to a small white room opposite the intensive care unit. There is nobody else in the room left waiting and so Joyce and Andrew sit alone and wait to see Angelica. The hours pass and Joyce and Andrew become increasingly anxious with waiting as they are still so unsure of what is happening to Angelica. Three hours later they are greeted by a doctor, a young man who seems to Joyce too anxious and restless with what he has to say. After a quick greeting the words, 'It looks like bub is not going to make it', stumble from his mouth without any warning or attempts made to try and cushion their impact on their unsuspecting audience.

Stunned by the comment that has just broken the silence of their isolation Joyce thinks to herself, What does he mean 'bub'? Angelica is six years old! Why is he calling her 'bub' ?'

'I don't understand', hastens Andrew, 'nobody has really explained to us what has happened yet'.

'Oh, replies the doctor, 'I see, well, uhm, Bub received the direct impact of a speeding truck that hit the back of the car she was in. She has suffered severe head injuries and sustained damage to her internal organs. Given that we have done all that we can and she

continues to show no signs of improvement, there is nothing else we can do and I am afraid you are going to have to accept that Angelica is going to die'.

Incredulous and lost for words Andrew listens as Joyce begs to see Angelica.

'Yes of course', replies the doctor who quickly stands and moves far from the pain he has just had to minister.

Ten minutes later a nurse greets Joyce and Andrew and welcomes them to follow her into the unit.

Taken to the bed where Angelica lay they find it hard to recognise, beneath the bandages and tubes, the little girl with whom they are so familiar. But the shape of her arms and legs, the curve of her nose and point of her chin soon rescue their familiarity.

The blood on the bandages encircled around Angelica's tiny head makes Andrew question the nurse about the extent of the damage.

'I can show you the CAT scan and Xrays', offers the nurse. 'I think they will be able to show you how serious Angelica's condition really is.'

Joyce, now at the bedside and holding Angelica's hand, hears this offer but is not interested in moving. Andrew follows the nurse to look at the films. Against a wall of bright light Andrew watches as the nurse traces her finger around the perimeter of dark image that she tells him represents the curve of Angelica's scull. He watches as her finger reaches a point where the curve falls away into nothingness. Andrew feels his soul fall into the abyss of this absent perimeter. Unable to speak he returns to the bedside and holds Joyce as she continues to hold Angelica's hand.

Andrew and Joyce stand for the next hour mesmerised by the slow rhythmical rise and fall of Angelica's chest. Despite the tell-tale signs of the bandages and tubes leading into her mouth Angelica looks as if she is sleeping. Joyce and Andrew find themselves waiting for her to wake. In the background Andrew can hear the nurse emptying the urine that has collected in a bag that hangs from the end of Angelica's bed. He hears the

doctor talk to the nurse as he glances through the observations that she is recording about Angelica's *unstable condition.*

'She's got good kidney function', whispers the doctor with an air of surprise.

Again Andrew is confused by what he is hearing as he fails to understand how Angelica can be dying but still have good kidney function.

Believing in the potential of miracles, Andrew decides that maybe Angelica's good kidney function is indicative of his prayers being answered; that maybe he can hold onto the hope he had been nurturing prior to the doctor stammering the words, 'You'll have to accept that Angelica is going to die'. While standing watching his daughter breathe, Andrew finds himself having greater faith in the power of his prayers to make things better. He believes his prayers will make all the doctors' efforts worthwhile. His thoughts circle around the belief and hope that God couldn't possibly take Angelica away from them, not when they had waited so long to have her. Andrew has faith that God will be fair and that their little girl will pull through this crisis just as she has done all the other times.

Caught in the midst of his prayers Andrew's faith is reaffirmed by their parish priest arriving to support them through their crisis. Buoyed through their pain by their faith Andrew and Joyce accept the staff's advice to go home for the night and get some rest.

Sitting at home however Joyce and Andrew are unable to sleep. Instead, they answer and weep through phone calls from friends and relatives who had somehow heard about their tragedy and wanted to send their thoughts and prayers. Sitting, waiting for morning to arrive so they can return to the hospital, Joyce and Andrew feel overwhelmed by Angelica's absence. Their house feels empty and cold, an emptiness only replaceable by Angelica's return home. The fear of this emptiness being ongoing is too painful to contemplate. The only thing that can replace this fear are their prayers. Joyce and Andrew spend their time praying with the Priest, praying for everything to be okay and for Angelica to return home. Although Andrew's faith is firm his prayers are disturbed by a constant recollection of the doctor's words, 'It looks like bub is not going to make

it'. How can he be so certain, begs Andrew? There must be some hope for Angelica, for us!

Morning soon returns and commencing their day's events, Andrew can't help but think about how different this morning is to yesterday's. The morning's sunshine and freshness seem indifferent to the darkness that has descended on his life. Saturday was typically a special day for their family. Both refusing to work on Saturdays, Joyce and Andrew always looked forward during their working week for Saturday when they could spend all day with Angelica, going on picnics or to the pictures or engaging in whatever else they had planned. But today was Saturday and though they would all be together Andrew did not look forward to the day unfolding.

Returning to the intensive care unit they were again asked to wait in the waiting room until the staff were ready to send for them. Hours passed and Joyce becomes angry and distressed at the time wasted away from Angelica. Again their waiting is ended by a doctor introducing himself. This time however there is a nurse accompanying him. The nurse sits bedside Joyce and waits for the doctor to begin a speech he had obviously planned.

'Mr & Mrs Daniels', commences the doctor, 'Angelica's condition has not improved and we don't believe it is going to'.

Joyce hangs her head as if unable to hold the weight of these words in her mind. The nurse embraces Angelica's shoulders in her arms. Andrew sits, alone and feeling vulnerable, exposed to the onslaught of words that he had hoped he had somehow overcome with all the prayers he had been saying. The hope for a miracle had seemed to fail him and he was lost as to where to begin to cope with the consequences of the words he was hearing.

'We believe that Angelica is brain dead, but we need to do some more tests to confirm this.'

Andrew looses interest in the doctor's need to tell him about how certain they are attempting, or going to be about Angelica's death.

Why do you need to confirm that my child is dead, on three separate occasions, by three separate people, is Andrew's consternation? If Angelica is dead, I don't need to be told three times that she is !

Finished with what has to be said, the doctor attempts to leave. But Joyce holds tight to the nurse and begs her to stay, to not leave her with all this confusion and pain.

'I need to see Angelica', pleads Joyce.

'I'll take you to see her', replies the nurse as she stands and helps Joyce to her feet.

Angelica looks the same as when they left her and both Andrew and Joyce are lost with what to think. The nurse remains with Joyce and Andrew trying to answer their numerous questions about brain death and what it all means.

'But I can see her hand twitching', cries Andrew, 'How can she be dead when I can see her breathing and moving like this?' Nothing the nurse seems to say removes for Andrew the understanding of these movements as signatures of Angelica's life.

The hours pass and Andrew and Joyce are asked to leave the unit while the brain death tests are being done. As each test is completed, Andrew and Joyce are again told that Angelica is brain dead; and each time they return to the bedside to see that nothing has changed. Unable to do anything but hold Angelica's hand, Joyce longs to hold her and asks the nurse when she can do this.

'Why don't we put Angelica on your lap', suggests the nurse. 'I'll get a large comfortable recliner for you to sit in and you both can take turns in holding her while I hand ventilate her from standing behind you'. Andrew and Joyce spend the next two hours taking turns to sit in the chair and hold Angelica in their arms. Feeling Angelica's limp body as she lay in his arms, Andrew finds it hard to accept that it was only yesterday that he was embracing the same body. Back then Angelica felt so strong and

healthy, so full of life in his arms. Now, he sits looking down at Angelica's broken and bruised body, feeling his heart break as he watches her limbs quiver and shake against the death that is consumming her. Watching Andrew hold Angelica, Joyce is struck with the compassion and sincerity of this nurse and how she has made this special moment possible for them. Joyce, being a nurse and knowing that this was not typical practice in intensive care units, is moved to tears with how intuitive and responsive this nurse is to their needs. Unable to hold back her tears of appreciation Joyce embraces the nurse, as she is lost with trying to find the words to thank her.

With Angelica returned to bed and Andrew and Joyce standing at the bedside lost with what to do next, the nurse asks Andrew if he understands what the doctors meant by saying that Angelica is brain dead.

'It's all so hard to understand', exhorts Andrew. 'I can see on the Xrays where the damage is, but Angelica doesn't look dead! She's moving and her heart is still beating so doesn't that mean that she is still alive?'

'I know how terribly confusing this must all seem to you', conceeds the nurse, 'but brain death means that Angelica is never going to wake up again. That she is dead and that the ventilator is the only thing that is keeping her breathing which is helping her heart to continue beating.'

Moments pass without any words being spoken.

'Have you ever heard about organ donation'? proffers the nurse, 'Because this is the sort of situation where it is possible for you to make a decision one way or the other, as to whether you wish to donate.'

'Do you mean donate Angelica's kidneys to someone who has kidney disease?' deliberates Joyce?

'Yes, that's right' replies the nurse. 'But it's not only kidneys that you can donate, other organs are also just as helpful.'

Disturbed by the thought that there may be nothing of Angelica left to bury, Andrew quickly replies that kidneys would be all they could give. With hesitation and confusion obvious in Andrew's voice the nurse rejoins, 'It's important for you to think about this a little more. I think it would be best if you went outside for a break and gave this option some thought and, if, after this time you still feel that you would like to donate Angelica's kidneys then we can make the necessary arrangements.'

Andrew and Joyce leave the unit as directed but only for a few minutes as they prefer to be by Angelica's side. Believing that Angelica is a kind and caring soul they quickly decide that she would want to help one or two children if given the chance. Returning to the bedside Andrew tells the nurse that they would like to donate Angelica's kidneys. Smiling with acknowledgment, the nurse then asks a doctor to speak to them and he appears at the bedside with a piece of paper for them to sign. Once the papers are signed Joyce and Andrew watch as the slow, quiet tempo of preparing for Angelica's death lifts to a hum of activity as she is now being prepared for donation. Again lost amidst this activity Andrew and Joyce wait to be told what to do next. Before needing to ask for directions they are told by the staff that they should say their goodbyes and leave.

Saying goodbye however seems absurd to Joyce and Andrew. So, instead of goodbyes, they stand at the bedside holding Angelica's hand and thinking back to just moments before when they were holding her in their arms—telling her how much they loved and were going to miss her. Numb and devoid of any feeling but a sadness that infiltrates every cell of their bodies Andrew and Joyce are led from the unit by the nurse. But before they are able to leave Andrew is told that he needs to identify Angelica to the policeman who is now standing before him. Without the strength to question why Andrew stands and listens to the policeman make his official declaration of Angelica's death. Having to agree before he can leave Andrew finds himself saying, 'Yes this is my daughter Angelica Maree Daniels'. Wondering whether his sorrow can cut much deeper Andrew leaves the unit to find Joyce sitting with their parish priest, who has been waiting to support them on their journey home. Collapsing into his support they declare

their loss in knowing how to recommence their life without Angelica. The emotional and spiritual emptiness that Joyce and Andrew feel as they walk from the hospital is matched only by their being empty handed. Before leaving Andrew attempted to find the reading badge that Angelica was wearing when he last spoke to her—but to no avail. Nothing leaves the hospital with Joyce and Andrew except sadness, sadness that remains with them today.

One week later Joyce and Andrew are preparing for Angelica's funeral when the postman delivers a letter. Thank you is the message of this letter which has been sent by the hospital where Angelica had died and donated her kidneys. *Thank you for giving so generously, and during such a painful time. Your gift has helped two people who have been suffering for many years with chronic renal failure.* Andrew's heart is momentarily lightened by this letter. Joyce however is disappointed as she would have preferred to receive a letter from the recipients. Thinking that she is expecting too much too soon, Joyce determines to wait—to give the recipients some time to become accustomed to their new life before they write. The months pass however and still Joyce receives no message of thanks nor notes of progress from the recipients. The letter from the hospital is all Joyce ever receives as an indication that Angelica donated her kidneys. Other than the coroner's report mentioning the presence of two surgical scars on Angelica's abdomen, Joyce and Andrew are left waiting for someone else to write and acknowledge the gifts of life that their daughter gave at her death.

Five months pass and still Joyce waits to hear how the recipients are doing. Unable to wait any more Joyce phones the hospital and inquires about their progress.

'Oh, Mrs Daniels', is the immediate reply from the transplant coordinator. 'Both the recipients are doing really well. Their lives have completely changed since the operation and of course they are eternally grateful for your gift as it has given them new hope.'

Although this news is good, Joyce battles mixed emotions. Joyce is happy that these people are doing so well. However, she is also angry and disappointed that the recipients and their family, have never bothered to make contact with the people that

have helped them achieve this new life. Unable to deal with these emotions, Joyce determines instead not to waste her time waiting, expecting to hear from the recipients; and Joyce seems to be able to do this for six months at a time until her need to know how these people are doing becomes so strong that she must again seek information. Once again Joyce is told they are doing well and once again Joyce wonders when the day will come that the recipients will take the opportunity to contact her and Andrew. Andrew lives with the hope that one day he will meet the recipients. But both Joyce and Andrew remain waiting.

Every year Joyce and Andrew attend the *Thanksgiving Ceremony* conducted in honour of the life saving practice of transplantation. They attend and silently watch and listen to the recipients talk about their experience and about how grateful they are to the doctors and donors. Listening carefully Joyce hopes that one day she will hear a recipient say that the date of their operation was 15th of June 1995 and she will be able to approach this person and say that the 15th was the day that her Angelica donated her kidneys. Joyce however continues to wait, disappointed at how everyone seems to have forgotten about Angelica and the gift she gave by her death.

Andrew and Joyce were directed through their loneliness and uncertainty by their religious faith. Despite feeling helpless from being unable to protect their child they had faith that their God would protect Angelica. Shrouded in their faith from the pain and sadness that surrounded them, one nurse's effort to make their need to hold Angelica a reality shines like a piece of golden thread in Joyce's memory. The nurse's empathy and care became the ligature between Joyce's capacity to realise that her daughter was dying and that there was really nothing more that could be done. Holding Angelica, watching as she lay wounded and facile in his arms, Andrew began to realise that their really was no hope, only his prayers left to keep her safe. Andrew held firm to his belief that if circumstances could have been different then God would have made it possible. Andrew and Joyces' faith however did not temper their disappointment in the lack of appreciation given to Angelica's gift of life. They gained the necessary strength to

consent from a belief that they were helping Angelica to perform one last gift. Now their grief and sadness is exacerbated by the uncertainty that their waiting to hear from the recipient has given to Angelica's gift. Has Angelica's gift been appreciated? Do the recipients ever think about or realise and appreciate what wonderful soul has given them a second chance at life? These questions continue unanswered for Joyce and Andrew and are therefore questions that keep them entrapped in an uncertainty about their decisions made:

> I think it would be nice if donor families had some sort of follow up. Not that they had to have follow up, but just to see. Have you seen the counsellor, have you got supportive friends, have you this, have you that? Just some sort of, acknowledge that yes you have given, your child has ... your person has died, they have given this gift and it is appreciated and whether those people are doing well. I mean all of that. Just sort of caring. I mean I don't know, is that asking too much? I mean there's lots of us do have support groups or friends or church or whatever that puts their arms around us and looks after us. But it would be nice to know that someone else was interested to know whether you were coping alright. I think that's maybe an area that could be looked into. Because the recipients get their sort of nurturing and you know that sort of thing ... I think there needs to be some sort of coordinator, not a transplant coordinator, they can't be the person who can care for both ... But some other sort of person that cares for them and some liaison between those two people. And I think that that could work. I mean transplant coordinators, I think they are lovely lady and they're doing their best, but there needs to be someone else who's going to look after the donor families. I mean ... energy must be in both camps. But a lot of the caring and nurturing and what have you for the donor families and sort of, it ... just a phone call Joyce, how are you? Because really ... every so often I think well you know is there anyone out there?(Joyce/ p. 10:13-21; p. 11:1-9).

As each story has shown, Andrew and Joyce are not alone with the way their waiting to hear from the recipients has extended their uncertainty and loneliness. Each parent values and appreciates all information from and about the recipients of the organs donated, but they seldom hear directly from the recipients. They do receive information from the transplant coordinators, but this is often general information about the wellbeing of the recipients. Not having any communication with the recipients therefore is a source of immense disappointment and regret for many parents. Feelings of disappointment and regret though are often considered inappropriate and problematic by those with whom the parents associate. A lack of any place and recognition for these

feelings leaves many parents feeling increasingly alone and uncertain in their loss. With no support and recognition of their disappointment and regret the parents are left to continue waiting for some confirmation of the value of their child's gift. For some, this wait has been more than five years and seems unbearable and never ending as they wait for some peace and comfort from their past decisions. Many who continue to wait do not regret the donation—for this regret would open a minefield of emotions—but they no longer gain solace or comfort from the concept of the gift:

> But I really wonder sometimes how it must affect people who don't have ways of dealing with it. And I was really interested when we went to this memorial service in Brisbane the other day, and you know we were sitting with the other donor families, and the thing that I found really interesting was to just look at the level of distress. Which I thought was really interesting and I thought there's stuff that has to be done with donor families on an ongoing basis, you know. That, that yeah. There's stuff that has to be done in lots of ways and you know, at some stage I really hope that I'll have the energy and the courage to deal with, even just little things like. I read of this wretched thing I think it was from Cahill and she'd bragged about, giving with a good heart is good and Giving with a bad heart is bad. And I sort of thought God it must be really tough for families who've, I mean they don't need to hear this. I mean they gave for whatever reason. I mean the last thing you need to be is lectured at ... And I think people need to get, to get real about it . You know that people give to the extent that they can, but it might, well it's never willingly really. I mean you don't want the person to be dead. And there's too much that has to be decided at a time when you're least capable of making those decisions ... But you certainly don't need the memorial to have those overtones of you know what's good giving and what's bad giving ... And we (another donor parent) were talking about it later and I just sort of said to her That's the first time I'd felt heard. Because she knew, other people don't know, so they can't, they can't hear. They haven't been through the experience. And I suspect that the stuff that has to be done, probably has to be almost a self help thing. Donor families have to do the work ... I think they're the only people that can effectively do it, who really understand one another's experience (Jerry/ p. 10:14-21; p. 11:1-15).

Communication from the recipients therefore brings great emotional relief to some parents as it helps to reconfirm for them that their struggle and sadness were not in vain; that the importance of their child's life has been appreciated:

> ... because we got the letter back from David, three months later and we'll show you the letter. His thank you we got ... a little card and that meant so much to us, and just before Christmas we got the other family's. That was about seven months later ... they did an

> anonymous letter as well. And I can remember just opening the letter, going downstairs and just reading it and just breaking up about it. But it did mean, it meant that to us, that the effort that we'd gone through had meant so much to another family (Thomas/ p. 17:1-6).

Once the procedure is over and the parents have left the hospital their capacity to cope is largely dependent on the care and compassion displayed by friends, family and the community at large. Exhausted by emotion many feel incapable of making any decisions about daily life. As time passes and they continue their wait to hear from the recipients they begin to feel angry and disappointed as their waiting makes them feel that concern and support seemed available largely while ever their consent remained undetermined. Once consent is given, concern for their opinions and emotional support seems to disappear and they are left alone with their needs largely unmet:

> I said that I wanted, I said that I wanted to be kept informed as to how the recipients are going and they've not rejected. And you know that I wanted to be informed in the way of letters. But it was really, it was very very poor. I feel very disappointed um I feel very disappointed that we haven't had more communication with the Red Cross and that we haven't. I don't know that they, that they don't just, I said that I didn't mind this, you know I didn't mind being told. And I just felt that from the day we walked away from the hospital, that we weren't taken care of ... the organ donation coordinator was present. And he talked to us so well, I felt that he was genuinely interested in us...While we were there but it was almost like the minute we went away, we were sort of forgotten (Ellen/ p. 17:6-18).

The opportunity to return to the hospital and have some questions answered is offered to all parents and appreciated by many. For some however, their questions continue to be unanswered as this subsequent information remains disappointingly incomplete.

Each parent explains how the enormity of the decisions made and the quality of the death they encountered has left them with an experience that they will never simply 'get over'. They are totally alone in their grief as this grief leaves them as witness to how different their loss is to others. Many speak of the frustration and disappointed felt when their friends and family begin to disengage from their pain and loss and act as if life has returned to normal:

> The attitude even now is 'Hasn't it been a lovely day, its been just a wonderful day'. I find it hard ... really hard to accept ... that when your actually trying to reach out and there's nothing, nothing ... Mum rang the other day and I'm trying to say to her again to listen ... could you listen to what I am saying. But it's too hard for her to listen to the pain. I understand that now. But what I need is for her to be able to and that's an expectation, I understand that ... and our friends and there was over 500 at our son's funeral ... but in the last year only 2 people have walked across this threshold, two people across this doorway (Daniel/ p.11:15-21; p. 12:1-7).

Some parents become further isolated and alone in their grief as friends attempt to avoid them rather than face the ongoing and relentless presence of their loss. Society thanks them for their gift in the form of a *Thanksgiving Ceremony*. Again however attention is focused during this ceremony on the joy and release from suffering that their gift allows and rarely on the sadness, uncertainty and loneliness they continue to experience in the seconds, days, months, years after their consent to give their child's remaining life to another.

Thomas, Pip, Ellen, Andrew and Phedra (and their respective partners) therefore are relatively alone in the experience they share as not only is it a complex interplay of the temporal dimensions of loneliness, unprepared, watching and waiting and uncertainty but these dimensions are apart of an experience of which the majority in society have a superficial understanding. Since the parents live in a society that prefers to avoid issues of death and loneliness as well as deny uncertainty, attempting to overcome their loneliness and uncertainty proves difficult. Their constant struggle therefore becomes one of attempting to be heard, let alone understood.

In this chapter I have shared with you my interpretations of the parents' experiences. In the next chapter I present my understanding of these interpretations while realising full well that such an understanding works to 'cover over' as many possible meanings as it 'uncovers'. This however is why Heidegger (1962) considered all attempts at authentic communication to be an act of *resoluteness* because in offering this understanding I am resolved to its paradoxical nature of revealing while also concealing other possible meanings for discussion.

Chapter Six

Crisis of Limitations

Introduction

> *We have become a society confused by its own contradictions ...*
> *and there can be no deeper fear than that of mortality unchained.*
>
> (John Ralston Saul)

Over the past two years of reflecting upon and dialoging with each of the parents' stories I have come to understand their uncertainty and loneliness, their waiting and watching, and feelings of unpreparedness to be the temporal expressions of their crisis with meaning, or what I have come to call their *Crisis of Limitations*. I intend, in this final chapter, to explain this concept and to discuss what nurses can do to support the parents through this experience.

From the outset I do wish to acknowedge that this understanding of a *Crisis of Limitations* is a theoretical abstraction of the parents' experiences which at first appears somewhat antithetical to the general methodological orientation of this thesis. However, by gathering all the fragments of meaning that I have made about the parents' experiences into a meaningful whole I succeed, as Shotter (1995) reasons, in placing such meanings into intelligible relation with the rest of my knowledge about nursing in particular and people in general. This theoretical abstraction therefore is not intended to be realised or discussed as a rule of practice about donor parents' experiences. Instead, the concept of a *Crisis of Limitations* is intended here to act as a central, coherent idea from where future arguments to support changes in policy and practice can be developed and advanced.

To begin relating this concept more fully I will first articulate the character of the parents' *Crisis of Limitations* and follow this with a discussion of how, not unlike other areas of nursing care, support of donor parents benefits from being well grounded in the

practice of ethical relationships. I am particular in the use of the term ethical to describe these relationships as they are relationships that I believe command considerable integrity. Such relationships revolve around a sensitivity that a nurse requires about the potential powerlessness each parent can encounter in their attempts to participate in the meaning making of their child's death. When sensitive to these inequities nurses can endeavour to understand each parent's dillemma and find ways to provide them with support and care that suites their particular needs. It is this relational focus on the parents' embodied, first-person, reactions to their experience and to other peoples' words that is central to the approach of care that I want to outline in the final sections of this chapter and completion of this thesis.

Confronting their Limitations

> *The story is told that when Persephone was imprisoned in the Underworld her mother Demeter sought her for many a weary day. In the course of her wanderings she took shelter with a young couple and was employed by them to care for their child.*
>
> *Demeter grew fond of this child and decided to make him immortal. In order to accomplish this she had to put him each night into the fire so that his mortality would be burned away. However, one night the parents discovered her laying the child in the fire and in terror chased her from the house. Thus the child never achieved the status which was intended: the status of a god.*
>
> *Suffering is the crucible through which life passes in order to purify itself. It is not enough to lie still and suffer; it does not suffice to switch off and render ourselves insensitive. We must fight through it with awareness, sensitivity, honesty and a full-blooded determination to keep our humanity. Only then will our mortality be burned away and the spirit find its truth.*
>
> *Suffering is the result of ignorance and the cause of wisdom.*
>
> (Anne Spencer-Parry & Majorie Pizer)

Throughout this thesis I have called upon the works of numerous scholars to emphasise how mortality has proved a constant source of suffering for humankind. This concept of a *Crisis of Limitations* in many ways extends this discussion as it refers to the psychological tension that has been created between our desire for freedom

(immortality) on the one hand, versus our mortal captivity on the other. When discussing the existential basis of our Being-in-the-world, Jaspers (1951) suggests that having our lives bound and shaped on a daily basis by the limitations of our mortality (that we bleed, are earth bound and grow old and frail) has encouraged within us an empassioned need to try and transcend these limits. Driven by a desire for freedom, everything we do, from building cars and planes to researching the source of magic elixirs and missing genomes can be realised as a constant effort to compensate in some way for these mortal limits. Transcending our mortal limits seems to have become a commanding purpose of our civilization.

Organ donation/transplantation is a prime example of our need to extend the boundaries and dare to question why not. However what cost, what moral price are we exacting in striving for freedom from such mortal bounds? Our cultural obsession for freedom seems to have propelled us into a tug-of-war of our own making. Enamoured by success at overcoming previously inconceivable boundaries we seem as a society, a culture, to have lost the ability to accept limitations. Fearful of our limitations we run in the opposite direction, searching frantically for ways to extend or transcend our boundaries.

Donor parents live in this culture that tends to encourage people to question, at every opportunity, their limitations. Accepting the brain death of their child seems totally alien to donor parents. Instead of accepting the mortal limits at play the parents prefer to hope and search for options, for other alternatives. Ideally, they would like to reject the situation outright, but cannot. Hence, the circumstances they are caught within tend to force them to confront and struggle with many fundamental issues about their physical, spiritual and emotional limitations which the majority of us choose to ignore.

The death of their child reinforces for the donor parents the realisation that we (human beings) are tethered to mortality by our deaths; a realisation that appears to have become psychologically intolerable for many. Today, within the comfort of our Western culture, not only do we enjoy the illusion of omnipotence but also omniscience. Through appeal to specialist knowledge and guidance we prefer to continue seeking ways to overcome our limitations. The parents look towards medicine as the most obvious hero

to help them achieve this end. The power and promise of medicine holds great hope for the parents. They live in times of achievement that affords everyone a degree of freedom that was once the stuff dreams were made of. We can fly through the skies, cross oceans, travel miles at great speeds in cars and trains. Yet their child lays before them seemingly beyond the help of medicine, who at this point is only capable of helping another.

Invariably the parents' experience becomes that of a struggle to acknowledge the limits of their situation. They are being challenged in the most profound way to surrender their expectations of a secure, predictable future and to accept the loss which is attached to the realisation of their child's finality. Even the time available to try and understand and accept what is taking place is limited. Invariably, when confronted with the mortal limits of their child, the donor parents try to cling to the security of past beliefs. They try to ignore, for as long as possible, the limitations they confront. To accept their child's death would mean they would have to accept a degree of suffering and loss which conflicts sharply with their previous taken-for-granted assumptions and expectations of their child's future. Instead they wait in hope that medicine will find a way to help their child; but their hopes remain unanswered as they wait and watch what takes place before them.

At first such avoidance is relatively easy as they stand beside a body that continues to live and breathe. Yet, caught within their circumstances the donor parents soon realise that ambiguous limitations are at play. They realise that although medicine has reached its limits in being able to help their child it has only begun to transcend the limits that confront another one, two or possibly five other people. Compounding this ambiguity is the very fact that donor parents are situated, are literally standing in a biotechnological cathedral that has been built to celebrate humankind's effort and successes in transcending the limits of its mortality.

Consequently, donor parents have become the living expression of this tension that we as a society have created between our mortal limits and empassioned desire for immortality/ freedom. Through a constant appeal to engage in activites that promise to

keep us healthy and free our cultural practices and preferences encourage in us an avoidance of death. Each parent's story, however, conveys the vacuousness of such an appeal. Their stories demonstrate the struggle they undergo in having to eventually confront the limits at hand. In attempting to consent to the donation of their child's organs the parents are having to contend with the limits of life and the limits of youth. They are forced to struggle with trying to accept the mutability of youth and life and the limited efforts of medicine to make them otherwise.

A Crisis of Reasoning

The parents find themselves in an ambiguous situation of having to accept the futility of medicine while also being asked to extend the limits of their present reasoning about death to accept a new death call brain death. Ultimately the donor parents are amidst a crisis of meaning.

Coming to accept our existential limitations is regarded by Jung (1968) to be an essential process of our psychological development and wellbeing. Various encounters that we have throughout our daily lives are considered to be helpful in nurturing within us an awareness of our finiteness. Donor parents, however, have to contend with a whole series of existential issues and within a relatively short period of time. Not only are donor parents having to surrender to the death of their child and all future plans, hopes and dreams embodied in this life, they are having to do so at a time when their taken-for-granted assumptions, their habits of mind, about life and death are being challenged in the most fundamental way. The uncertain, almost limitless state of brain death, is not the death they have been enculturated to expect. Trying to comprehend and accept brain death subsequently becomes a primary catalyst for their *Crisis of Limitations.*

Suddenly the parents are being forced to let go of various grand narratives about life and death that, until this point in time, have been formative in their capacity to live and create a sense of purpose about their lives. This breakdown of old beliefs and expectations leaves many of them feeling vulnerable and alone. The goal posts have moved and have done so during a time when the parents are relatively incapable of

comprehending anything else but the loss they are experiencing. This experience makes donor parents acutely aware that their identities and certainties about the world are not fixed and secure but insteady, highly mutable. An inner struggle ensues for the parents where chaos and confusion reign. Seemingly abandoned by the personal and collective myths which have grounded their reasoning in the past they are left begging for answers which simply are not available.

The parents, like the majority of us, have lived their lives according to the 'rules'. Suddenly, however, and at a time when they need these 'rules' more than ever, the rules have changed. The most challenging of these changes is the request from specialists to ignore what they see and witness as 'life', and instead accept a diagnosis which, for them, fails to make sense. In a society where we are encouraged at every opportunity to only trust what we can see (the empirical basis of reason) the parents are being asked to forego such conditioning, and in doing so ignore the precious signs of life that they witness and dearly hope will continue. Invariably, circumstances fail to make sense as such requests challenge a fundamental tenet of rationality and logic that has dominated the way the parents have been enculturated to think and reason. A crisis of meaning is provoked as the parents observe life, a life they are told to ignore as life, since this life only has potential value for someone else—not their child.

Suspended Between Two Worlds of Meaning

I liken the parents' *Crisis of Limitations* to be an example of what Turner (1964) calls a liminal state. Liminality is a term which ascends from the root word 'limen' and means, threshold. This term liminal, suited Turner in his want to describe the experiences of people engaged in a 'rite of passage' that is commonly associated with a cultural ritual. Such people he considers, are on the margin between two worlds of meaning—the old and the new. Given the many cultural rituals associated with a 'rite of passage', people engaged in such rituals tend to passage their threshold or liminal state with a sense of purpose and a reasoned expectation of the outcomes. The 'new' world of meaning they are entering is replete with rituals that are overseen by elders who help them accommodate any ambiguities and uncertainties of meaning that they may experience a

long the way. Passage of these liminal states is therefore a time of celebration as it often promises a new perspective on life as well as power to the initiates.

Although clearly experiencing a liminal state, donor parents differ in a number of significant ways from the people that Turner (1964) writes about. The first and most obvious difference is the lack of ritual and cultural support that donor parents quite clearly experience. Despite the medical and nursing practices associated with organ transplantation having a degree of ritual associated with them, the community the parents return to does not. Subsquently, donor parents often remain within a marginal state, suspended between two worlds of meaning. Unable to traverse the threshold to new meaning they are surrounded by people who cannot begin to comprehend their experience and therefore do not know how to communicate with nor identify their needs.

Caught between two worlds of meaning, the parents are alone in having to make a decision about this new death based on a still firmly entrenched and valued understanding about the 'old' death. Unlike the initiates, donor parents are devoid of any real purpose with which to help them transcend this change. The purpose they are offered is so profound and challenging to their basic assumptions about life and death that a crisis ensues. The new life promised is not a life they want. The new life they are entering is full of ambiguities that fail to provide any easy answers. They are alone in attending to the limitations with which they are being confronted and so feel helpless to stop or make them otherwise. There are no elders, nor 'wise ones' ready at hand to help the parents make sense of the conflicting and ambiguous signs they encounter. They are alone.

The Support of Ethical Relationships

The donor parents' experiences are somewhat analogous to a ship or aircraft entering the Bermuda Triangle. Suddenly the navigation equipment (previous beliefs and assumptions) is useless, but orientation is still demanded as decisions need to be made. They need support. Through realising their experience as such, I have come to believe

that a valuable focus of nursing care can be one of attempting to develop ethical relationships with the parents through the establishment of honest, open dialogue. I call such relationships ethical as they are born from an urgent need that each parent has to trust those who surround them. Acknowledging and working with this trust requires considerable integrity on the nurse's behalf.

The parents have little choice but to trust. With the majority of parents unfamiliar and uncertain with the clinical environment they need to trust the intentions, actions and words of those who surround them, even when these are not fully understood nor understandable. Conversations that inform the parents about their child's condition and the choices they need to make ultimately indicate to the parents a need they have to invest their *trust* in the professionals, machines and other paraphenalia that surrounds them. Similarly, through the many conversations that take place, the parents are being signaled to be strong and to think about someone else's need at a time when they desperately feel their own needs wanting. In such a situation they are being asked to be morally courageous even though their pain threatens to overwhelm their very capacity to comprehend, judge, choose, compare, feel or will beyond the immediacy of their loss. Without any real choice to choose who helps them work through this experience, each parent has to trust that the staff present will guide them through their uncertainties and confusion towards making a decision about their child's life/death that they wont regret.

As a nurse, my compelling response to the parents' crisis is a want to 'fix it' by suggesting how or what they should think and do to ease their sorrow and pain. Netherthless, such an approach fails to appreciate that how one interprets an existential limit, such as death or human tragedy, is very much dependent on a person's context and history of meaning. Consequently, there are no answers, no clear cut rules to be found about the parents' experiences that can be fashioned into a policy or procedure of care. Limitations are ultimately self-defined. What proves to be one person's limitation may be another's bliss.

Under the circumstances, simply being available to listen and enter honest, open dialogue with the parents may truly be the most supportive and morally valid care

possible. In the remaining sections of this chapter I attempt to outline some of the central features of this ethical relationship and also discuss how, in practice, such a relationship might be promoted and upheld.

Given that these relationships revolve around the process of dialogue I shall comment first on both the character of the words and the stances appropriate to such a practice, before turning finally to the character of ethical relationships themselves.

Languaging

An ethical sensibility not only encourages a special sensitivity to the language of self and other, but also an appreciation of the positions of speakers and their addressees. Attempting to remain open, arrested or moved by certain 'fleeting' occurences in the parents' conversation is essential in the nurses attempts to develop an ethical relationship with the parents. The first and most important point becomes that of generating an appreciation for the words that parents use and the way they choose to use them. Subsequently, the language necessary for ethical relationships emphasises:

1. the difference between talking in the first person and talking in the third person; as well as the difference between talking as a participant who is able to affect events and that of a mere spectator or observer.

2. a needed shift from 'talking about' to 'talking of' and 'talking with' that re-positions the parent as talking from within a particular ongoing, dialogic moment, rather than looking back on something already completed.

Speech that encompasses these two principles is responsive and open to possibilities as it navigates between different worlds of meaning. The language is conversational and collegial. Rather than holding fast to a single fixed realm of meaning, this language invites a sense of trust and a willingness to open up to other possibilities of meaning that are taking place within the conversations. It is language that is still 'young' rather than fixed and objectifying. Language that is looking forward, prospectively, toward new possibilities rather than existing through predefined assumptions and expectations.

Stance

If the forms of talk described previously are those that invite an ethical sensibility, then stance is about how nurses can position themselves in their conversations with donor parents in a way that enhances trust and acceptance? There is however, no single position that suites all needs. Instead, when trying to facilitate trust and a sharing of emotions, a shifting of stances or an ability to conduct what has been called 'Boundary Crossing' (Walker 1994) or 'Fringe Dwelling' (Parker 1995) is preferred. From moment-to-moment the nurse needs to navigate, negotiate, or move among:

1. different languages or discourses: for example, medical, professional and public; the voice of the parents or person versus the rhetoric of medical terminology; the use of medical diagnostic language that tends to narrow the focus compared with the metaphoric style of relational dialogue that opens and expands possibilities (Shotter 1990).

2. the cultural context of issues including their moral worlds where what is at stake for each parent is heard or translated into another domain of discourse. Worlds of meaning so local that they change from moment-to-moment.

With these two principles in mind, the effort for nurses becomes that of talking 'with' rather than speaking 'for' donor parents. Conversing in this manner moves the dialogue from one dominated by 'Buts' to one punctuated with 'Ands'. Instead of making sense of the parents' behaviour by imposing upon it a category, system or abstract theory, their utterances are allowed the freedom to be heard and to strike a level of meaning never before realised.

Pacifying Communications

One of nursing's priorities of care has always been to try and instigate alternative means of communication. However, at present, because of the medically dominated policies of care associated with the practices of organ transplantation, nurses have a somewhat truncated or passive role in the process of organ donation. Nurses have become the 'pacifiers' of the ambiguities. Their main role has been that of attempting to appease the

disharmony or bridge the disparities that exist between the rhetoric or rules of donation and the experience of the families as lived.

At once invited to support doctors in their conversation with donor parents about their child's condition, nurses are inturn dismissed to the margins of the same conversations, rarely allowed to initiate discussion with the parents about organ donation/transplantation. The parents capacity to trust and reach out in their conversations with the nurses is however, nurtured by the way that nurses are the professionals who remain at the bedside with the parents' throughout their pain and confusion. With a good appreciation of the vernacular and idioms of all parties concerned, nurses' greatest skill and value is found at the bedside in their efforts to arbitrate communications for the parents. As interlocuters nurses move readily between the worlds of public and professional discourse about organ donation. Nurses are involved in a voyage of boundary crossing. They move between the land of theory, definition, policies and rules regarding organ donation/transplantation versus the experience as lived. In this voyage nurses bear constant witness to the pain and uncertainty being suffered by parents in their efforts to confront the disparities at play.

Nurses act as a communication bridge between the worlds of medicine and public discourse concerning practices of organ transplantation. Like the parents the nurses' shifting position, betwixt and between, is a liminal position. A liminal position of formative not coercive power as they can continuously work the spaces of conversation to formulate and raise questions of relevance to the interactive processes and dialogue occuring between the parents and doctors. In navigating these worlds of difference, nurses can attempt to make room for significant conversation and meaning to occur. From within this position nurses can inform each parent about what is at stake in their act of consent and so support them in their decision making.

Ironically, it is in this shifting, moving stance that at once holds nurses in the margins—seemingly dispossessed of any power—that nurses are given the majority of power. Within this liminal position nurses are afforded the necessary space to witness 'arresting' moments of the parents potential to express themselves, to make their world

and needs known. Without this position, such special moments are so fleeting they are easily ignored and lost within apparently routine conversation. The focus of establishing ethical relationships therefore becomes one of the nurse remaining alert to these moments and navigating these conversations so as to shed light on the mutlitplicity of agendas at play. Through these subtle processes nurses are able to evoke an atmosphere of invitation and inquiry that legitimates all parties involved in the conversations at hand to the detrement of none.

Ultimately, nurses have this privleged position as they are the professionals who watch, wait and witness with the parents the dying of their child. It is during these silent, private moments that the parents show nurses their world meaning in their fleeting reactions to, and understandings of, what is occuring around them. If aware and sensitive to the parents' display of emotions, nurses can respond to any implicit as well as explicit needs that may arise. Since these needs are highly contextual they can never be known or anticipated in advance by some disengaged policy of care. Instead, they can only be identified and made available from knowing the context of the parents' experiences as lived and this primarily occurs through having spent time actively listening to their experiences as told.

Caring in the Moment

When conversations with the parents are treated not just as a way to give 'voice' to information but also as a way to generate important questions, a sense of agency can be invited into the parents communication. The parents' conversation is given primary importance which can in turn help them to develop a confidence that what they have to say is being heard and valued. Such conversations are important as they can become the source of knowledge about how to support parents. Despite their confusion and uncertainty, the parents can reveal through their conversation how they need to be helped and so play a significant part in the decision making being made. Through these conversations nurses can learn not only the 'what', 'when', 'how' and 'who' of the people the parents were prior to this accident, but also possibilities of how this event is going to change the people they once knew themselves to be. How they will be is

inextricably woven within the current situation. Listening carefully to their conversations nurses can be guided in how they might support them through this event. As Shotter (1995) encourages, it is in such living moments (of conversation) between people that utterly new possibilities are created, and people live out solutions to their problems which they cannot hope to find solely in theories or policies of care.

The nurse who offered to help Joyce and Andrew hold Angelica is a perfect example of the contextually responsive and specific care that is demanded in these circumstances. For Joyce and Andrew this prompt to action was exactly what they needed. Through the nurse responding to this relatively simple need both Joyce and Andrew were able to begin to accept what was happening to their lives. Andrew was able to venture an understanding of the ambiguous concept of brain death and Joyce was able to begin her mourning. However, to extrapolate from this experience and try to develop a policy that stated all parents *should* hold their child when in similar circumstances would be totally inappropriate and possibly detrimental to many.

Thomas too had his needs attended in the most contextually specific manner. The nurses openly shared with Thomas their sadness and uncertainties which helped prevent him from feeling the loneliness and uncertainty that Pip so sadly suffered. The nurses stood with Thomas and appreciated the disparities that existed between what he was witnessing and what he understood. Remaining with Thomas throughout his experience the nurses were able to provide him with information that spoke directly to what he was experiencing at the time. Pip however was left alone. The care she received was primarily policy driven and directed, with the most obvious example being the gradual absence of Hamish's name from all activities of care. Sadly, such practice reflects a common policy that has been promoted by transplant coordinators and is based on a theory that states it is best for all involved to treat the donor as a corpse, as dead, even though they are breathing and their heart is still beating. I believe that Thomas' story reveals the problematic nature of such policies. For me, Thomas' story conveys that when nurses openly share in the parents' confusion, uncertainty and loneliness, the

parents are more able to surrender to their limits and make choices that reflect their intimate needs and values.

To attend to the delicate negotiations between the parents and the doctors nurses need to take care to notice all the extraordinary features of the parents' conversation, such as its tone, its emotional richness or emptiness, its nuances and variation. The task becomes one of trying to be open, arrested or moved by certain 'fleeting' occurrences in what the parents do or say. Without such relationships the parents have no choice but to submit in defeat to the confusion and uncertainty that surrounds them. Submission however is not a real choice for the parents. Many emotionally fraught and complex questions left unanswered do not disappear when left unspoken. Left unspoken these questions remain idle only to rise at a later date in search of further clarification. A later date though is often too late as then the parents have to also contend with the finitude (another limitation) of the decisions they made while amidst their uncertainty. If unable to accept their previous decisions the parents can become haunted by guilt, shame and an insatiable anger at failing to make the *right* decision.

Ideally, instead of either extreme, simply providing each parent with open, honest communication and support to make a choice that suits their individual needs is a more ethical and morally supportive policy of practice. For the doctors the story ends with the diagnosis. The path is clear about what needs to be done and how. For the parents however, the story takes on a new dimension as the diagnosis leaves them totally uncertain of what to expect or do. It seems therefore that while engaged in the care of donor parents nurses are faced with a moral imperative to not only assume a role of 'boundary negotiator and pacifier' but also to attend this role with a determination to help the parents become aware of all the implications of any choices they are having to make. Through open, honest dialogue nurses may be able to help the parents realise that there are no right or correct answers or choices, only that which is right for them at a particular point in time.

Confronting Professional Limitations

Being committed as a nurse to support parents through such an experience is never easy as the honesty demanded can force upon the nurse an awareness and needed acceptance of their own limitations. Without doubt, the ability and willingness of a nurse to be open and honest, to surrender to the situation, is highly dependent on how confronting the circumstances are to their own personal limits—limits they may feel incapable or unprepared, at the time, to face.

Any unwillingness on the parents or nurses behalf to surrender to the limitations of this situation is therefore not surprising. Limitations are often understood as problems and difficulties to be overcome rather than possible gateways to new opportunities. Subsequently, denial or avoidance of their limitations appears to be the more appropriate response. We are a society that has only begun to appreciate the humility and wisdom inherent in the words of people such as Gibran (1926), who suggests that the extent to which we are able to experience joy is directly related to the extent to which we have suffered. Surrendering to our limitations though by no means places the pursuit of suffering for the sake of suffering as the preferred position. This I believe is pure masochism or nihilism. Frankl (1997) however argues that our efforts in life should not be the obverse: attempting to avoid pain or trying to gain unlimited pleasure. Instead, a balance needs to be struck and our efforts directed towards trying to discern the meaning of one's life, and in particular our sufferings through an appreciation and acceptance of our mortal boundaries.

Walker (1997, p.4) clearly distinguishes acceptance or surrendering to our limitations from submission which she believes is a mere capitulation in order to 'fight another day'. Walker explains that instead of accepting one's limitations which is commonly associated with surrender, the person who submits typically does so grudgingly. Encumbered by submission the person is often left nurturing a smouldering rebellion of 'if only' which can later evolve into a form of revenge. Accepting one's limitations, suggests Walker (1997), is a more complete submission to the changing circumstances at hand. Surrender or acceptance of the limitations that confront us is a response we make

when we realise that no futher movement in a particular direction is possible. To surrender to the various limitations that may confront us in a situation is only achieved through great deliberation and understanding that there are no alternatives available. Invariably, the demand on donor parents to make a choice of loss (death of their child), which paradoxically gives unlimited potential to another, in a time frame that denies the possibility of any real understanding to occur, is fuel for confusion and a crisis that easily encourages submission rather than surrender.

Yet, through the establishment of ethical relationships nurses can help donor parents make a choice that is not dominated by social ideals and expectations but rather one that is true and responsive to their present circumstances, their present limitations. To do this nurses need to continuously focus on the parents' experience as lived rather than retreat into theories and expectations of behaviour. Creating frameworks of care that are responsive to the particular needs of each parents' experience rather than care that is dominated by policies that are augmented by expert opinions about one best or right way to practice is a start.

To achieve this style of care I believe nurses need to realise their care of the parents as a journey, a journey alongside the parents in the decisions they need to make. Joining the parents on this journey encourages an appreciation within the nurse of their own limitations in understanding the parents' experiences and the inherent knowledge each parent brings to the interpretation of their crisis of meaning. From there, nurses can develop an approach to care that supports donor parents to make choices which are best for them as they move through an endless series of choice points. This approach to care is one that is not governed by expectations of particular scenarios, but one underpinned by a willingness to see and respond to the boundaries of each situation as lived.

A key to this process is the sharing of uncertainties and fears. Nurses can support donor parents to accept these challenges effectively, through providing them with time to look, acknowledge and own the discordance they are confronting. Within this time of critical reflection the parents can be afforded the necessary insight to break free of the cultural rhetoric and ideals which until this point have tended to lull them into a false sense of

security. During this time it is important that donor parents realise they are not alone in their confusion. Many people suffer from attempting to confront the disparities at play in the transplantation process.

Changing the current focus of care for donor parents from being one that is governed by pre-existing policies of care to one immersed in the chaos of experience as lived is only possible if nurses are willing to enter a process of listening to the voices of experience; and so move beyond the pieties of the past that keep them numb to changes that are needed. A primary challenge for nurses within this partnership is to find ways which enable donor parents to make sense of their lives while under the influence of these limitations. To effect positive change in their lives any choices that parents make needs to be based on their own understandings, intuitions and values.

To be effective, these partnerships in care depend on an awareness and acceptance of each person's strengths and weaknesses, as well as a keen appreciation for balance. There is a need to respect the unique needs of others as well as the need to search for a ground of commonality. Such an approach to care is challenging for most of us as one needs to be comfortable with messy processes rather than tidy solutions. Because our current thinking is largely based on a dichotomy between right and wrong, good versus evil, we have a tendency to prefer solutions rather than chaos. However, focusing on lived experience rather than ideals and rhetoric can encourage within us an appreciation of the world as being far more complex and less clear cut than our theories suggest. Finding ways to dance with uncertainty, continuous change and choice is rapidly becoming a central challenge of the 21st century.

The focus of care therefore changes in concert with a change in the style of support and advice from one that is dominated by expert/professional opinion to one that is a partnership of mutal respect. Donor parents can only surrender to that which they are ready to understand. Open honest conversation can provide donor parents with a common ground from where further understanding and support can grow. Once this common ground is found it can be built upon and result in a dialogue of meaning making that takes on new directions never truly anticipated by both parties. Simply being

available to freely engage in conversation with the parents regarding anything they may wish to talk about becomes, in my opinion, the central focus of an ethical relationship of care.

The key to success in this focus of care is that any expectations about what 'should' happen are abandoned. A humility develops that appreciates there is no right or wrong answers for the parents nor methods of support. Instead, nurses and parents come together for a period of time and embark on a journey of meaning making that is directed by their particular shared understanding of what could happen in that moment. Perhaps the most hopeful trend emerging from this dialogue is a growing acceptance of valuing 'truth' as a situated, lived event rather than an abstracted and predefined law. The courage and risks necessary to accept this kind of truth, however, requires above all cooperation, support and a willingness (on both nurses and parents behalf) to allow this crisis of limitations to radically change who they are and how they see the world.

At first, this approach to care may seem too precarious or messy to be effective, particularly when such care takes place within a system that is largely driven by dichotomised ways of thinking and managing solutions. Having no clearly defined outcomes except a want to support the parents in whatever ways identified by them to be of value in the moment can be too disconcerting for people who expect solutions. Yet our patterns of care need to change. This research helps us to question the success of our traditional approaches to care. Most of the structures we have inherited are not serving the parents in this situation. Indeed the very fact that we tend to think in terms of structures rather than processes, inhibits our supporting them in an open and honest manner. By 'managing' the parents according to some protocol of care we lose the invaluable opportunities to truly hear their needs and concerns when expressed. Ultimately, we need to move away from systems of care that are primarily run for the convenience of those who manage and administer them, and towards approaches of care which are centred on those who are being support.

Through donor parents being the source of information about the type of care they require a powerful, affirming process can be set in place that helps to facilitate their

continued long term survival of their child's death, in spite of the many ambiguities that prevail. Consequently, one of my hopes about the significance of this research is that nurses will come to acknowledge support of donor parents as a process that is realised in the moment and achieved through continuous engagement in open, honest dialogue, rather than governed by rigid policies of care. It is however foolhardy to believe that institutions will exist without such policies, since their very means of establishing and demonstrating effectiveness/quality of care is primarily achieved through rigorous adherence to policies of care. Nevertheless, instead of the policies being identified and used as hard and fast rules of practice, they can instead be understood more constructively as negotiable guidelines. In being understood in this way the institutions (hospitals, government agencies and corporations) that we work within have the possibility of becoming more responsive and part of this process and focus of care rather than existing as bastions of deleterious rules and policies.

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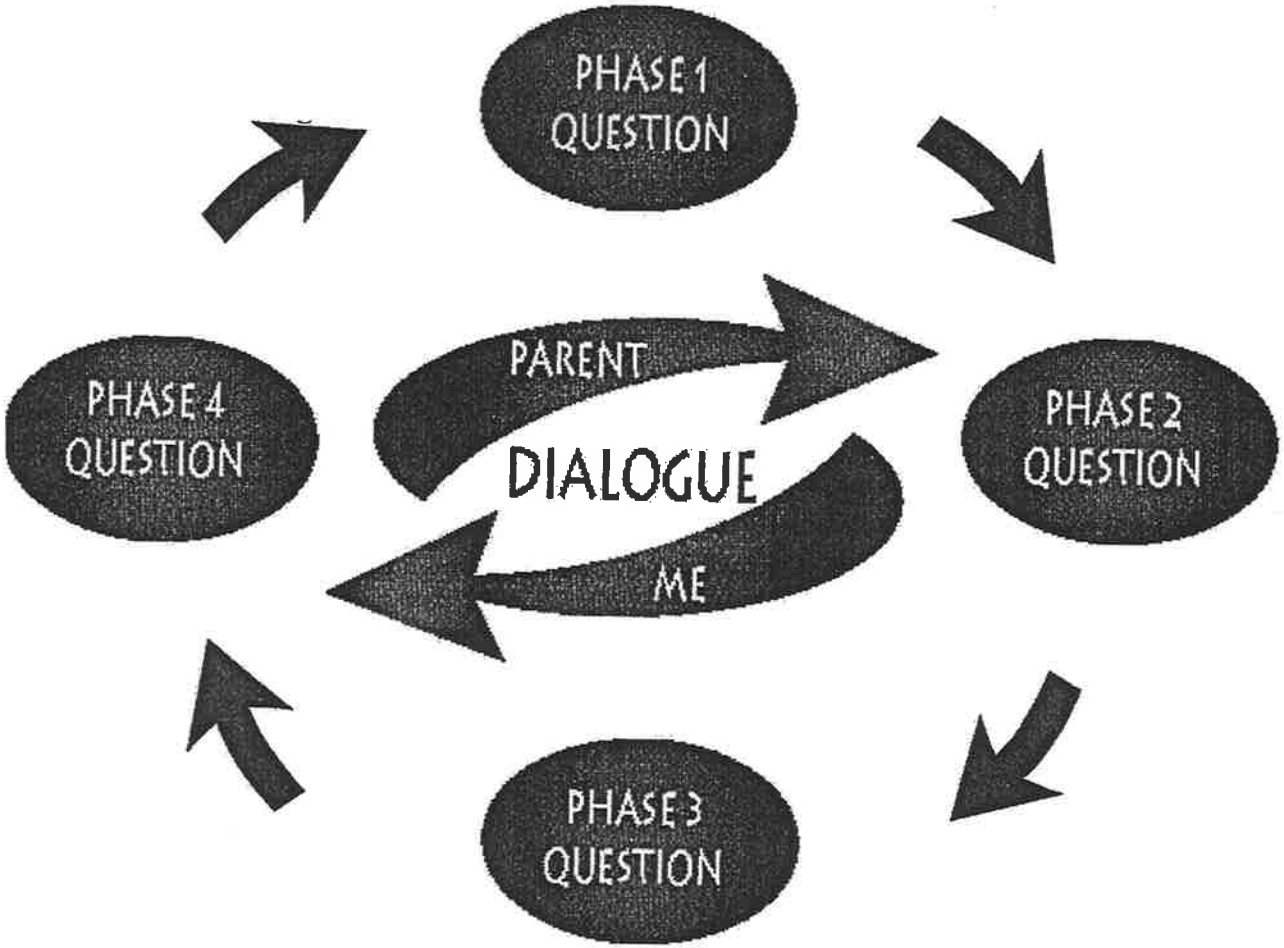
The Dynamic of Dialogue



THE UNIVERSITY OF ADELAIDE

Faculty of Medicine
Department of Clinical Nursing, Royal Adelaide Hospital

INFORMATION SHEET

Project Title: The ambiguity of the Gift of Life: exploring the experiences of donor families and health workers and the public discourse on organ donation

The aim of this study is to examine the process of organ donation in Australia, and as part of this study, we wish to identify the feelings and experiences of the relatives of people who have become organ donors. It is anticipated that the study will make a significant contribution to the ongoing discussion of organ donation, and to the development of policies and procedures for minimising the stress and trauma for families and hospital personnel.

Should you choose to participate in the study, you will be asked to share your experiences and feelings during an interview with a researcher. The interview will be recorded on audiotape, and a written transcript will be made. The tape and transcript will be identified only by a code number, and all records containing personal information will remain confidential and no information which could lead to your identification will be released.

While there are no physical risks associated with this study, it is possible that talking about your experiences may raise some issues that you find difficult or uncomfortable. The researchers are experienced in working with people in such situations and will be sensitive to this as a possibility. If you decide that you need further assistance, we will assist you to find appropriate counselling support. You may contact us at any time following the interview if you require such assistance or have any questions.

If you wish to participate in this study you will be asked to sign the agreement below. You should note that you can withdraw this consent at any time during the interview for any reason.

Any questions that you may have concerning the project can be directed to :

Professor Alan Pearson (Principal Investigator)
Department of Clinical Nursing, University of Adelaide, tel (08) 3033593

or

Ms. Suzie Robertson-Malt
Department of Clinical Nursing, University of Adelaide, tel (08) 3033640

THE UNIVERSITY OF ADELAIDE

Faculty of Medicine
Department of Clinical Nursing, Royal Adelaide Hospital

CONSENT FORM

Project Title: **The ambiguity of the Gift of Life: exploring the experiences of donor families and health workers and the public discourse on organ donation**

Investigators: **Professor Alan Pearson**
Ms. Suzie Robertson-Malt

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not directly benefit from taking part in the trial.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage.
5. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Volunteer: _____

Signed: _____

Date: _____

I certify that I have explained the study to the volunteer and consider that he/she understands what is involved.

Signed: _____
(Investigator)

Head of Department
Professor Alan Pearson

The University of Adelaide, Adelaide, South Australia 5005
Telephone: (08) 303 3595 Facsimile: (08) 303 3594

Appendix III

Pip & Daniel's Themes

- Unanticipated , unexpected loss - the questioning that remains with an unanticipated , unexpeced loss
- Overwhelming - life transforming, confrontation with loss
- Needing to be close to love one - be close by there side - resenting the lack of control to be able to freely achieve this
- Overwhelming - life transforming - confrontation with loss
- Absolute loss of control over trying to avert the loss of life - incapable of altering the chain of events despite every ounce of your soul wanting it to be otherwise
- Frozen memories - indelible remembrance of the experience - frozen in time
- Being controlled- trying to overcome the control that was being forced upon you
- Alone in the immensity of the tragedy - life continues on as normal around you whilst your own is slowly falling apart- limited help and support or recognition of need for support
- Valuing any compassion and support that was offered
- Limited access - access to loved one was being controlled by others when the greatest need at that time was to be with loved one all the time (Being controlled)
- Hoping against hope - wanting to control the outcome - to stop the loss
- Isolated and alone in loss - struggling to survive the aftermath alone and in isolation
- Watching and waiting for something to change - some miracle to happen
- Asking for more help - other ways to manage the situation - reaching for hope - exhaust all avenues before accepting lack of hope
- Regreting the lack of compassion and help given to loved one
- Alienated - impersonal treatment and managment of loved one - watching
- Regretful lack of support and compassion displayed for family (isolated and alone - watching)
- Receiving - given time for hope
- Loss of control - helpless - watching from a distance unable to help or alter the course of events that are taking place
- Limited space and privacy - impersonal uncaring environment
- Helpless - overwhelming loss of controlNeeding direction , information to work with - manage life withStruggling to survive the aftermath - and part of that struggle is the continuous revisiting the experience and reliving the loss again
- Needing to remain by loved one's side - unable to leave loved one alone
- Watching - removed from the care - uninvolved , not welcomed to be involved in the care - had to seek to ask questions in order to be involved - was not simply offered
- Watching and running out of time - running out of hope and chances
- Regretful lack of care and compassion or concern for the families needs form the staff
- Managing or attempting to cope with the experience and the technology
- Preparing to confront the reality of the situation
- Overwhelming - uncontrollable loss
- Uncontrollable loss - that the family somehow feel guilty for because they see themselves allowing it to happen by signing a consent agreeing to donation
- Lasting anger and distrust for the procedure
- Limited time and capacity to understand what was taking place
- Struggling to survive the aftermath - surrounded by lots of unanswered - unaskable questions
- Lack of information and deceit turns into anger and determination to find out the hole truth
- Regretful impersonal formalities and procedures forced to follow
- Surrounded by uncontrolable emotions
- Running out of time - rushed decisions because of limited time
- Seeking - Needing direction and support in decision making. Being told to leave unable to leave of own accord - directed to leave - following any advice because unable to make decision for self
- Incapable of leaving loved one's side - agonising
- Surrounded by lack of understanding of what was actually taking place or what was really involved in the procedure for donationIncapable of making decisions - returning - stepping back into the flow of life as normal - needing help needing some direction
- Dissociated but associated by guilt
- Struggling to survive the aftermath - Surrounded by questions and concerns
- Unable to be with loved one after they had died - unable to have needs met in saying goodbye
- Struggling to survive the aftermath

Andrew & Joyce's Themes

- Unanticipated, sudden unexpected loss
- Access to loved one was controlled - freedom of space and time with loved one was out of families control
- Waiting alone and removed from loved one's side - separated from loved one
- Unanticipated - unexpected loss of future
- Watching and waiting from a distance - watching others help loved one whilst left to stand by and wait
- Waiting - watching, wondering about the prognosis - hoping against hope - confronted with the reality of the situation - watching the life slip away
- Seeking support, strength to survive the experience
- Disappointed with the lack of compassion and care in informing them of brain death and the request for consent
- Needing to maintain a degree of control over what was donated - wanting to limit what was taken
- Regretting the limited time and knowledge to make irreversible decisions
- Regretting the lack of compassion and ability to engage with the emotions of the family - regretting the objective formal nature of the request and decisions to be made
- Regretful experience of a sense of urgency to take organs once consent was given
- Regretful formalities to follow
- Confronting the technology and the overwhelming lack of control of the situation - left watching whilst others care for loved one - unable to help in trying to save loved one's life - just watching
- Needing to hold and touch love one - have intimate contact with loved one in final moments - final goodbyes - valuing the compassion from the staff that helps achieve this end
- Unsatisfactory (limited) recognition of the event - How something so tragic and a loss so immense end with virtually nothing to show for itRegret for the lack of / limited acknowledgment from the recipients for the gift given - regret that it became a thankless gift
- Regreting the lack of inclusion in viewing the tests to confirm brain death - seeing is believing and possibly accepting the diagnosis
- Struggling to survive the aftermath alone (regreting the lack of support situation)

Ellen's Themes

- Explaining the life - giving shape/ personality to the experience
- Unexpected, uncontrollable circumstances/ loss
- Helplessness
- Uncontrollable circumstances/ random loss
- Regretable abscence from scene of the accident
- Transposed from life that once was into and uncontrollable tragedy
- Confronting reality and valuing the honesty that forced the confrontation
- Unable to control the loss
- Confronting the technology - coping/ adapting to- with the technology that is keeping loved one alive
- Confronting the damage - the injuries to loved one
- Transposed from life that once was into and uncontrollable tragedy
- Staying close to loved one. Needing to be with loved one in case they wake up or need help.
- Accepting - adapting to the technology and the demands of care
- Reaching out for help and guidance
- Confronting the tragedy and valuing the honesty the forced that confrontation
- Remaining close to loved one- needing to be close to loved one
- Uncontrollable loss - tragedy
- Needing to control - change/ alter the tragedy in some way
- Alone - drifting or removed/ suspended from reality - trying to survive outside of the tragedy
- Needing - reaching out for support
- Needing to be close to loved one / unable to leave loved oneGuided through the experience - receiving guidance and direction through the experience
- Confronting the uncontrollable loss
- Confronting the technology - being helped to adapt to the technology by the staff
- Guided through the experience
- Unable to comprehend the diagnosis - incomprehendible diagnosis
- Guided through the experience
- Confronting the pending/ loss
- Needing to alter the enormity of the loss - regain some control over the loss
- Guided through the experience
- Trusting the diagnosis of death before consenting - having faith in the doctors diagnosis of death / strength of decision came from faith in the doctor's diagnosis of brain death (Guided by faith in medical decision)
- Uncontrollable circumstances / regretful speed of decision making - lack of time to make such irreversible decisions
- Guided by faith in doctors decision making - waiting for the final diagnosis
- Uncontrollable circumstances - lack of time to make such irreversible decisions or to accept - confirm - feel right about the decisions made.
- Regretable formalities - distressing objectification / process and procedures of donation
- Confronting the loss - the final death
- Regretable loss of time to be with loved one - limited privacy to say goodbyes
- Regretable formalities that guided but also limited freedom in decision making about loved one therefore failing to meet their emotional needs
- Valuing knowing that the donation has helped others
- Regreting the lack of correspondence between recipients - feeling forgotten by the recipients
- Needing to have faith in the doctor's diagnosis (because of the Incomprehendable diagnosis
- Unanswered questions - persistent concerns

Phedra's Themes

- Loss of future
- Unexpected - unanticipated uncontrollable loss
- Maintaining hope
- Anticipating the death
- Alone -
- Confronting- coping the technology that is maintain loved ones life
- Intuiting the death
- Overwhelmed by the environment
- Confronting reality - unprepared for the diagnosis or request for organ donation
- Guided by memory of loved one as to whether or not donate.
- Excluded from decision making
- Rapid process once decision was made
- Welcoming loved one's and friends - acceptin g the need of loved ones and friends to say goodbyes
- Distressing aspects of care especially the tubes and invasive monitorings
- Confusing diagnosis
- Needing to hold and touch love one-trying to overcome the barriers presented by the technology
- Regretable lack of involvement in formalities
- Excluded / forgotten to be included in the decision making process for the formalities - lack of fore-warning about the process
- Questioning in hindsight the circumstances ordering the formalities or process of organ donation
- Valuing - gaining solace from the potential loved one has to help others in need
- Unsupported and alone in informing others of the lossLoss of control over needs with loved one
- Valuing the support and counsel given
- Given space and time to say goodbyes - valuing this time
- Surrounded by uncertainties that need clarification - needing guidance in spending time with loved one
- Concern for the difficult care the nurse needs to perform
- Valuing the compassion shown by the staffCoping with the final goodbyes
- Perplexing diagnosis- incomprehendible diagnosis
- Excluded from the decision making - resenting being excluded
- Regreting the control over the recipients and donors communicating
- Valuing the correspondence from the recipients
- Gaining strength to accept death from learning about the life that has been given to others from the death - despite the pain some sense of worth is gained

Thomas & Emma's Story

- Needing to talk about the experience to others - Struggling to survive the aftermath
- Struggling to accept the experience and gain as much positivity out of the experience as possible in order to overcome and survive
- Needing to know all the details of the experience and being involved and supported by staff to see all the details of the diagnosis - helped in the final acceptance and understanding of brain death and the consent to donate.
- Knowing - committed/ valuing the need for organ donation from previous experience
- Unanticipated - unexpected loss
- Needing to be close to loved one through out the experience - remain by the bedside
- Unexpected - unantcipated loss
- Aware of the surrounding grief - other families and there own grief - not the only family suffering - waiting, hoping for positive outcomes
- Valuing - appreciating the care and compassion given to love one by nurses
- Watching the loss - unable to control the loss of life
- Confronted with the overwhelming reality of the loss of life - the struggle for life had been lost
- Aware of the surrounding grief- surrounded by grief
- Valuing the care and compassion - support given by the staff in their needs to be with - remain close to loved one through out experience
- Accepting the diagnosis by seeing the tests taking place and seeing that no response was present - no trust or faith in doctors diagnosis was needed because present and saw everything
- Sharing the sorrow - valuing the freedom of emotion displayed by staff regarding their inability to avert the loss
- Accepting of the diagnosis and approaching - controlling the request for consent
- Knowing - Intuiting the loss - knowing before the official diagnosis that all hope was goneAccepting the diagnosis by considering the alternatives - or knowing what the alternatives were like
- Protected from distressing circumstance by the staff
- Needing to remain by loved one side - valuing the freedom of access to loved one
- Valuing the support and compassion given by staff throughout the waiting - the process
- Guided through the experience by staff - informed about what to expect with the procedure
- Limit to the capacity to give
- Waiting and watch the care given to loved one throughout the process
- Waiting and watching the staff struggling to maintain the body throughout the process and the waiting - witnessing the lack of hope and the loss of life - helped with accepting the diagnosis
- Valuing the care and respect given to love one through out the process
- Needing to hold and touch and be with loved one - spend private time alone with them for goodbyes
- Regretting the last memory of loved one - the deterioration of the body due to the waiting
- Surrounded by sorrow and grief at the loss - Struggling to survive the aftermath
- Struggling to survive the aftermath - maintain the memory and love of
- Knowing - accepting the diagnosis because totally involved
- Sharing the sorrow - valuing the freedom in display of emotions
- Valuing - gaining great solace and emotional repreave from hearing about the outcome of donation
- Disappointed with the lack of communication from recipients and the gatekeeping/ barriers mentality of the transplant coordinators
- Valuing - gaining great emotional repreave through contact and communicating with recipients
- Knowing - seeking answers to many unanswered questions that surface months after the acute experience