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Death Rights: Hearing the Voices of Older Women in the Voluntary Euthanasia Debate

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Date

Declaration on Ethics

The research presented and reported in this thesis was conducted within the guidelines for research ethics outlined in the *National Statement on Ethics Conduct in Research Involving Human (1999)*, the *Joint NHMRC/AVCC Statement and Guidelines on Research (1997),* the *James Cook University Policy on Experimentation Ethics*, *Standard Practices and Guidelines* (2001), and the *James Cook University Statement and Guidelines on Research Practice* (2001). The proposed research methodology received clearance from the James Cook University Experimentation Ethics Review Committee (approval number H1504).

Madge Sceriha Date

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And finally, in loving memory of my partner, Evan and my sister, Jo, whose dying has taught me so much.

Abstract

This thesis explores the opinions of older women about end of life issues with a particular focus on whether voluntary euthanasia and physician assisted suicide should be accessible as options for the terminally ill. It describes, and critically reflects upon, the opinions and experiences of 12 older women from the University of the Third Age (U3A), an organization for older people here in Townsville in North Queensland. These women had responded to a letter from me, published in the local U3A Newsletter, in which I had invited women members interested to participate in this research to contact me to arrange an interview.

My interest to hear the voices of older women in this debate emerged heuristically as I reflected upon my personal experience as an older woman who had felt helpless and ignorant when confronted by my terminally ill partner’s suffering. Many questions had arisen for me about why there was no way he could have accessed assistance to die as his condition worsened. This interest grew as I read widely about voluntary euthanasia and was reinforced by the publicity surrounding a radicalised voluntary euthanasia lobby and the suicides of two older women supporters of the voluntary euthanasia movement. I pondered opposing viewpoints also, especially those which predicted older women would be among the most vulnerable to the ‘slippery slope’ consequences which opponents believed would follow the legalising of voluntary euthanasia. I wondered if other older women were questioning as I was and how to encourage more widespread community conversations about these controversial issues. I decided to inquire further and this thesis is the outcome of that inquiry.

I used a guided interview schedule based on broad areas of interest around end of life challenges which encouraged a conversational approach to the purpose in hand, and allowed other relevant ideas and issues to emerge which may not have arisen otherwise. I applied the principles of theory triangulation to the analytic process as an heuristic tool. This involved embracing feminist standpoint theory from a perspective not unlike post modern feminism, as well as utilising the principles of a broadly based critical tradition to engage with post modern thinking. In this way I was able to acknowledge the importance of subjectivity, but from a perspective in which the individual is perceived as being socially located in complex power relations and structural divisions (Hirschmann, 2004; Thompson, 2000; Young 1990). At the end of each of these chapters I have critically reflected on aspects of the socio-cultural and political context within which the participants opinions have been formed to highlight the significance of the personal-political nexus in that process. This critically reflective approach allowed me, as the researcher and as participant-partner, to add my voice to the analytic process as a feminist, an older woman, a woman with a disability and an activist in all these three areas of interest.

The findings have been reported as thematic clusters under the chapter headings: Older Women Speak Out: About Death and Dying, About Voluntary Euthanasia and About Quality of Life. It appeared that, while death was not feared, the dying process was a more daunting prospect, especially if it was likely to involve a protracted period of decline and deterioration. Few of the participants had any experience with palliative care and, those who did, were disappointed that it had not lived up to their expectations. Most adamantly rejected the prospect of admission to a nursing home and, though several speculated that suicide may be their only alternative, most hoped they would be able to remain living independently in their own homes, with support if necessary, till they died.

The concepts which emerged in the findings chapters as the critical reflective process unfolded, appeared to cluster with the concept of ‘ethics of care’. Some feminists,, including feminists within the disability movement, advocate working with ethics of care from within a political rather than a psychological framework and, as a consequence, to locate this important ethical issue within the social domain (McLaughlin, 2003; Sevenhuijsen, 1998). This perspective informs the final chapter in which I take the critically reflective process forward to vision a different future in which ethics of care understandings about the interdependencies between people are given full scope. I propose tentative strategies to implement this at grassroots, professional practice and policy development levels.

These strategies for change include exploring opportunities for alliances to be negotiated between groups which have interests in common around social care provision and the protection of the rights of vulnerable people. Such alliances are particularly relevant in the light of what has been identified as a health care crisis. Locating care in the social domain challenges the privileged position of medicine as the current model of practice but not in a way which denies the importance of medicine in end of life care. Both are vital to good quality of care which, ethics of care feminists identify, is central to social functioning. This is as important at the end of life as at any other time to ensure a holistic approach to end of life management

centres on the well being of the person who is dying, is sensitive to that person’s right to be heard and respects her/his wishes. This is a process which has been likened to a ‘midwifing’ through the dying process and, making the hard choices which those who seek an easeful end request.

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Chapter One: Introduction

The Origins of the Study

This thesis had its genesis in the disquiet I felt about my husband's end of life care and a lingering feeling I found difficult to shake off that I had somehow let him down. He had talked of suicide, tentatively on one occasion and guiltily on another but each time, I had diverted him from pursuing such thoughts in any depth. I was fearful of where such talk might lead although not sure what I feared exactly - perhaps that he might fail and exacerbate the devastation to which his body was succumbing; perhaps of the stigma which attaches to suicide; perhaps of imagined legal and financial consequences. Avoidance was an effective strategy then but, as I came to reflect later, could not protect me from my memories and an awareness that, if he had successfully suicided, he would have been spared the suffering of those last hours of consciousness when his disintegrating insides could no longer be contained. Even in his final drug induced coma there was only a brief period of quiet before hours of laboured breathing suddenly ceased and he was at peace.

Palliative medicine and the competent, compassionate medical care he had received from the nurses who came to our home had not been enough to alleviate his pain and suffering, and the good dying experience I had understood palliative care could offer did not happen for us. Each day of that experience had brought its unique demands and, although there were precious moments of closeness which transcended the awfulness of what was happening, it was difficult not to wish he could be freed from the ravages of this illness. It was difficult too, not to compare our helplessness when confronted by his suffering, with how differently we had dealt with the suffering of our beloved dog when the vet advised us it was time to let him go. In that situation we, his human family, had held him close as he made his final exit peacefully, painlessly and swiftly within seconds of receiving that last lethal injection.

I seemed unable to argue this with the doctor at the time or to question anything about the medical model, which was the way I later came to think of the care regime we had been under. This was a model of care which was treatment rather than patient focused, often patronised us when we raised concerns and left me feeling intimidated and almost fearful that asking questions might threaten our relationship with the doctor who seemed to hold all the cards. However fanciful this may seem, that sense of powerlessness and vulnerability was very real for me at the time. It was only later, as I began my new life as a single woman, and seriously reflected on the whole episode, that I became aware of a deep sense of outrage. I realised that the assertive woman I had learned to be over the past thirty years of identifying as a feminist had, for a time, been replaced by an unquestioning automaton overwhelmed by the situation, my fears and the reality of death and grief.

I knew that my sadness and despair at losing my life partner of forty years and the outrage that had come in its place were quite normal grief reactions. But it also seemed to me that, while grief explained some of my vulnerability and sense of powerlessness, there had been much about what had happened that exacerbated those feelings.

As my questing mind sought answers, a seemingly synchronistic sequence of events occurred. I became aware of the media attention a radicalised voluntary euthanasia lobby was attracting here in Australia and, when Philip Nitschke, the director of the national voluntary euthanasia organization, Exit Australia (as it was known then), came to Townsville to address a public meeting and conduct workshops, I decided to attend both. Soon afterwards, Queensland woman, Nancy Crick, attracted widespread media attention for her very vocal and passionate advocacy for voluntary euthanasia in the lead up to and following her suicide.

Heuristic Research Beginnings

In the process of negotiating this *"liminal phase of* (my*) experience…the betwixt and between*" (Denzin, 2001: 39) terrain of emerging awareness and understanding, I found I was struggling to relate my personal disquiet and subsequent anger about the circumstances of my husband's death with the very publicly divisive and fiercely contested issues raised by protagonists in the voluntary euthanasia debate. I found that my interest in and knowledge about voluntary euthanasia were changing the direction of my life as I reflected more on where, and/or whether, voluntary euthanasia had a place in end of life management generally. I discovered there were many in the disability movement who held opposing views (Swain, French and Cameron, 2003; Parsons and Newell, 1996) and that some feminist voices were also raising concerns about the bioethical implications of any change to the status quo (Wolf, 1996).

My husband’s death had been a life changing event for me but the full extent of this epiphany was more fully realised with my decision to explore the voluntary euthanasia controversy, and other end of life concerns, with other older women like myself as a formal research project. My research approach had elements of verification and corroboration but more particularly it has been heuristic, that is, an approach which has encouraged me, as the researcher, to embrace the process of discovery and to use methods which enabled the investigation to evolve beyond what had emerged from the data (Moustakas, 1981). In this I have relied heavily on critical reflection and the exploration of a range of literature streams which, while totally relevant to the themes I was identifying in my data analysis, nevertheless enabled unanticipated conceptual links to emerge. The research process has been a very challenging and absorbing journey of discovery about myself, the issues and the social, economic and political significance of these important questions about end of life care.

Theoretical and Socio-political Context of the Research Process

This research is informed from a feminist perspective which identifies the importance of hearing women’s voices as they describe and reflect upon the circumstances of their lives in a society which, despite more that thirty years of second-wave feminist activism, has not overcome the impact of sexist-ageist oppression on older women’s access to power and privilege (Adamson, 1996; Arber & Ginn, 1995). It is from within this reality that concerned feminist bio-ethicists have warned against the legalising of voluntary euthanasia. They argue that older women are likely to be vulnerable to pressure to be self-sacrificing to avoid being a burden on society or worse, to become victims of the ‘slippery slope’ effect in which non-voluntary euthanasia insidiously assumes credibility and acceptability as a legitimate strategy in a resource poor, demand heavy, system of care provision (Wolf, 1996).

These concerns assume a more urgent relevancy from a feminist standpoint given current demographic projections which suggest that older women’s vulnerability on a range of socio-economic indicators is likely to continue into the future. It is also projected that women are more likely to outlive their male cohorts which suggests that the disadvantaged and vulnerable old person will have a female face (AIHW, 2007). How much older women are aware that they have a vested interest in raising their voices in any debate about their position in terms of these and other end of life issues is, however, open to question in a societal climate more attuned to staving off such conversations.

This silence is particularly evident when the conversation turns to dying and death (McNamara, 2001; Griffin, 2000; Cline, 1995). Dying at home was common in Australia prior to World War 2 and brought more people in touch with the realities of the experience and its management as a natural part of the life cycle. These days it is more likely for dying to be seen as *"… the final illness"* (Kellehear, 2000: 7) and, therefore, a health issue best dealt with in the hospital setting where, with sophisticated treatment technologies, death may be held at bay for as long as possible. This medicalising of death also tends to privatise it because it is *"… hidden from public view and becomes a technical matter to be dealt with by experts*" (McNamara, 2001: 7).

That there are challenges to the undisputed authority of this expert intervention is nowhere more evident than in the widespread support for voluntary euthanasia which has been reported by national opinion pollsters over recent years (Nitschke & Stewart, 2005; Cosic, 2003; McNamara, 2001). However, while voluntary euthanasia is only one aspect of resistance evident in the complex power dynamics surrounding terminal care, it is so emotively divisive it obscures other areas of contention. As a consequence, the tendency for arguments in support of voluntary euthanasia to be construed as arguments against palliative care, diverts attention from what is happening in the field of palliation itself - its under-resourcing on the one hand and, what is seemingly a move away from the social model its original ethos embraced, to a medical model more attuned to a hospital than a hospice environment (Magnusson, 2002; McNamara, 2001).

An important aspect of the ageing population phenomenon has been the impact post retirement 'third agers' have had on the way age is being reconstructed and construed. These changes have resulted in a blurring of age specific role transitions and the cultivation of an ideal of agelessness. Though such an ideal is seductive it is also deceptive because *"(t)o assert agelessness is not to challenge ageism but to internalise it"* (Twigg, 2006: 49). These myths of agelessness tend, therefore, to exacerbate the existential challenges of advancing years, especially as increasing frailty and/or disability mark the arrival of fourth age dependence and possible admission to residential care. Residential care is another domain in which the medicalising and privatising of dying prevails, hidden away, often even from the residents themselves. Focus on the body during this period of protracted decline, debilitation and the ever present possibility of loss of control over all bodily functions, is the dominant concern of care provision, leaving little space for attention to the subjective reality of dying. It is a focus, moreover, which feminist thinkers have identified is refracted through a gendered lens and fails to detect the injustice underlying care which is of questionable quality (Twigg, 2006; Harper, 1997).

Thesis Structure

This introductory chapter has set the scene for the thesis by identifying the confluence of experiences in my life which led me to question the place of voluntary euthanasia in end of life options for the terminally ill. I explained how this study then evolved to become an heuristic journey of exploration and discovery. Finally I outlined relevant socio-political and cultural features of the society within which the date was sourced to contextualise what follows.

The second chapter provides a review of the literature pertinent to this study. In it I contextualised the controversial and contradictory nature of the debate about voluntary euthanasia. Aspects of the experience of dying and death in contemporary Australian society which have particular significance in the voluntary euthanasia debate were then introduced. This opened the way for consideration of the complexity of the arguments for and against legalising voluntary euthanasia, and projected some of the challenges that lay ahead as the debate continues.

Chapter three outlines the exploratory research process and the methods I chose as relevant to the research aims. It describes working within a feminist framework and offers an explanation of the theoretical determinants of the research design decisions which shaped the data analysis and the critically reflexive discursive process of interpretative interaction from which the findings chapters have evolved. The research limitations of an exploratory study like this were considered as was the pragmatic value of its explanatory power in generating ideas for practice and activism.

Chapters four, five and six detail the findings of the analytic process and the thematic clusters which emerged. In chapter four the focus is on how these older women spoke out about death and dying, in chapter five on how they spoke out about voluntary euthanasia and in chapter six on how they spoke out about quality of life issues. The critically reflexive discursive process of interpretative interaction through which each of the thematic clusters evolved appears as the last section of each of these findings chapters.

The final chapter takes this critically reflexive process further to develop relevant concluding observations and to propose strategies for practice and activism. These proposals are based on what emerged as an urgent need to engage our ageing population, the majority of whom it is projected will continue to be women, in meaningful conversations about end of life management decisions.

Chapter Two: Review of the Literature

Controversy and Contradiction

Few subjects have polarised public opinion in Australia more than voluntary euthanasia (VE) and, because the increasingly radicalised VE movement has been so widely reported upon in the media over recent years, few would have escaped hearing about the death by suicide of Queensland VE advocate Nancy Crick in May, 2002. Nancy took her life under circumstances which challenged the legal system in this state (Queensland) in a way which has only partially been resolved (Syme, 2008; Nitschke & Stewart, 2005; Tulloch, 2005). That challenge involved determining if her suicide was assisted or not for, while it is not illegal to commit suicide, it is illegal to be assisted to do so (Tulloch, 2005; Magnusson, 2002). Nancy had invited twenty-one people to be with her when she died and had been very publicly supported leading up to the time of her death by VE crusader, Dr Philip Nitschke. It was only after two years that those present were told no further action would be taken, but it was not a decision made by a court which leaves the questions the case raised still shrouded in uncertainty (Syme, 2008; Nitschke & Stewart, 2005).

This case was very controversial for more than its medico-legal implications, however, because it raised complex questions about older women and their alleged vulnerability to exploitation by the VE lobby. Nancy Crick became a prime example for this argument despite her insistence, to the end, that her support for VE was an informed choice, made freely. There has been little chance of her views being taken seriously though, because once it was found that at the time of her death she was in remission from cancer, she became the target for widespread and vituperative criticism from the anti-VE movement and from many within the media. She was negatively stereotyped as a sad, lonely, depressed old woman whose death was unnecessary and unforgivable, and should be condemned (Cosic, 2003; Bolt, 2002; Mudge, 2002).

The subsequent deaths by suicide of other older Australians who publicly expressed their support for the VE movement, and for legislative change to allow the terminally ill access to assistance to die, have been met with similar criticism whether they were terminally ill or not (Allison, 2002; Bolt, 2002). Their determined stance as pioneers in the struggle to challenge the status quo in our ‘death defying’, ‘death denying’ society has undoubtedly fuelled the VE debate (Smith, 2000: 303).

The furore about voluntary euthanasia has also drawn more attention to what is happening in palliative care because it is promoted by opponents of VE as the appropriate, as well as the legal, choice for the terminally ill (McNamara, 2001). European perspectives on the ethics of palliative care have, however, pushed the boundaries of the debate to allow open discussion of VE as a complementary option rather than a competitive one, which is the way it is currently presented (ten Have & Clark, 2002). Two prominent American medical specialists, Tom Preston (2006) and Timothy Quill (1996), and Australian urological surgeon, Rodney Syme (2008), have taken a similar approach in advocating for acceptance of what has come to be known as, patient-directed dying. They are also adamant that good palliative care is a vital element in end of life care but, they argue, it is sometimes not enough.

Rodney Syme has very deliberately challenged the law by making candid, public statements about the many people he has assisted to die over the past thirty years but, there has been no official response to his revelations several months after the publication of his book *A Good Death* (2008). Syme's provocative action may prove to be a significant development, not only in the VE debate, but also in drawing attention to other problems in palliative care than its adequacy in relieving pain and suffering. That is because, however appropriate good palliative care might be as a viable option, accessing it is presently a problem in many parts of Australia. It has been described as *"… a very low profile, small area of health provision …"* (Smith, 2000: 307), and one that is subject to political infighting and fears of medicalisation as demand for it grows. This implies that the provision of palliative care is likely to increasingly occur in mainstream hospital systems, where medical power prevails and, it is believed, will inevitably pose a threat to the multi-disciplinary ethos of palliative care (McNamara, 2001; Smith, 2000).

As the VE debate escalates it is becoming increasingly obvious that there are many contentious issues to be challenged and that if we, as responsible citizens, are to contribute in a meaningful way to that debate, we need to become more informed about the issues central to that debate.

Dying and Death

Sociologist, Beverley McNamara (2001), points out that death, far from being the 'great leveller', all too often aggravates entrenched inequalities in our society. Those who have known greater agency and privilege in their lives are likely to be more aware and feel in greater control of what is happening to them. It could be argued that women like Nancy Crick and the others who have also taken their lives and been outspoken about their belief in and support for VE, are examples of this agency in action. It seems from what they have said, that it was not fear of the dying process which motivated them to suicide but rather, fear of living when they had reached a point where life was too miserable, distressing, painful or otherwise intolerable, and where they would no longer be able to take action for themselves. They were though, raising issues about dying which are often hidden away from public view in hospitals, hospice and nursing home settings or, as is not uncommon these days, in private homes behind closed doors (McNamara, 2001; Nyatanga, 2001).

McNamara (ibid) talks about this as the privatising of death. Many people are uncomfortable talking about death and dying, and perhaps because of this unfamiliarity, efforts to demystify the process have had variously successful outcomes. Elizabeth Kubler-Ross' seminal research into loss and grief and the founding of the hospice movement by Dame Cecily Saunders, which both occurred in the late 1960s, have laid the foundations of present day developments in these fields of study (McNamara, 2001). And while care of the terminally ill has continued to be perceived as the preserve of palliative care, its holistic ethos, as suggested previously, is under threat of falling victim to *"… budget driven managerialism* … (and the privileging of) *easily measurable service outcomes …* (over) *less tangible relationship-driven or alternative user-defined measures of quality*" (Holloway, 2007: 24).

In the years since Kubler-Ross opened the way to better understanding of grief and loss, there have been exciting advances in our knowledge about the personal, cultural and structural components of the grieving process and, we have also been encouraged to appreciate the multi-faceted aspects of its origins and consequences (Leming & Dickinson, 2007; Thompson, 2002). For all the information, however, free and open discussion about dying and death is far from common, especially about one's own death (Nyatanga, 2001).

The voice of the VE lobby has sounded a discordant note, therefore, with its focus on dying and its insistence that the terminally ill be afforded the right to access assistance to die should their level of pain and suffering become intolerable. They argue that the promise of such assistance would be like an insurance against despair and the prospect of premature suicide, and point out, somewhat paradoxically, that the dying person may never choose to access such assistance if they found they were able to cope with what lay ahead. The oppositional voice, however, counters with the claim that, far from being a possible insurance against premature death, legalised access to assistance would end up becoming a ‘slippery slope’ to abuse and misuse precipitating, rather than postponing deaths (Leming & Dickinson, 2007; Tulloch, 2005; McNamara, 2001). Thus the right to make a choice voluntarily could, all too easily, become a non-voluntary imposition, particularly if resources are scarce and bewildered, powerless and isolated old people are perceived as expendable.

Supporters of VE are typically elderly (Nitschke & Stewart, 2005) which is not surprising when studies consistently show that the older we get, the more likely we are to think about death and to make preparations for it (Holloway, 2007). This acceptance of the inevitability of death does not preclude wide ranging concerns about the dying process, especially about becoming a burden to family and/or facing the prospect of an undignified and painful prelude to death. And there is still all too little known about how the elderly cope with the existential challenges of confronting impending death and any unfinished business from having lived a long life (ibid).

For elderly supporters of voluntary euthanasia who fear they will not live long enough to witness any change in the law, therefore, the activities of organisations like Philip Nitschke’s Exit International have a very pragmatic appeal. That is because they offer do-it-yourself information about suicide (Nitschke & Stewart, 2006). *The Peaceful Pill Handbook* (2006) (banned from sale in Australia) was written to provide this information because, the authors say, they want to prevent people making unnecessary, and unwanted mistakes when it is their right to make the choice to suicide. The number of older people among suicide deaths in Australia, Britain and the US is reported as disproportionately high which is worrying, especially as it is understood this has more to do with ageist marginalisation and structural dependency than any diagnosis of terminal illness (Holloway, 2007).

The oldest old, the fourth agers, as they are becoming more widely thought of (Twigg, 2006), have few role models to guide their passage through this unknown territory at the end of a very long life and, nor have their carers. Dying in old age seems the most timely of deaths but, the protracted nature of the dying phase, when it is characterised by fourth age frailty and/or disability, presents dilemmas and complexities which require attention to a different end of life care than we are familiar with in palliative care. However, we may find that the approach may turn out to be not totally dissimilar (Hudson & Richmond, 1998). The way this evolves, moreover, will need to take cognizance of the fact that *"… the experience of ageing is gendered. More women than men live to late life and the stigmatised and oppressive images of the aged female body stand in contrast to the socio-cultural value placed on bodies which are young, male, able-bodied and* heterosexual" (Cameron & McDermott, 2007: 167-170). The frail older woman burdened by the stigma of ageist-sexism, racism and/or ableism is also, very possibly, poor (ibid), characteristics previously identified as precursors of suicide in the vulnerable elderly.

Voluntary Euthanasia – No Simplistic Solutions

Euthanasia policy as it stands today in our society is not about a choice between no euthanasia on the one hand and making it legal on the other, it is rather, about *"… a choice between driving it underground and seeking to make it visible"* (Magnusson, 2002: 263). The research which has highlighted this reality and introduced the concept of the 'euthanasia underground' into the debate was focused on people with AIDS, and their carers, but the issues it raised are relevant in the broader context, particularly what can go horribly wrong in an unregulated environment (ibid). The research also challenges the perception that euthanasia is an issue of concern only to the elderly and infirm and, by exposing it as a reality about which only the extent is unknown, it challenges the effectiveness of the law as it currently stands. Fear of legal repercussions works more to inhibit free discussion about assistance to die and end of life decision making generally rather than to prevent people seeking and/or providing that assistance. Consequently, misinformation and uncertainty about safe practices abound which increases the chances of botched attempts but does nothing to stem dangerous and illicit practices (ibid) This reality tends to cast the 'slippery slope' argument in a different light insofar as prohibition has not protected the vulnerable nor stopped the illicit practice.

The situation is reminiscent of the 'backyard' abortion tragedies of not so long ago. Syme (2008) refers to the two tier system of access which prevailed in those days when safe and clean medical abortion was procurable for those with the money to seek it out, but not for others. He speculates that the situation could be analogous today but that knowledge and connections, rather than money, will afford some access to assistance leaving the rest to take their chances.

Invoking sanctity of life prohibitions against killing has not proven any more effective in curbing breaches of the law as it currently stands. The concept of the doctrine of the sanctity of life in its absolute, religious sense has traditionally held precedence over quality of life concerns, regardless of the degree of suffering involved (Leming & Dickinson, 2007; Humphry & Wickett, 1986) but has been increasingly challenged as a more secularised, better educated and ageing population confronts its future (Magnuson, 2002). The VE movement reflects this shift in emphasis but provides a different interpretation. They suggest that it is respect for the sanctity of life which underpins the actions of a doctor who responds with compassion to a request from a dying person for assistance to die, by enabling them to achieve a peaceful, gentle death rather than condemning them to continue to endure intolerable suffering (Syme, 2008; Battin, 2005).

Religious teachings which imbue suffering with redemptive value have also yielded somewhat over the years. Compassionate management of pain is now more widely acknowledged as a moral responsibility as long as it does not directly cause death, a position which is evidenced in the Catholic Church's embrace of the Principle of Double Effect as a morally acceptable end of life practice (Battin, 2005). This principle *"… provides that if the doctor's purpose in administering potentially lethal drugs to a terminally ill patient is to relieve pain and distress, such treatment will be lawful, even if it has the incidental or secondary effect of shortening life"* (Magnusson, 2002: 25). Thus it is the doctor's intention rather than the outcome which gives this practice its moral and legal acceptability. The VE argument is that this principle, *"… and the practice of terminal sedation which it justifies"* (Cosic, 2003: 190), does not require the dying person's agreement which is a violation of their right to choose (Tulloch, 2005), and ethically questionable given the opinion of bio-ethicist, Helga Kuhse, who is adamant that patient consent and not the doctor's intentions should be the proper focus in end of life decisions (Parsons & Newell, 1996). And in the opinion of Philip Nitschke, the principle of double effect is virtually slow euthanasia which he refers to as *"… a doctor's loophole"* (Nitschke & Stewart, 2005: 150).

There has been much discussion among doctors about whether a distinction can be made between 'killing' and, 'letting die'. If there could, it would provide an option for those doctors who want to have something to offer to dying patients requesting assistance to die. The more widely accepted, and increasingly legally recognized right for a patient to refuse treatment and/or to have this decision officially documented in an Advanced Health Directive, is a way in which individual autonomy can be respected about end of life management (Syme, 2008). But withholding or withdrawing treatment without such permission, remains within the grey areas of moral and legal legitimacy (Warnock & Macdonald, 2008; Battin, 2005; Tulloch, 2005).

A high level of public support for legislative change has been consistently reported in national opinion poll results over many years and, even within the medical profession, support is not insubstantial (Nitschke & Stewart, 2005; Magnusson, 2002). This hasn't been reflected in the response from parliamentarians, however. The Northern Territory's Rights of the Terminally Ill Act, brought into law in 1996, ensured that jurisdiction the reputation of being the first in the world to legalise voluntary euthanasia but, as it was quickly overthrown the next year by the Federal Parliament on a conscience vote, it gave little hope that change would come easily through legislative channels.

The most recent attempt to challenge this resistance has come with the introduction of *The Medical Treatment (Physician-Assisted Dying) Bill 2008* into the Victorian Parliament and the *Euthanasia Laws (Repeal) Bill 2008* to come before the Senate in the near future (http://www.vesq.org.au/). There is no guarantee that these bills will be any more successful than previous attempts have been to change the law. The Victorian bill is modelled on the Oregon legislation which has been in effect for the past ten years with no reported abuse of the process. It seems also that palliative care provisions have improved. This is reassuring evidence which the promoter of the bill hope will convince the parliament to pass it into law (Syme, 2008).

The momentum for change has continued unabated despite past legislative setbacks and more people are becoming aware of the diversity of issues churned up in its wake. Clearly there are many grey areas, both legally and morally, as matters stand in the VE debate. Without legislation change, however, current practices of omission and commission will continue into the future unmonitored, and virtually invisible, as they are now (Syme, 2008; Magnusson, 2002).

The Future, Ready or Not

There is a degree of urgency about engaging with these issues in a meaningful way if, as a society, we are to take a more responsible attitude to what is already upon us with a burgeoning population of older people and no precedents for managing such exigencies. If we project on-going and ever more sophisticated medical and other technological development to continue, more of the population is likely to live even longer, and there is even more reason to be concerned (Warnock & Macdonald, 2008). The social consequences of increasing numbers of frail and or disabled dependents have already begun to be felt as inadequately resourced social care provisions fail to meet the needs of many of the elderly in their care (Holloway, 2007; Kellehear, 2007; Twigg, 2006).

The value our society places on being able to take care of one's self, weighs heavily on those who are no longer able to meet that goal. And, even though dependency on others is an experience which can happen to anyone, anytime through accident or illness, there is a difference in the way such dependency in the elderly is perceived, not least by themselves (Twigg, 2006). Questions about how dependency can and should be understood and managed continue to be core concerns in disability rights politics. The social model of disability which emerged in the latter decades of last century has challenged thinking and actions which stigmatise, marginalise and creates barriers to inclusion which are as impenetrable as any physical barriers might be. Disability politics is evolving further as the diversity of its population demands inclusion within its own ranks as well as within the wider social environment. Among the voices being heard are those which identify the importance of the nature of impairment in understanding the complex dynamics of the experience of disability (Swain, French & Cameron, 2003; Thomas, 1999). An ageing population has much to learn from the disability movement and other identity-based movements like feminism. For example, collecting and using personal narratives to expose the extent and diversity of experience, and the political impact of being 'different' (Twigg, 2006).

There are many within the disability movement and within feminism who have serious reservations about voluntary euthanasia (George, 2007; Meekosha, 2001; Wolf, 1996). Their concerns are, that any violation of the rights of vulnerable people to adequate and appropriate care which may underpin requests for assistance to die, may go unrecognised and be ignored. They call for improvement in the health, social and economic support systems which all too often fail to meet the needs of vulnerable and powerless people rather than providing them with legal means to end their lives other than suicide. The question of choice which features in VE discourse, may be a non-choice for them or the catalyst for women in particular, who are likely to live well into old age and who are socialised to altruism and self sacrifice, to 'choose' not to be a burden on family and society (George; 2007). George speaks about the danger of legislative change which permits VE because women are more likely to choose *that* approach than physician assisted suicide or, as it is also known, patient directed dying. This may be an important conclusion as her research indicates, but most current proposals for law change are (like the Victorian bill in process), modelled on the Oregon legislation which permits only strictly controlled self administered, doctor prescribed, lethal medication. If the Victorian bill is passed into law, it will provide an opportunity to test George's findings.

Language too is a feature of the confusion, uncertainty and challenge surrounding how the future will unfold. The term euthanasia is often used interchangeably with assisted suicide. It is not always clear if reference is being made to voluntary active euthanasia, where the doctor acts deliberately to cause death at the patient's request; or voluntary passive euthanasia, where at the patient's request treatment is suspended; or whether indeed it is a non-voluntary act or omission where the patient's wishes have not been considered (Tulloch, 2005). It has been argued also that the way the discussion about VE is framed makes a difference to the way it is perceived. This argument suggests that the use of the description 'physician assisted suicide' is a much more emotionally charged, value laden, politically significant alternative to 'patient directed dying' because the former shifts the emphasis from a patient-centred care focus to place attention on the actions of the physician. This argument also *"… questions why the framing of this topic has centred on principles of autonomy, paternalism, and beneficence as well as on slippery slope hypotheticals, instead of discussing care giving, compassion, responding to needs, interpersonal relationships, dignity, empowerment, and love"* (Tucker & Steele, 2007: 319).

There is speculation that an extended lifespan made possible by advances in biomedicine and biotechnology will raise even more ethical dilemmas into the future and that choosing the right time to die may be as big a challenge then, as seeking the right to die is for western society today (Battin, 2005). There are many issues which require urgent discussion, especially for those approaching their latter years, but this will not be an easy challenge to meet if the reluctance to engage with these issues continues. The ideas of researchers like Rosemary Clews (2005) who recommends using the narratives of seniors, their carers and professional helpers in formulating values-based policies for the future, might be one creative way to meet this challenge.

Chapter Three: Methodology

Introduction

The research process informing this thesis has evolved in a way which clearly reflects my commitment to feminist politics as this has been forged over the past three decades. In particular, it reflects my belief that listening to women's voices speaking out about their experiences of the personal-political nexus is important to validate them as individuals, and to contextualize those experiences within the broader socio-political and cultural milieu of their lives. I believe it is also necessary to explain my location as the researcher and the "*researcher's standpoint*" (Reinharz, 1992: 259) I have brought to this study and accordingly, I have prefaced discussion of the theoretical determinants and other research decisions that guided the direction this research journey has taken with that explanation (Kincheloe & McLaren, 1994; Reinharz, 1992; Young, 1990).

Consistent with the heuristic approach I have taken from the beginning of my interest in the research topic, this has been an exploratory study. I have, consequently, used methods which not only sought answers to the research question, but also provided opportunities for me to engage critically and reflectively with ideas arising from the interaction between myself, the woman being interviewed and the core issues being addressed where these were relevant to the direction of the inquiry overall (Kincheloe & McLaren, 1994; Janesick, 1994; Moustakas, 1981).

Research Goal

To explore older women's opinions about voluntary euthanasia as an end of life option for persons who are terminally ill.

Research Aims

- To identify older women's knowledge about and attitudes to death and dying.
- To identify their knowledge and attitude to voluntary euthanasia.
- To identify their knowledge about end of life options for the terminally ill including palliative care, Enduring Power of Attorney (EPOA) and Advance Health Directive (AHD) documentation.

- To validate older women's experience of and response to being an older woman in today's society.
- To validate older women's opinions and engage their *"… active engagement in the construction of data about their lives* (Reinhartz, 1992: 18).

Locating Myself as the Researcher

My feminist view of reality

It is my belief that, although the influence of second wave feminism - in tandem with the other social movements which emerged on the world stage in the 1960s - has had a transformative impact on the lives of women, claims that feminism is no longer a relevant politics represents a blinkered view of its liberatory vision. This is because the changes wrought by the complex dynamics of the transformative process have been orchestrated as much by the forces of oppression against which feminist and other social justice politics were pitted as by any activism inspired by those liberatory politics. Moreover, these changes have overwhelmingly and increasingly privileged the market driven economic philosophy of neo-liberalism and, in the process, have seemingly displaced social justice values with economic rationalist interpretations of the world, thereby giving ascendancy to individualism (Preston, 2006; McKnight, 2005).

It is an individualism which has, however, itself been transformed. The origins of individualism as "… a master idea of modernity" (Elliot & Lemert, 2006: 7), gave rise to the belief that the basis for a more meaningful, fulfilled life, was the free, autonomous individual working toward a more intimate knowledge of and relationship with the self, and from there, reaching out to form more and richer relationships with others. According to this scenario, the individual, though free and autonomous, had a sense of public responsibility and was involved in maintaining the integrity of the social fabric. This had been particularly evident as the pattern for social justice was being woven more intricately into that fabric by the efforts of feminists, and other social activists, who had challenged the way structural injustice and marginalisation privileged white, male dominated, heterosexual and able bodied world views (Elliot & Lemert, 2006; Preston, 2006).

The imprint of modernity's original mould is evident still, and entices belief that free, autonomous individuals who make the right choices can access the good life. But the mould is seemingly less deeply etched with beliefs about a common good; tending rather to project a view that those who have failed to achieve the good life only have themselves to blame. This new individualism reflects neo-liberal driven influences towards the privatisation of responsibility and *"… a shift from a politicised culture to a privatised culture* (Elliot & Lemert, 2006: 9). Pushed too far, individualism looses its potential to be *"… personally liberating and socially invigorating* … (becoming instead) … *personally isolating and socially fragmenting*" (Eckersley, 2004: 179).

This new individualism is the antithesis of the vision of personal and collective liberation which motivated me to become a feminist activist all those years ago, but its effects on that vision are what sustains my commitment to feminist activism still. It has been a frustrating and often dispiriting struggle to hold onto a belief in that vision when so many of the gains that had been made in providing women with real and socially just choices about the direction their lives could take have been eroded. Indeed Anne Summers has gone so far as to talk about the end of equality in her book of the same name in which she gives voice to the extent to which a depoliticised and privatised culture has impacted women's lives. Urging women to action once again, especially in speaking out about the reality of inequality in our lives, she reminds us that as individuals we do have the power to speak out, and that we should use it creatively in collaborative advocacy and collective organising to ensure equality is restored to Australia's socio-political agenda (Summers, 2003).

I am aware that, although I have been deeply influenced by my feminist consciousness and activist experiences for half my lifetime, I nonetheless, carry within my consciousness other influences from my pre-feminist existence. I am reminded of this when old patterns of non-assertive compliance with the dictates of authority rise insidiously and threaten to undermine my confidence, especially at times when I am vulnerable, or fear vulnerability. My earliest experiences of oppression date from those early years and again, I am reminded of this whenever I am confronted with the many challenges which living with a disability present. I was born with a disability and learned while still very young that negative and disempowering attitudes which stigmatise, and practices which marginalise, can often be more disabling than the impairment itself (Thomas, 1999; Morris, 1989). As I also now identify as an older woman, I am aware of the subtle - and not so subtle – ways in which negative attitudes to the ageing process can translate into and exacerbate practices which marginalise and/or often patronise older persons. My awareness of the gendered nature of the political significance of these other sources of disadvantage and oppressive disempowerment emerged as I added different filters to enhance the woman focused view of reality my feminist lens had initially provided (Arbor & Ginn, 1995; Young, 1990; Ford & Sinclair, 1987).

That woman focused feminist political awareness and activism did though, pre-figure my interest in and involvement with the disability movement and the concept of advocacy in the early 1980s, and my later particular connections with Women With Disability Australia (WWDA). It has since played a similar role in ensuring that I am now also an activist in older women's politics as a member of the Older Women's Network (OWN). These feminist based organisations provide their members with a voice as well as support and encouragement to become involved as self advocates, and to engage in group actions. They model strategies for action, mindful that such action is most effective when understood as an holistic concept which engages body, mind and spirit in practices which encourage participation and offer opportunities for the wit and wisdom of participants to be harnessed, as issues of concern to all are confronted. They are mindful also of the dynamics of power relations which affect them as women with varied needs and from diverse backgrounds within the socio-political and cultural context of twenty-first century Australia. This is especially relevant because in neo-liberal economic conceptualisations, older people and people with disabilities are widely perceived to be unproductive and, therefore, burdens on the public purse (Mathers, Vos & Stevenson, 1999).

In Interaction with the Participants

All these aspects of myself – feminist activist, woman with a disability and older woman – are reflected in the methodological approach I have taken. This was most obvious in my predisposition to identify with the participants as an older woman with interests in common about end of life management, a combination which lent itself to a relaxed, conversational style of interview situation. My working life experience as a counsellor and group worker was an advantage when it came to establishing rapport and facilitating discussion around the broad topic areas, although I had to ensure that I stayed mindful that this was a data collection encounter not a counselling session. This did not mean there were no occasions when tears flowed or some other emotion was present requiring acknowledgment, because the content which guided our conversations was bound to elicit sensitive memories and feelings. There were such occasions and they were dealt with respectfully and empathically as the situation dictated and in accordance with the requirements of the university ethics committee.

Overall the consensus of opinion was that the opportunity to discuss these issues was a valued experience and one which they were of one voice in suggesting could be of benefit to the wider community.

In Critically Reflective Discourse

My grounding in professional practice as a feminist counsellor-activist predisposed me to adopt a critically reflective approach throughout this thesis. This approach to understanding and knowledge building is generated by self-reflection, exploration of relevant theoretical and research evidence and the analysis of interactions *"… in order to analyse, resist and change constructed power relations, structures and ways of thinking"* (Fook, 1999: 202). My research journey began with critical reflection about my experience with end of life challenges, the outcome of which is represented in the background information presented in the preceding paragraphs. This was the self I brought to research design, data collection process and to the analysis.

It has been suggested that, from a hermeneutic perspective *"… we become a self through our relationship with the other* … (and that) *writing oneself into the research enhances authenticity* … (as we) *engage the self-other nexus* (in conversation) *to learn more about the other, to hear their voice*" (Ezzy, 2002: 155). From a hermeneutic perspective, this interactive process happens within the interpretative circle – the metaphorical descriptor for the theories and pre-existing interpretations of the world the researcher brings to the inquiry, which surrounds the process throughout, and which evolve and change as data collected and existential realities continually inform understanding (Ezzy, 2002; Denzin, 2001; Reason & Rowan, 1981).

Interaction in this sense is multi-layered: with the self, with the other and with the theoretical and relevant popular and research material resources which become the various data sources in the inquiry. Such an interpretative interactional approach is appropriate for the researcher interested *"… to examine the relationship between personal troubles … and the public policies and public institutions that have been created to address those troubles"* (Denzin, 2001: 2). This was consistent with my research aims and my belief that the issues lend themselves to the development of policies which encourage a discursive engagement with the issues as a community wide responsibility and an example of critical reflectivity writ large.

Theoretical Determinants

Feminist Framework

As a feminist doing this research, I was committed to ensuring gender was uppermost in my thinking at all stages of the research development and pivotal in the interpretative and critically reflective processes involved in my attempts to understand the dynamics of dominant discourses in the voluntary euthanasia debate.

This was a position consistent with a feminist methodology characterised as being *"… politically* ***for*** *women …* (having*) some grounding in women's* ***experiences****, and in how it* ***feels*** *to live in unjust gendered relations"* (emphasis in original, Ramazanoglu with Holland, 2002: 16); a methodology that could therefore also be characterised as embracing a feminist standpoint perspective (Ramazanoglu with Holland, 2002; Ezzy, 2002; McLaughlin, 2003).

In this sense, a feminist standpoint is more a *"…method of approaching life and politics, rather than a set of political conclusions about the oppression of women"* (Hirschmann, 2004: 319). It is a methodological strategy which acknowledges that, while there will be multiple feminist standpoints, their confluence has the potential to reveal different aspects of the bigger picture as *"…women speak their truth"* (Ramazanoglu with Holland, 2002: 64), and negotiate meaning as part of an on-going discursive process that is contextually and temporally located. The *"permanent partiality"* (Hirschmann, 2004: 322) of knowledge which is negotiated in this on-going way nevertheless has political significance given that, when groups come together *"… through common location within hierarchical power relations … patterns of oppression …* (can*) emerge from group based experience"* (McLaughlin, 2003: 65), and this knowledge can become a rallying point for social action to challenge the privileged power so revealed. This view gives feminist standpoint the appearance of a kind of *"postmodern feminism"* (Hirschmann, 2004: 323).

Postmodern thinking applied in this way can be a valuable conceptual tool for sharpening feminism's critical edge when it is applied to the process of uncovering the commonalities of political, economic and social taken for granted assumptions inherent in the diversity of gendered oppression which underlie and shape everyday experiences (Pease & Fook, 1999; Kincheloe & McLaren, 1994; Frazer & Lacey, 1993; Young, 1990). Furthermore, thinking like this which is aware of the multiple realities challenging the permanency and predictability of meaning construction (Ife, 2001), imposes an exciting, but also a daunting, responsibility on citizens in a society like ours which is often described as a pluralist democracy (Sevenhuijsen, 1998; Young, 1990). This is because it suggests there is a ‘partial permanence’ to meaning making as much as the ‘permanent partiality’ mentioned previously, which gives substance and continuity to core values and beliefs, but which allows for review and reinterpretation of those values and beliefs over time and as contexts change. Meaning construction is, therefore, a dynamic process in which we as citizens have a responsibility to be engaged because our lives will inevitably be affected by the outcome.

Realising that responsibility is, however, constrained, for although identifying meaning making as a process suggests that *how* we engage with contested issues is as important as the outcome, there are few formal mechanisms which encourage and enable such participation. Aspirations in Australian society today seem to be directed less toward an engaged and socially responsible citizenship and more toward the privatising of responsibility and an individualism which is socially fragmenting and politically disengaged (Eckersley, 2004).

It has been suggested that this is a product of the postmodern cultural condition in which hyper-reality - the ‘quasi-fictional places’ created as the electronic media in its rapidly multiplying incarnations and ever increasing representational forms - influences many *“… to trade community membership for a sense of pseudo-belonging to the mediascape”.* There they can find comfort in identifying with media personalities who model responses to, and thereby, cushion *“ … the emotional effects of the social vertigo”* emanating from information overload and over exposure to media created popular culture and its representation of what counts for ‘natural’ and ‘normal’ in a rapidly changing world (Kincheloe & McLaren, 1994: 142 -143).

The ubiquity of this same electronic media and its voracious appetite for contentious and contested issues which have the potential to boost ratings has, though, also been strategically harnessed by activists concerned to challenge the voices being privileged in any such debates, and to raise the profile of alternative voices, especially where matters of rights, ethics and injustice are involved. This has been particularly evident in the voluntary euthanasia debate where a radicalised voluntary euthanasia lobby has mounted a vigorous protest against the voices of those who currently dominate meaning making about this issue and who have been labelled the

“Unholy Trinity – Medicine, Law and the Church” – by Philip Nitschke, spokesperson for that lobby (Nitschke & Stewart, 2005: 68). This ‘Unholy Trinity’ is a powerful alliance which presents its case in terms of the universalist certainty of absolute truth, and in a way which rebuts the very idea that there is any basis for contest about interpretation (Nitschke & Stewart, 2005; Tulloch, 2005). Many cling to the comfort of such institutionalised authority finding reassurance in its continuing influence and ability to adapt to and find a place in hyper-reality territory.

I was interested to explore the context within which this issue was being so vituperatively contested because of my own experience of confusion and feelings of powerlessness when confronted by the reality of my ignorance about how my partner’s dying might have been handled differently. Furthermore, there was the almost total silence, withdrawal even, when I hesitantly, but desperately, raised the issue of helping him to die as his misery intensified. I have been guided in my exploratory endeavours by the insights which feminist thinking has brought to my understanding of the politics inherent in totalising world views like those attributed to the ‘Unholy Trinity’. That is, that when such views are presented as reflecting the natural order of things and *“innocent knowledge”* (Fook & Featherstone, 2000: 12), there is reason to question the neutrality and impartiality this suggests in terms of whose interests are being served by perpetuating those particular views. Where power is obscured under the guise of impartiality it can go unchallenged and perpetuate the potential for injustice inherent in hearing only the voice of the privileged (Young, 1990).

At the time of my husband’s dying, I heard only the echo of the voice of the ‘Unholy Trinity’ resounding against the wall of silence which greeted my effort to discuss what was happening. Though I felt the political significance then as a sense of powerlessness, it wasn’t till later when I became aware of the case being made by the voluntary euthanasia lobby, that I questioned the dynamics of power involved in end of life decision making and how that impacted on the lives of other older women like myself. In exploring how they might position themselves in this dynamic struggle, indeed whether they would identify it as a struggle at all, I was mindful that gender may not resonate for them as a source of oppression and disempowerment as it did for me.

Critical Perspectives

I decided that insights from a critical theoretical perspective could be useful in broadening the base of my data analysis to ensure I offered the opportunity for aspects other than gender to emerge from the data. I was especially drawn to a description of the *"… critical tradition* (defined) *very broadly and heuristically"* by Kincheloe and McLaren (1994: 139-140). Their definition includes reference to: the social and historical context of the power relations within which thinking and knowing is mediated; to the privileged power of certain groups over others in our society; to the perpetuation of that privileged power and its oppressive consequences when it is accepted as normal and natural and goes unchallenged; to the many faces of oppression; and also to the danger of focusing on only one of those faces at the expense of others because this *" … often elides the interconnections among them"* (ibid: 140). I believed this broad exposition of the 'critical tradition' to be compatible with the feminist philosophy which has guided my thinking throughout the course of this research journey in that it seeks to expose and confront injustice, it is overtly political and is guided by a vision of a fairer more just world.

Feminist thinker, Iris Marion Young, who has utilised a critical theoretical framework to explore injustice, argues for it to be understood in terms of two "*disabling constraints",* oppression and domination. She suggests these concepts overlap but that while most people in societies like ours are subject to some form of domination associated with hierarchical decision making structures, not everyone would identify as experiencing oppression. Oppression according to Young really names a family of conditions which she has divided into *"… five categories: exploitation*, *marginalisation, powerlessness, cultural imperialism and violence"* (Young, 1990: 39–40). Young describes this approach as *"pluralising"* (ibid: 63) the concept of oppression and suggests it accommodates both the diversity and the similarities within and between groups who identify as experiencing the effects of oppression. It also demonstrates how a critical theoretical perspective engages with issues of postmodernism insofar as it *"… recognises the importance of subjectivity but also recognises that each individual is 'socially located'"* (Thompson, 2000: 52) within the complex relations of power and privilege which inhere in structural divisions.

By providing a broader understanding of the way injustice is experienced and perpetuated than one based primarily on the redistribution of social goods, Young reminds us that any one individual may be privileged in one domain and oppressed in another. The potential for identification across a range of experiences which this opens up presents possibilities for alliances to be formed outside the usual boundedness of group affiliations. This is especially so where the structural mechanisms involved in the perpetuation of oppressive practices are being challenged in the name of social justice – *"power-with"* harnessed to resist *"power-over"* (Frazer & Lacey 1993: 195).

Applying a more broadly focused lens on data in this way is consistent with *"… theory triangulation … a term used to describe the use of multiple perspectives to interpret a single set of data …* (a strategy which) *is meant to be a heuristic tool for the researcher"* (Janesick, 1994: 215). It is also consistent with the model of an *"heuristic paradigm"* developed by Jim Poulter to explain the *"… many functional linkages … between various theories …* (which) *have yet to be formally defined"* (Poulter, 2005: 210) but which are used in reflective practice in social work situations. An heuristic methodological approach was the logical choice for an exploratory study such as this insofar as it involves *"… an inductive searching, insight-stimulating and synthesising … learning by immersion … process"* (Poulter, 2006: 334). Poulter talks about the goal of an heuristic approach as being *"… utility rather than certainty"* (ibid: 335) and, therefore, an approach which aims to make problems more manageable and to provide useful information).

Qualitative Research Decisions

Guided Interview Schedule

My purpose in using a guided interview schedule was twofold. Firstly, I sought to provide an environment sensitive to the possibility of power imbalances in the interaction between myself and the participants, and this process will be described in a subsequent section. Secondly, I came to each of my meetings with the participants with broad areas of interest to explore, and open ended questions designed to initiate discussion from which other questions would suggest themselves as the interview proceeded.

These broad topic areas were, on the one hand, central to the euthanasia debate current at the time the interviews were conducted (and relevant still in 2008). On the other hand, they would I believed, have the potential to make feminist politics real by offering these women the opportunity to reflect on their experiences of and opinions about those issues and to explore the psycho-socio-cultural and political influences embedded in those experiences.

The broad areas which follow were not necessarily covered in this order nor in the same breadth and depth in each interview situation. That was because the format allowed for flexibility in following the participant's lead into one or other area or into quite a different but related area of concern. In this way the emphasis most relevant to each participant was respected and acknowledged as important to the data pool.

- Attitudes toward death and dying;
- Opinions about voluntary euthanasia;
- Personal experiences of and knowledge about Palliative Care, Enduring Power of Attorney and Advance Health Directive documentation;
- Other end of life concerns;
- Major decision making challenges already faced and/or anticipated; and
- Experiences of being an older woman in today's society.

Participant Recruitment, Profile and Welfare Considerations

Recruitment

I was interested to hear the voices of older women because older women have featured prominently among advocates lobbying for legislative change in Australia and abroad to allow access to voluntary euthanasia for the terminally ill (Nitschke & Stewart, 2005; Tulloh, 2005; Cosic, 2003). At the same time, however, older women have also been identified as the most vulnerable to misuse of such legislation were it to be introduced (Wolf, 1996).

An invitation was extended to the women members of the local University of the Third Age (U3A) through their bimonthly newsletter asking for expressions of interest in participating in this research project (see Appendix 1). U3A membership is only open to persons who are 50 years of age and over and the majority of Townsville members are women. These women are for the most part from a white Anglo or European background and are representative of a wide range of socio-economic, cultural and political influences.

I asked those interested to contact me by phone, email or at my home address to make further arrangements. I was at that time a tutor with U3A and my contact details were accessible to members and I had no concerns about publishing this information in the newsletter. I indicated in my letter that I was interested to hear from both sides of the debate. I had to republish the letter (see Appendix 2) because the first attempt brought only half as many responses as I needed. The second attempt was more successful and overall 12 volunteers contacted me. Ten phoned for further information, one woman emailed me and another called at my home. They were all interested to proceed and I provided them with a letter (see Appendix 3), confirming our arrangements an Information Sheet (see Appendix 4) explaining the purpose of the research, the process I proposed to follow, how their confidentiality would be protected, how the data would be collected and what would happen to it after the analysis had been completed, and a copy of the Consent Form required by the James Cook University Ethics Committee (see Appendix 5).

Profile

The following table presents a broad demographic profile of the 12 participants which shows something of both the diversity and similarity of this small sample.

Table 1 - Broad Demographic Profile of Participants

Age	**Marital Status**			**Disability**		**Carer for terminally ill**			**Religious Affiliation**			**Education**			**Employment Pre-retirement**
	Married	**Divorced**	**Widowed**	**Self**	**Family Member**		**Migrant**	**Refugee**	**Christian**	**Agnostic**	**Atheist**	**Tertiary**	**Secondary**	**Primary**	
56-65	2	1	2	1	1	4		2	1	4		2	3		3 nursing 1 office
66-75	1	1	2	1	1	2	1	1		2	2	1	3		1 academic 1 office
76-85		1	1	1		1		1	1	1			1	1	1 office 1 home duties 1 misc
86-95			1	1						1				1	1 home duties
Total	**3**	**3**	**6**	**4**	**2**	**7**	**1**	**4**	**2**	**8**	**2**	**3**	**7**	**2**	

Welfare Considerations

The research design adhered to the ethical principles specified by the NHMRC and the AASW (I am a member of the latter). My ethical responsibility throughout all stages of the research process was, therefore, to acknowledge the rights, wishes and interests of participants, with special attention given to the inherent sensitivity of the broad subject areas included in the guided interview schedule.

Because participants were recruited through an open invitation to be involved in the research project, their participation was entirely voluntary and I believed it reasonable to assume they would be genuinely interested in sharing their views and experiences about end of life concerns, particularly voluntary euthanasia. I had indicated to each participant in the Information Sheet that the interviews would probably take approximately 2 hours, that I would like to tape record the interview and that they could choose a pseudonym if they wished which would be the name they were referred to in the interviews and in any reporting involving direct quotes from the interview. We negotiated mutually suitable times, dates and a venue in each instance where we would be uninterrupted.

Enough time was allocated at the beginning of the interview process to allow for introduction and preliminary arrangements to be concluded. The women were all very interested in the issues being raised and pleased to have the opportunity to contribute. All agreed for the tape recorder to be used and signed the Consent Form after I ensured they understood they could stop the interview at any time, ask not to have some things recorded and felt free to include ideas which may be relevant but which might not be covered in the broad areas I had identified.

It was important to me to ensure participant confidentiality concerns were addressed. I assured them, as an item on the Information Sheet and, verbally at the time of the interview, of the strict ethical requirements of the University Ethics Committee and invited them to raise any concerns they may have in this regard. All were satisfied with the arrangements I had made, namely, that no identifying information would be held with the data collected, that identifying information would be held separately and that all information would be held securely. The Consent Form reiterates the strict confidentially requirements of the University which was an added reassurance. The data will be retained in accordance with NHMRC guidelines in the secure location for at least five years after the research is complete.

I was aware that the subject matter to be covered during the interviews is sensitive and could elicit emotional and stressful responses. The research project had been identified as a Category 3 classification and it was my responsibility as the researcher to:

- Avoid the interview becoming a counselling session at the same time;
- To utilise my professional competence as a counsellor to closely and actively listen to and monitor the verbal and non-verbal responses and manage them responsibly;
- To have resources available to participants who may need to debrief or access other support; and
- To fully inform the participants in writing as well as verbally of how to access these resources.

I had confirmed with the resource persons chosen that they were willing to accept referrals from participants and I believe I fulfilled the professional responsibilities indicated.

There was time after each interview to effect appropriate closure and ensure that the participants were not left in any distress or confusion as a result of the interview process. In all instances this proved to be a time when participants engaged in thoughtful reflection on the process we had just been engaged in together. There was agreement that being able to talk about these issues freely and at length had been valuable, on the one hand as a way for them to have their voice heard, and on the other because it had stimulated interest in thinking more deeply about the issues covered.

The Interview Process

In our exploration of the broad areas of interest included in the guided interview schedule, there had indeed been opportunities to follow ideas and concerns which the participants had brought to the interview session. That allowed our sessions together to be *"interviewee oriented"* around the topic areas (Reinharz, 1992: 21) which, I believe reinforced my efforts to encourage an evenly balanced power relationship.

The interaction between myself and each of the participants would best be described as *"… partially structured personal conversations"* (Reinharz, 1992: 34) in which we related as peers seeking to understand more about our end of life concerns through dialogue focused on, and around, the broad areas I had identified. This was a natural progression from our initial contact and negotiations about the interview process and, was reinforced during the initial stages of our meeting together when the women gave demographic information and we trialled the recording system. Establishing rapport and beginning the process of listening beyond the answers for cues suggesting areas to probe in more depth at that stage, provided a relaxed, comfortable environment in which a trusting, conversational like, relationship between us could develop. It is within such a relationship that *"… a probe into experience …* (can take) *the representation of experience far beyond what is possible in an interview…. Indeed there is probing in a conversation, in-depth probing, but it is done in a situation of mutual trust, listening, and caring for the experience described by the other"* (Clandinin & Connelly, 1994: 422).

Data Analysis

The data was produced over an eight week period in the first half of 2003 and transcribed by myself in the weeks following the final conversation. At that time the process of formal analysis began although, preliminary discoveries made during the course of the data production and the subsequent transcription process had allowed several thematic possibilities to emerge. I took an heuristic approach to the data analysis similar to that attributed to Moustakas (cited in Janesick, 1994) which offered *"… room to use inductive analysis through five phases"* (ibid: 216).

The first phase, which involved ***immersion*** in the data, really began from the first data producing session, but it required all data to be transcribed and for a period of time to elapse during which that material was read and re-read and notes made of categories, groupings, connections and queries arising from that process, before it was appropriate to proceed to the second phase of ***incubation***. This involved thinking through nuance, comparisons, contrasts and meaning more purposefully, looking for insights to understanding. I found a matrix useful here using thematic issues suggested by the broad subject areas included in the guided interview schedule as one dimension and participants by age along the other. This close, careful engagement with the data in a more organised form ushered in the third phase of ***illumination*** and expanding awareness in which I explored several thematic options in a mind mapping exercise which provided opportunities to explore different arrays of the salient themes until I had exhausted their illuminative potential and was ready to move to the fourth phase. In this fourth phase of further refinement, thematic clusters emerged as the ***explication*** which seemed to encapsulate the experiences and opinions participants had shared with me in the most succinct and productive way . The fifth and final phase of ***creative synthesis*** was the one in which these thematic clusters were moulded into the findings chapters where the voices of these older women could be heard and where the conceptual links which emerged were identified and their significance to the central concerns raised in this thesis discussed.

It is also where my voice can be heard most overtly joined with theirs, albeit in a reflective interpretative role in which I also echo the voices of protagonists and commentators who have featured in various ways within the debate over the years and throughout the course of this study. I came to think of my research journey in terms of a critically reflective discursive process. In this process I engaged in conversations not only with the participants, but also with the data, the socio-political and cultural context within which we were and continue to be located, the theoretical framework which informed my critical reflections and the relevant literature and other sources of information about end of life concerns to which I had access.

Research Limitations

The small number of participants and the fact that they were self selected from the membership of one local organisation for older people in Townsville, which is a regional municipality, are among the most obvious limitations on the generalisability and validity of the findings from this study. The participants were also all from white Anglo-Australian or European backgrounds so there is no suggestion that the findings would reflect the lived experience of our Indigenous older sisters. These were consequences of the exploratory nature of the study but, did not preclude its usefulness. There is a ‘t*rade off’* in the form of the ‘*explanatory power’* of such research (Thompson, 2000: 58–59).

In this regard, as the findings illustrate, the critically reflective discursive process was generative of ideas which opened up different perspectives on which to base explanatory arguments and to present them as having existential relevance especially at this current time of crisis in the health care system. Explanatory power has pragmatic value at a level which helps inform professional practice in the human services as well as in providing a possible spring board for grass roots activism.

I had adopted an heuristic approach from the beginning of this research endeavour because it encouraged an inductive searching out of ways to make the problems I was investigating manageable. It is an approach which is, therefore, purposeful in seeking insights which have utility rather than any claim to certainty. I have made suggestions on the basis of these insights as they emerged from the findings chapters in the hope that they may be usefully applied to engage a broader, more diverse citizenry in on-going and purposeful conversations about these important issues.

Summary

This chapter outlines the qualitative nature of this research and the feminist framework within which is has evolved. I began by locating myself as the researcher: firstly from within my feminist view of reality, then in interaction with the participants, and finally within the critically reflective discursive process of data analysis. I followed this with an explication of the theoretical determinants which formed the basis of research design decisions and shaped the process of the data analysis and the critically reflective discursive process of interpretative interaction with the various sources of data which have informed the findings chapters.

The finding chapters which follow represent the results of that analysis and the suggestions which the data generated. The voices of the participants are presented as I heard them speaking out in specific chapters about: dying and death; voluntary euthanasia and about their quality of life concerns. These were the thematic clusters which suggested themselves as the data analysis process evolved and opened the way for insights to emerge which have implications for practice and activism.

Chapter Four: Older Women Speak Out About Death and Dying

Introduction

In this, the first of the findings chapters, I have drawn upon the participants understanding and experience of death and dying because this forms the background upon which their opinions about voluntary euthanasia (VE) and other end of life concerns are overlaid. What they have to say should be seen also as contextually located within the socio-political and cultural influences that have shaped their understanding and experience of death and dying. In this chapter I have, therefore, set the scene by touching briefly on some of the characteristics of those socio-cultural influences about which these women 'speak out'. What follows then focuses on how they speak out about death and dying; how they confront their own mortality and that of significant others in their lives; what they know about terminal care and managing suffering and on their perception of the impact of advances in medical and technological treatment regimes. The reflection section of this chapter explores emergent conceptual links between this and subsequent chapters and questions the consequences of not speaking out about death and dying.

Setting the Scene

The inevitability of death is certain for us all but how we talk, or don't talk about it, how we deal with thoughts about it, how we respond when someone close to us dies, how we prepare, or don't, for it are all questions which are fraught by much uncertainty. At least that seems to be a characteristic of contemporary western societies like ours (Kuhl, 2002; McNamara, 2001, Kellehear, 2000). How death will come is yet another question fraught by uncertainty but, swift or lingering, if there is substance to the observation that while "… *there is often a serenity – sometimes even a dignity – in the act of death, … rarely* (is this so) *in the process of dying"* (Nuland, 1993: 268), it would be very surprising if any of us would not want to be counted in the 'rare' category.

As far as death is concerned, we are privileged to live in twenty-first century Australia because we can expect our lives to reflect demographic lifespan indicators which suggest that people are more likely to die in old age than at birth or in middle age (McNamara, 2001). This is especially so if you are white and a woman as were the participants in this study. The downside though, is that the privilege of living for so long is countered by the privileging of life in dominant cultural conversations which determine attitudes to ageing. These reflect the healthy, strong and fit, independent lifestyle of the young as the desirable norm to which to aspire and nowhere is this more evident than in the relentless focus placed on the perfectly-functioning, body-beautiful images of sporting heroes, fashion icons and media stars who feature as heroes and role models in popular culture.

With such a value base it is not surprising that ours has been described as a death-denying society. Death as an old people's concern can more easily go unnoticed when the focus is on youth, health and beauty and can be pushed further into the background because many people find death difficult to talk about and are embarrassed to raise it in polite conversation (McNamara, 2001). Kuhl (2002) suggests ignoring it may serve to allay any fears of drawing it to us, because we want to delay, even elude it. This is a time too in which technological advances and sophisticated drug regimes have not only expanded our horizons of hope for cures and/or the containment of life threatening conditions, but have also provided a means of defying death by delaying it for as long as possible even in terminal illness. We are not only a death-denying society, but a death-defying one as well it would seem.

These characteristics help create the illusion that a mantle of silence surrounds the subject of death and dying and, while it is not a totally taboo subject, it is not uncommon to hear people say they feel uncomfortable and at a loss for words in the presence of a dying person or those grieving the loss of a loved one (McNamara, 2001). The participants in this study found that few of their contemporaries wanted to talk about the subject and while this reluctance reflects the societal norm, it denies a voice to those who do. Allen Kellehear (2003) reminds us that, when it is our time to face death, we might want to know how others have negotiated the challenges. He believes that without hearing what dying people have to tell us of their experience and feelings we have no idea of what it is like and don't realize that *"… talking about death can be instructive and valuable* (even) *to those of us who are not directly facing that prospect …"* (Kellehear & Ritchie, 2003: 3).

Death and Dying

On Speaking Out

The women in this study counted themselves among those who did welcome the opportunity to speak out about their encounters with death and dying. Each had, however, variously experienced the widespread avoidance of discussing this and other end of life concerns which is characteristic of our society, except in certain circumscribed situations. Specific groups, for example provided a safe space in which to broach the subject, at times, but there seemed to be tacit acceptance, in the majority of situations in which these women found themselves, that it wouldn't be raised.

> "These issues are not discussed anywhere I go except at our ladies group (a discussion and support group that had been together for many years). The subject just doesn't come up. None of my other friends have sat around discussing death (Gladys has made many friends through her bowling interests). It would be interesting I think to hear what they had to say but it's just not talked about. Most of my friends are on the religious side anyway, and they're planning on going to heaven, I think." (Gladys)

Gladys was not alone in speculating that religion played a role in inhibiting open discussion about death and other end of life concerns.

> "It's such a taboo subject … the religious thing plays a part in that for some people I think in how comfortable they feel talking about it and how they think about heaven and hell. They've got these very definite ideas of what's going to happen to them when they die, it's almost like putting a fear into people. They don't want to think about it because there's this awful dilemma, you know, have I been a good soul while I've been on earth. A bit of denial, and I think the real basic sadness of the whole thing is not a lot of people or organisations are prepared to talk about it … so sweep it under the carpet." (Ann)

> "I think it's something to do with religion that stops people talking about death. Be good and you'll go to heaven, if not they might be punished so don't want to think about it, don't want to talk about it." (Madeleine)

Eva, a ninety-three year old widow and the eldest participant, still felt the impact of socio-cultural influences from her earliest years which inhibited her confidence to express opinions about anything, but especially about death and dying.

> “We were always taught to be quiet unless you were asked, sort of thing, and we never talked about death and dying. Even in my 50’s I couldn’t. This was possibly because I would hide things rather than talk about them. I was never one to have my say. When I was growing up children were seen and not heard. (Eva’s family were practicing Seventh Day Adventists). As I got older other people had better lungs than I perhaps, and could express themselves better. I had my own opinions but wouldn’t speak them, partly because I would think oh, who would want to hear and I wasn’t sure I knew anyway. Partly it was the psychology of those times … partly because I didn’t have the confidence. My family were from the lower part of the social scale and when I was growing up I think the feminine part of the family would talk among themselves about things (like death and dying) but certainly not over the males in expressing opinions (about that or anything) … I feel freer in this latter part of my life to talk especially about death. I thought it could be a bit nerve wracking being interviewed … I’ve felt OK talking here, it was sometimes a bit painful, but impersonally personal.” (Eva)

Alicia, one of the younger women, felt that the far reaching consequences of a strict Methodist up-bringing had ensured that she too:

> “… didn’t have a tongue. We were told that you spoke when you were spoken to even if the house was on fire you did not open your mouth, and we didn’t. Our house was so ruled by the Methodist religion while I was a child, we were just so controlled. We were taught that you turn the other cheek. God is love and if you do the right thing nothing bad will happen to you … (in a violent first marriage she said) everything that happened I blamed on myself, that’s what you’d been taught, the other person is right. I didn’t have a defence, no voice to speak up, I didn’t know how to. I had to learn to speak to do my job (later as a single mum with four children selling real estate). I’m very different now, absolutely different!” (Alicia)

She hadn't learned to speak out about the intense anger she felt about her second husband's sudden death, however. According to her doctor it was repressed anger that had precipitated the heart attack which had left her with a pace-maker.

> "I eventually went to a counsellor who said what do you think would help? I said I think if I went out and I burned down a few churches I'd feel really good and after I said it I thought, oh now he'll probably put me in hospital because he'll think I'm mad, but strangely enough once I'd said that, I felt quite a lot better. I just looked at him and he said do you feel better now, and I said I think I do, it's really strange!" (Alicia)

She had very strong opinions about end of life concerns at the time of the interview including this idea for disseminating information about the challenges that lay ahead for older people moving into retirement.

> "I've thought about this and I know this sounds a bit far fetched but my idea is that there should be a permanent body like the press club and when a person reaches 65 and due to get their pension, they would go to a forum where this person, and I always think of it as a man, stands up and says now you've got the pension these are all the things you can do. I tend to think women around my age will have had fathers like mine and are used to being told by a man, are more likely to listen (to what he has to say." (Alicia)

Male authority and religious authority were significant influences in the formative years of both Eva's and Alicia's lives. The form of religious influence was rigid and controlling in both instances with similar outcomes despite the thirty years which separated them in age and the increasing secularisation of society generally over that period (McNamara, 2001). Both identified that over the years they had experienced a certain degree of liberation from the constraints which that oppressive authority had placed on their confidence levels.

Joy, the youngest participant and who was nearly ten years younger than Alicia, could say on the other hand that:

> "I don't find it unusual to talk about these end of life things and wouldn't feel backward in talking about them. In my sewing group we joke about who will finish any unfinished projects (when one of us dies)." (Joy)

Joy described herself as a practicing Christian but spoke of her religion as supporting rather than controlling her. She had found the seminal work of Elizabeth Kubler-Ross helpful following her mother's early and sudden death and believed more education was needed to encourage open discussion because "… it's still something that's not talked about". This comment led her to reflect that she too was not always open to opportunities for such discussion.

> "I don't talk about death with my grandchildren and they weren't around when my parents died and I think they're not really prepared in any way. I had not talked a lot with my children while they were young but I do now. The boys don't want to hear about it but I talk with the girls (she has seven children) especially since I've done the palliative care training." (Joy)

She wondered if her sons' resistance had something to do with their limited exposure to death in the course of daily living or to the impact of seeing death more often in violent scenes on television. They distanced themselves from it in this way, she thought, as something that happened to someone else and/or as part of a storyline.

Several of the women had concerns that very practical duties were not being attended to by avoiding discussion about end of life issues.

Pat said that while her children:

> "… don't want to talk about death, they aren't totally rejecting and let me talk about arrangements. But they never think about it themselves. I don't think they've made wills." (Pat)

Pat had also graphically observed that:

> "… people don't want to talk about it (death and dying). It's a bit like sex in the Victorian era isn't it. Nobody wanted to hear about *tha*t but it still went on. They'd talk about death in those days but not sex. Now we won't talk about death." (Pat)

Inge was sure that her children would say if she talked about her death.

> "But Mum you have 10 or 20 years ahead. Don't think about it (death). It's not time yet. They were reluctant to read the papers for my Enduring Power of Attorney (EPOA) and it took about three months for me to get them to sign." (Inge)

The three oldest participants had not only attended to the preparation of their wills and EPOA documentation, they had each also completed an Advance Health Directive (AHD). All three had been prompted to take this latter action when the subject was raised by someone from one of the support networks into which they were linked. For one woman this was a guest speaker at a Legacy women's group, while the other two had heard about this option from their Community Health case workers. The AHD was the means by which they could ensure that, figuratively speaking, their voices would be heard at a future time even though they could not then actually speak the words that would express their wishes about their health management.

> "… I've done them (EPOA & AHD) … I feel very keenly this needs to be made known that this should be done …" (Judith)

> "… I don't want any life support. I think that's the main thing (with the AHD). I don't want my life prolonged." (Inge)

> "… in the latter part of my life I'm more able to accept that things have to be done and I can't run away from them so I've made my will and I have the other papers (EPOA and AHD). At my age (93) I know I want help with pain but then let me go quietly over the rainbow when it's time." (Eva)

Of the other participants, all were aware of the value of having an EPOA in place and four had done so formally. Only two had not heard about AHDs and they asked for more information about them. All expressed an intention to follow up on these options, which would formally register their health and legal wishes, where they had not yet done so. Ann for example said:

> "I never did one, it (AHD) hadn't come up and that will be something I need to look at. I must do it. I've got set ideas and I've told my daughters what I want to have happen to me." (Ann)

Joy knew that she had the option of arranging to have an EPOA and AHD but observed that:

> "We haven't done that yet. We've only just done our wills last year. You think that you will worry about that when you need it but you may not have time." (Joy)

Joy's husband had been resistant to making a will but needed to for business purposes. She thought it would be difficult to persuade him to think about any other legal documents just yet but commented as she left:

> "It's making me now think to put something down on paper (she was referring to an AHD)." (Joy)

That both her mother and sister-in-law had died in their early fifties, when they were younger than she was at the time of the interview, had not been enough to motivate Joy to attend to her will until recently. It would seem though, that talking about the issues, as we had done that day, had made her more aware of the value of taking some action.

Ann recommended that talking about funeral arrangements was another important responsibility. She had distressing memories of her mother arranging her father's funeral as a burial service without any knowledge of what his wishes had been. Ann's father had discussed his wishes with her brother and herself and had insisted that under no circumstances were they to bury him.

> "He spoke to his children but not to his wife for probably the reasons a lot of people don't, they don't want to upset the partner. It's upsetting for them to talk about their impending death." (Ann)

Confronting Their Own Mortality

Death had touched all their lives and had variously influenced the way they thought about their own end of life expectations.

Syd compared her attitude to death with that of her elderly mother.

> "Mum sees it as, I wish I could go to sleep tonight and not wake up tomorrow, because she can't cope with the pain and discomfort of old age, but then says I don't want to go there (on an outing) I might get flu. There's still a very strong life force. She can't say don't talk to me about my will or an EPOA but makes it very clear that's what she means. We see it very differently." (Syd)

Without directly challenging her mother's resistance to facing her own mortality, Syd compromised with her by talking about death indirectly as:

> "Popping off, not unlike being born is popping out, of our mother's bodies." (Syd)

Her reasoning was that the euphemism was a way to normalise the subject in conversations with her mother where the opportunity presented itself. She had also found it a helpful way to talk with an old and frail friend about what was happening for him as his health deteriorated and death drew nearer. Normalising the way she talked and thought about death was important to her and involved using humour and accepting that no-one had the answers to life's, and death's, mysteries.

> "We don't know what questions to ask let alone the answers. If you want to make God laugh make plans and decisions." (Syd)

Eva had used the birth analogy also to illustrate her view of death but added a coda:

> "… like birth is a journey for mother and child – and I find that a very interesting concept – I have a feeling it's a journey the other way. If it's to sleep, where I go when I die, I like to sleep. If it's another life, I'll face it like I've faced this life with the same amount of courage and cowardice. What else can you do?" (Eva)

The philosophical acceptance that death would bring change and a preparedness to face that change whatever it might be was characteristic of the responses of all the participants, regardless of their spiritual beliefs, which indeed were quite diverse.

One woman was adamant that she had:

> "… no interest in an afterlife, as far as I'm concerned it does not exist. I don't dislike people who are really religious, I feel sorry for them. I don't need it. I've had a good life and I just think it's (death) the end of life. I hope I have a peaceful death. I'd like that and I want to be cremated. My husband and my son's ashes were put out off Manly Beach and that's where I want to go." (Gladys)

The other non-believer was calmly accepting of her own mortality.

> "Strangely enough it (death) doesn't bother me anymore. I've really quite come to terms with not living forever. Anytime I go that's fine but that does not mean that I'm not enjoying life. Each day I wake I think, oh, another day. (To a question about an afterlife she said) … as far as I'm concerned, I don't think it exists." (Marian)

A 'near death experience' (NDE) had been reassuring for Ann who as an asthmatic had needed resuscitation on two occasions in her adult life.

> "I've always been a strong believer that there's something after death. I've no religious belief, it's a spiritual thing and I'm very comfortable with that. I don't have a fear of death … (she described the detail of an 'out of body' experience as hospital staff worked to revive her as she watched) … it was a bit scary thinking about it afterwards. As far as I'm concerned this has no religious significance but tells me there is something there for me later on." (Ann)

Alicia was another with an account of a NDE. She had been at a function:

> "… and I'm standing there and the next thing I know I was in this place that was absolutely beautiful. There were just these rows of little things like hills with grass and beautiful flowers and blue sky and I'm as happy as a two bob watch and all of a sudden this voice yells out 'Mum!' and a hand like you see the statues in Greek sculpture and they're white and made of concrete, this hand which looked exactly like that came tearing through this sky and she grabbed me and I woke up. Then I went out again and the next time I woke up I was in the ambulance. There's no way I'm scared of dying. It was truly absolutely beautiful." (Alicia)

The two participants who identified themselves as practising Christians found comfort in their belief in a “life after life” as Joy described it but were not constrained by rigid adherence to the dictates of their church, preferring to rely on their own judgment in certain situations. Joy believed “God would understand” while Judith declared “I’m a no nonsense lady and that’s how I feel” when talking about the controversial issues which had arisen during their interviews. Both believed there were circumstances where it was appropriate to support voluntary euthanasia and Judith declared herself pro-abortion as well.

On Being a Carer for a Dying Person

It wasn’t fear of death which these participants found confronting, rather it was what they might have to go through in the dying process. Eight of them had been carers for a dying person and had been challenged by living with the certain knowledge that death was near but never knowing just when it would happen. They had also known the helplessness of not being able to provide what was needed to relieve pain and suffering.

For Eva the carer role had been:

> “… a bad thing yet a good thing … a close time … you were glad to do anything, even when there wasn’t much you could do doing even little things you didn’t feel so helpless ...” (Eva)

Ann had cared for her dying husband at home which she thought of as a very natural thing to do.

> “It’s always been my desire to be a nurturer and a carer.” (Ann)

The challenges she faced though because of inadequate back-up support were very stressful, a situation which will be returned to later.

Joy had sat with her father in hospital during his last days:

> “I think because I didn’t have a chance to say goodbye to my Mum it made it extra special to be there. We shared a lot in that last week.’ (Joy)

Her role as a volunteer carer now has brought her into contact with a somewhat different situation:

> “I am working with a lady at the moment and that is extremely difficult, she has motor neurone disease, not a nice end.” (Joy)

Judith reflected on the emotional strain of caring. Her husband had a long lingering death and she had also been a carer alongside the family of a neighbour who:

> “… was literally decomposing in the bed but didn’t want to go to hospital.” (Judith)

Judith considered it her duty to be there for others and was currently visiting several older people as part of what she perceived as the caring-role responsibility of a Christian but she had begun of late to say to herself that she could:

> “… walk away. This is something new for me to say. I could never say no but now I’m moving on.” (Judith)

Her change of heart was because she sensed she was being imposed upon by others from the church congregation who could have taken on some of the responsibility but chose not to. This feeling that she was at risk of being exploited was exacerbated by what she perceived among some of the older women she visited as a tendency to:

> “… molly coddle themselves. You have to move on if they won’t help themselves.” (Judith)

About her own possible need for care she said:

> “If I’m terminally ill I don’t want to be a burden to anyone. I just want to disappear.” (Judith)

The implication from Judith’s comments would seem to be that there is a connection between needing care and being a burden and that this was more so the less deserving the recipient of the care was perceived to be.

Lucy also linked providing care with being a burden when she was talking about terminal illness.

> "I think women are more aware of things like this, I don't think men are aware of these things. Women care more about how they live. Women are more aware of the burden they may be to others. They don't want to be a burden." (Lucy)

These quotes from Judith and Lucy raise important and contested aspects of feminist theorising around the concept of care as it has emerged within the ethics of care debate and the challenges to traditional gendered models of care which are central to that debate (McLaughlin, 2003). It could be argued that their choice of the word burden carries the pejorative overtones which are consistent with a view that "(a) *model of autonomy as the ideal condition lies behind the celebration of the person who gives care"* (ibid: 85) and an implication that there is a hierarchical relationship between carer and cared for.

Furthermore, Lucy's reference to women caring more about "how they live" suggests a tacit awareness of the gendered dimension in quality of life concerns. All participants had concerns about how circumstances might shape the quality of their lives as they aged, especially as this affected their independence, possible disability and consequent need for care. Their quality of life concerns will be returned to in a later chapter and discussed within an ethics of care framework.

Terminal Illness

Palliative Care

Ann, the woman who had cared for her dying partner at home, and who had felt let down by inadequate support services, had been particularly distressed by the lack of:

> "… a synchronised process at the end of life after a diagnosis of terminal illness. You don't need to fight the system (at such a time)." (Ann)

She had managed on her own after her partner's diagnosis but, when he had to be hospitalised for a short period, she had been linked into palliative care and the

Cancer Fund services and had found this reassuring at the time. Unfortunately though, she was later to be disappointed by certain aspects of palliative care.

> “There was a lot of talk of support (for her as a carer) but none of it happened. Promises, promises, but then nothing, just when you need that emotional support. I guess I had high expectations of palliative care and it didn’t happen. And I know of others who have had similar experiences. Maybe their caseload is too high but they need to make it clear what they can offer.” (Ann)

Ann had appreciated the in-home nursing and volunteer support provided to meet her partner’s medical needs, although there had been challenges there too, about the attitude of one of the nurses involved. Ann had also felt marginalised by a system which failed to provide her with guidelines about what to expect as her partner’s condition deteriorated.

> “Knowing something is about to happen gives you a chance, like if they up the dose (as happens when the principle of double effect is invoked) you could do things differently like saying goodbye or being there especially.” (Ann)

Having no guidelines either about what pain control measures might have been on offer had added to her distress.

> “He was on patches (for pain control) in the end which could have helped him not go through so much misery in vomiting and clenching his teeth and refusing to take it (other pain control medication). When I look back, he should have been on those patches earlier … it could have been a cost factor, but for the comfort of the patient you would have paid for it yourself (if she had known she had that choice)”. (Ann)

More open discussion about what is happening in palliative care could expose disparities between the reality and the rhetoric of what these services can be expected to provide, as Syd argued very tellingly.

> “The theory, the ethos of palliative care is wonderful – not to prolong life, but not to shorten it, making the patient as pain free, comfortable and distress free as possible - but the expertise of those in charge of dying people, who each

> have their own belief system and own judgment of what is appropriate for a dying person or not and what is adequate pain control or not, is too dicey …" (Syd)

Madeline and Alicia had neighbours who were caring for a partner at home with the support of palliative care resources and it seemed to them that the carer was managing, although this opinion was based on observation rather than any specific evidence. They had great respect for the carers and the contribution they were making to the wellbeing of the person in their care.

Madeline's neighbour was caring for her husband who had cancer and Parkinson's Disease and who wanted to die at home. Madeline felt that by talking openly with her neighbour about her daughter (Madeline's daughter had died of a degenerative disease a few years ago) her neighbour felt she was understood by someone who had lived through similar experiences. This was another example for Madeline of the value of feeling comfortable talking about death. "Not talking and by yourself you get depressed" she had observed.

Alicia understood palliative care as providing care and comfort, but not cure, and had come to this understanding through her neighbour's involvement as the carer for his dying wife in the home setting.

> "They didn't have the facilities to keep her in hospital so they sent a hospital bed, a wheelchair and a commode. They sent her home because they thought it was nearly her time but she's so improved under his care. Being home is marvellous for her but she's lost a lot of weight." (Alicia)

The option of dying at home as opposed to hospital is preferred by many who have someone to provide the primary care needed but as Ann's experience illustrated there are no guarantees that back-up support will be adequate or available when and where needed.

Suffering

All participants had witnessed the pain and suffering of a loved one or friend who was dying. Most did not believe that suffering was an ennobling experience to be borne stoically when it was associated with intolerable pain, especially when that pain was not amenable to available pain control measures.

> "Well my view is if you can put a man on the moon for goodness sake surely people don't have to suffer." (Alicia)

Marian believed there were differences in thresholds for pain that she had witnessed in herself and others and commented:

> "… suffering is so idiosyncratic. I'm not sure I feel pain the way others do." (Marian)

a point echoed by others.

> "You don't know till you get there …" (Joy)

> "It depends if you have the will to go on, but when you can't make the effort … I challenged the priest who said (about a friend she had been visiting in hospital) he was cross the fellow wasn't making any effort." (Judith, a practising Christian)

> "At my age I would like them to help me with my pain, but, if it is so great you want it blocked out, and you feel so miserable and life isn't worth living … you would want to know there was someone there to give you this cocktail, or injection, someone you had given permission to." (Eva)

Syd was reminded of the Catholic Church's influence in her life.

> "As a good Catholic I would believe we are doomed to suffer in this life so that we can enjoy paradise in the next. Yes, suffering to help me get out of the shell of my body as a pathway. I'm open-minded. I don't know because I haven't walked that path. I don't know." (Syd)

Her concern was for those who would have to witness her suffering. She then recounted a story from when she was a child of having had to kill an animal injured on the road. The irony of the story was that she had had the opportunity to save the animal from any harm had she felt she could pick the strange looking creature up but, because she had hesitated, it had dashed into the path of a car and been injured.

> "I can't kill anything unless it is suffering." (Syd)

She found this knowledge about herself challenging and wondered how it might influence how she would make decisions involving suffering in the future. She struggled with the contradictions in herself.

Ann was quite adamant that:

> "I think at the end of my life I'm not looking at too much personal growth (referring to the alleged ennobling potential of suffering). I guess for my family probably, those with me, and having watched Roy (her partner) have a terrible last few hours, I feel that shouldn't be necessary, that somebody shouldn't have to endure those last few hours gasping for breath. I wouldn't like that to happen to me." (Ann)

Ann's story of her husband's terminal illness highlighted many of the realities which can confront the dying person and those who care for and about that person. Uncertainty about what was happening or was to be expected next exacerbated the trauma of the physical pain and suffering. For other people, however, it is the certainty of what is to come that challenges the capacity to endure, as Joy was discovering as she provided support to the woman who had motor neurone disease.

Inge had been deeply affected by the story, relevant at the time of our interview, of the English woman, Dianne Pretty. Dianne who had motor neurone disease and knew what an horrific death she faced, had fought a long and fruitless battle through the court system for the right to have assistance to end her life before she reached the extremis of her condition. For Inge this example challenged any suggestion that suffering could be good for you and illustrated why people could want to support voluntary euthanasia.

The use of drugs for the relief of pain and suffering other than those currently available on prescription, such as cannabis and heroin, was an issue about which these women believed there needed to be more open discussion. They thought any claims that these drugs might be more effective in relieving suffering than other treatments should not be dismissed because their use was currently illegal. The right to use cannabis for pain control has frequently been contested in courts around the country and the legislature of at least one Australian state has had a proposal on its agenda for decriminalising such use in past years. This remains a contentious issue, however, and one which will be discussed in more detail in the next chapter.

These women all believed access to cannabis and heroin for pain control should be decriminalised especially for the terminally ill if they wished to use them for that purpose. One woman said had she known about the possible benefit which cannabis biscuits (as described in Pauline Reilly's book *Cannabis and Cancer: Arthur's Story,* (2001) could have been she'd:

> "… have popped over to (she named a male friend and ex-colleague) with some biscuits and made him feel a bit better if I could, yes absolutely. I'd be hanging around the school gates for a supply (of cannabis), that's where they hand it out to the children so I hear." (Pat)

The Medicalising of Terminal Care

The Technological Imperative

One of the many changes in the way terminal care is managed in society today, in terms of who provides it and where this most often happens, centres on medical and technological advances in treatment regimes over recent years. As already noted, several of these women had reservations about these advances. This was not only because they had experienced, or knew of, limitations inherent in aspects of pain control, but also because they had concerns about communicating their wishes about what they wanted to happen to them, when and if, they became involved with the medical system as they age and/or face death.

They were particularly concerned that, because *"(m)edicine continues to be driven by a technological imperative … to ward off death"* (McNamara, 2001: 4) they could be hooked up to a ventilator or tube fed at the end of their life because this was a treatment frequently made use of. Lucy's comment reflected the general view:

> "… we've gone too far in the medical side of things. We keep people alive against their wishes. Have we got the right to just because we have these

> things we can do? What we are able to do is fantastic but there should be a cut off point. I don't want my life prolonged. Make me comfortable and let me go when it's time." (Lucy)

Madeline agreed "I don't think I would like to linger". Marian was somewhat more emphatic.

> "What I would *hate* is to have someone fiddle with me and keep me alive when I no longer could enjoy life." (Marian)

She had made sure her daughters had signed her EPOA and was prompted by what she had just said about this to reflect that:

> "I think the lawyer included the AHD (when she was making her wishes clear). I will have to check. I'll definitely look into that." (Marian)

Alicia had mixed feelings about the process of being kept alive. Her husband had collapsed at home and been rushed to hospital where he had been revived and placed on life support "… to see what might happen …" even though he had been declared brain dead. He survived two weeks. She was of the opinion that:

> "I personally don't think I would have had the strength to tell the doctor to turn the machine off … (Later talking about her mother-in-law, she added) … mind you even with her I personally would not turn off any buttons, but if there were something in writing with her will that would be legal that said this was her wish, that would be marvellous. I do think you have a right to instruct as to what you want in your own situation." (Alicia)

Pat reflected on her experience from some years ago and expressed relief that she had not been the one responsible for disconnecting her mother's life support system.

> "In the end whatever tubes there were in her were removed. My brother and I were never asked. Certainly I'm very grateful they didn't ask because it was the hardest thing to watch someone die when every breath they're taking you're thinking oh God, let her go now, yet halfway through your very thought, she breaths in and you think, oh thank God I thought she'd gone … you want it for one reason and you don't want it for another." (Pat)

Inge talked about how hard it had been for her daughter when her father (from whom Inge was divorced) had been hospitalised.

> "She went to the hospital after a couple of days and asked them to turn the life support off. He had throat cancer and was suffering badly. He might have lived a couple of weeks longer, but what for when he was suffering so much." (Inge)

These are examples of two facets of the dilemma surrounding how decisions are made on behalf of someone without knowledge of their expressed wishes. On the one hand responsibility was taken by the family, on the other by the hospital, but just how transparent that decision making process is may depend on the hospital management practices and protocols and how this information is relayed to relatives.

Organ Donation & Stem Cell Research

Another contested issue connected with end of life decision making has centred on what is described as the *"harvesting"* (see for example Kellehear, 2007; 241) of organs for transplant purposes. Lucy raised organ donation as a particular concern and referred back to her first experience of being part of the 'organ harvesting' routine as a scout nurse in theatre.

> "I felt good about the whole thing … I was in and out of the theatre and everything seemed so fine. There were lots of people in the theatre, lots of surgeons. All of a sudden I came back to the theatre and I thought there's something wrong, what is it, and the respirator wasn't going any more. They'd turned it off because they'd finished taking all the organs. That is when it hit me. I looked around at the surgeons and I thought to myself they are just like a lot of vultures grabbing what they want, and they leave us with the empty shell there and we have to do the rest. I thought my job was to make someone better and we're not doing that here. We're ending someone's life. It may well have ended anyway but you know it didn't seem right. I do these operations and it's good that they help someone else but I don't think I would feel right about it if I had a child needing one of those organs. Knowing they'd be on drugs for the rest of their lives, that their body may reject the organ. I believe that if your time has come, for some reason or other you're not required here on earth any longer that should be it. I wouldn't let anyone take

> my children's organs. It's not an ethical thing … it's just something I feel strongly about and the money side of things like planes, police escorts … it costs hundreds and thousands of dollars to do these retrievals. I just know it grates on me …" (Lucy)

Joy, however, found it:

> "… surprising the number of young ones who won't sign on their driver's licence for organ donation. You have to keep harping about it." (Joy)

Organ donation has been a contested issue from its inception as a procedure. The opinions expressed by Joy and Lucy, which place them somewhat at odds regarding support for what medical science is now more technologically competent to achieve, illustrates this and suggests something of the ethical dilemma when ending a life is the inevitable outcome of the procedure.

Ann and Madeline, both mothers of daughters with disability, had questions about sophisticated technology also, but from quite a different perspective. Both spoke out in support of its application in stem cell research which they believe has the potential to improve the life chances of people with disability.

> "I have a daughter with MS and stem cell research is vital for that condition." (Ann)

> "I think stem cell research is all right, perhaps it would have helped my daughter (who had died a few years ago)." (Madeline)

For them, stem cell research exemplified the point that Lucy had made that "… what we are able to do is fantastic". They had concerns, however, that the government would oppose this research proceeding because it is a highly controversial and contested issue. The ethical dilemma for government centres around the use of *embryonic* stem cells in the research process. The primary concern is on how the embryos are sourced and this is exacerbated by the fact that the harvesting of embryonic stem cells results in the destruction of the embryos from which they are taken (Mackay, 2004). That there may also be those who would engage in this research with the intention to clone human life adds another dimension to the dilemma (Rickard, 2002).

Ann and Madeline had been inspired by the hope that this ground breaking research would enhance the life chances of people with disability by extending their life expectancy beyond what it is presently. Advocates of this research who included, till he died, high profile celebrity Christopher Reeve (The Reeve Foundation website continues this promotional and advocacy role) have argued also that this research has the potential to relieve suffering and improve the quality of life for many with disabilities - although this view is not without its opponents in the disability movement (Leipoldt, 2005).

Critical Reflections

Bioethical Dilemmas

For Ann there was an existential urgency about her description of stem cell research as “vital” which hinted at underlying fears about her daughter’s future living with a degenerative condition. The death of a child is a challenge to the natural order and, living with the knowledge of that impending loss is well recognised these days as evocative of chronic sorrow (Roos, 2002). Her experience with an under-resourced palliative care service was no comfort to her either. Stem cell research offered hope which she feared might be dashed if that research were not allowed to proceed.

Fears of a different sort have fuelled the arguments of many opponents of stem cell research who condemn it because they perceive it as human life being used as a means to an end. That is the view expressed by both the Catholic Archbishop of Sydney, George Pell and his Anglican counterpart, Archbishop Peter Jensen who believe embryonic stem cell research violates the sanctity of life (Mackay, 2004). Despite this and other more general opposition from within the Australian community, the Federal Parliament voted in late 2006 to lift the ban on therapeutic cloning, basing its decision on recommendations from the Lockhart Committee of Review Report which had been released in late 2005. It was, nevertheless, a contentious decision. Members were allowed a conscience vote and both the then Prime Minister, John Howard, and then Opposition Leader, Kevin Rudd, voted against the Bill (ABC News Online, December 6, 2006).

We have, however, already seen how quickly decisions made to resolve complex bioethical dilemmas can become the norm. This is nowhere more evident than in the way the concept of brain death has been integrated into the practices involved in organ donation procedures as well as into everyday language use. In the early days of organ transplant history, it had been necessary to find an ethical solution to the technology-driven problem of defining death in order to accommodate the processes involved in transplanting vital organs such as the heart, and that task was allocated to the Harvard Ad Hoc Committee. Their decision on a definition for what constituted brain death was hailed at the time as a *"… solid bio-ethical achievement"* (Tulloch, 2005: 12) and has since gained widespread medical and community acceptance. Outspoken ethical philosopher, Peter Singer is one who has, nonetheless, demurred from such opinion. His bluntly critical description of that decision as *"… an ethical choice masquerading as a medical fact"* (ibid: 20) presents a reality-check reminder that, community acceptance of the brain death definition, casts a different light on the concept of sanctity of life.

There have recently been moves to extend the definition of brain death and pressure to accept:

> "… *the notion of cortical death – death of the higher brain, which regulates consciousness* (as the preferred medico-ethical criterion*)…. (With) advances in imaging … it is now possible to detect in what areas of the brain the blood is still flowing. Without blood flow, the capacity for consciousness has been irretrievably lost* (as then would also be the hope of recovery from a comatose state)" (Tulloch, 2005: 12 & 18).

Technology has thus provided more empirically based evidence to help allay ethical dilemmas around the definition of death as pressures for organ donation mount (Tulloch, 2005). Peter Singer's plain talk about masquerading a desired outcome as fact does, however, serve to remind us of the power of language in creating illusions about what is a fact. That power extends to sanctity of life arguments too, which it can be argued, pursue illusory ends when they imply on the one hand, that it is only God who has the right to say when a life should end, yet on the other hand, support human intervention with life support measures, even condemning decisions to withhold treatment when this is the wish of the dying person. Surely these are both instances of defying death and defying the divine will as well. Lucy highlighted the dilemma such an argument presents when she observed

> "We're not obliged to keep people alive just because we have the facilities to do so when without them they'd be dead." (Lucy)

Lucy had tellingly described her unease when confronted with a body, minus its harvested organs and surrounded by the silence of the switched off life support system. She had first hand experience that removal of the organs from someone in an irreversible coma leaves no doubt that life is extinct (Tulloch, 2005). Death happens under the surgeons' hands during such procedures and it is legal. There are, of course, strict protocols which must be followed once it is determined a suitable donor has been found. And the whole process could not be initiated without consultation involving the medical team (or its representative) and the next of kin.

This paradoxical consequence of organ donation practices in which one life must be lost to enhance the life chances of another – possibly even several others - seems to be an outcome around which there is little public ethical concern. Perhaps this is because it privileges life over death and is consistent with the death defying ethos of our society.

Embryonic stem cell research which, it would appear, has a focus on 'cure' as its holy grail, has elements of both death defying and death denying associated with its projected possible outcomes. Though these may be limited by law to a concentration on repairing and regenerating body parts and not on the more ambitious aspects of cloning, the implications for people with disability are far reaching. For those like Ann and Madeline in this study, the hope for cure is compelling but there is disquiet within the disability sector among those who perceive the bio-political as well as the bioethical implications of this research. There is disquiet from within the feminist movement too about the bio-ethical and bio-political implications of the harvesting of women's eggs as an alternative to the use of embryonic tissue leftovers from IVF procedures (Salleh, 2007).

Health System Crises

The disquiet Lucy had felt about the process of organ donation had been exacerbated by her awareness of the enormous costs involved. She questioned how such expenditure could be justified when other demands for access to technology, albeit of a more prosaic kind such as for hip and knee replacements and other repair and remedial procedures, were not always able to be met at the rate required. These latter procedures are among those most likely to be sought after by older people to relieve pain, improve mobility and improve their quality of life. They are also costly and there have been warnings that the health needs of our rapidly ageing population will be a serious drain on the public purse which, according to neo-liberal driven fiscal thinking, is already being stretched almost beyond its capacity to meet health budget demands (Intergenerational Report, 2007).

The costs of not meeting the demands for such procedures does not seem to rate similar concern in health budget debate – well being and quality of life are, of course, difficult to place a dollar value on. The government is, however, actively encouraging the public to register as organ and/or tissue donors, even advertising in the Centrelink News for Seniors Newsletter. With this headline: "*Have you thought about signing on to save lives? You're never too old to register …"* and displaying a card with which registered donors would be issued which states "*I have signed on to save lives*" (Centrelink News for Seniors, 2007: 16), the government seems to be indicating a positive commitment to expenditure from within the health budget for advertising, recruiting and supporting the donor scheme. Lucy had a legitimate basis for questioning how decisions are made about what expenditure in the health budget is, or is not, likely to be perceived as a source of potential crisis. It is doubtful if many of us know how protocols are developed to inform such decisions, if and how they are monitored, and how we, as the public likely to be affected by them, can influence this process.

Within the small sample of participants in this study there were experiences which exposed inconsistencies in the management of end of life decision making and consultation processes (Alicia, Pat and Inge had differing experiences of the management of life support systems). This is concerning for anyone unexpectedly and traumatically confronted by their ignorance of what to expect by way of information and/or treatment options at such a time. It is also concerning because of what knowledge may be withheld, including what weighting is given to cost factors in the decision making processes. Lucy had challenged the technological imperative "… to keep people alive just because we have the facilities …" but had also identified the selective influences of an economic imperative to prioritise procedures.

Emergent Concepts – Care: Burden or Right

These influences are reflected in the language which frames the discourse of health care costs, most notably where it refers to the "*disability burden"* associated with diseases, injuries and risk factors (Mathers, Vos & Stevenson, 1999). This is the language of those who control the purse strings and/or influence how the dollars are allocated. The Department of Health and Aged Care funded research which uses this language in its title is seemingly indifferent to the powerful message it sends to the community, not only about disease, injury and risk factors being a burden, but also about disability per se – those who are disabled are, by implication, a burden. Yet this language appears to have aroused barely a ripple of protest and has not been withdrawn.

It would seem that the voice of disability activists who promote a social model of disability has not been resonant enough to effect much change in societal attitudes and the way disability is perceived given they argue that *"… the fundamental issue is not one of an individual's inabilities or limitations, but rather a hostile and unadaptive society* (Len Barton, series editor in preface, Swain, French & Cameron, 2003: viii).

Lucy, Judith, Ann and Joy had spoken about not wanting to be a "burden" should they need care at some future time but their concerns had been about the physical and emotional costs of providing care rather than the dollar costs. Paradoxically, all were more than willing to be care providers, believing this was a natural role for women. Pat's fears about the increasing loss of mobility likely because of her degenerative back, were about the likelihood of a future beset by pain and frustration rather than that she may be a burden. Inge, who had already experienced lifestyle changes as her vision deteriorated, had angrily protested:

> "Now I am dependent and I hate it. I'm quite happy with the money and help I get but it doesn't go far enough. What's missing is something to keep my brain occupied." (Inge)

Rather than feeling a burden, Inge was confronting the reality of an "unadaptive society" which allocates resources for people with disability but does so from a 'no frills' perspective. What is offered may, as far as possible, be tailored to the individual's needs, but from within a limited resource pool and often as a standardised package.

Eva, the oldest participant, had become frailer and less mobile in the preceding twelve months and had decided not to continue to live alone.

> "I miss my life as I was then. In here (she touched her hand to her heart) I feel quite able to do all the things I used to do but at 93 I'm getting near the

> end and I'm not going to spoil a minute of this time dwelling on what I can't do. If I can't run, I'll walk. If I can't walk, I'll be pushed. If I need care I'll take it as a gift when I can't help myself." (Eva)

Eva and Inge had first hand experience of age related disability and, although they grieved the loss of their previous independent lifestyle, being able to continue to live at home with support from community care services and/or family, cushioned the pain of their grief. Neither perceived themselves as being a burden, believing they were entitled to receive the government funded support they were receiving, but aware also that this may not always be available. Inge feared hers may well be the last generation to have the right to an age pension and the benefits this entitles the recipient to receive.

That could well be the outcome if the minimalist commitment to welfare provision, characteristic of the neo-liberalist philosophy currently driving our economy, prevails into the future. As the philosophy which has spawned the label "disability burden", neo-liberalism seems to privilege a concept of the self funding autonomous individual in a privatised care system and to cast a pejorative shadow over expectations that care for the vulnerable and needy is a basic human right.

Contemporary feminist analyses of the place of care in society has generated considerable debate and what is emerging is a politicised *"ethics of care"* argument at the centre of which *"… lies a rejection of the 'self-made' autonomous individual who can exist without care*" (McLaughlin, 2003: 89).

Moreover, as it is an argument which privileges interdependence over independence, it allows the focus to be on care as a social practice and for it to be placed within concepts of *"democratic citizenship"* (Sevenhuijsen, 1998: vi). This view promotes care provision as a public sector responsibility and as a citizen's right to access and as such, seeks ways to engage the most vulnerable stakeholders in helping to set priorities for resource allocation.

Summary

Participants in this research would have welcomed such an opportunity to have their voices heard. With minimal constraints on the direction in which our conversations about death and dying were to proceed, they gave voice to a wide range of care-focused end of life concerns. Most had felt the silencing effects of the dominant socio-cultural taboos which inhibited their contemporaries from engaging in discussions about these issues. They, on the other hand, had no such inhibitions in conversation with me and for some of them it was a relief to unmask and explore their fears and uncertainties about what might lie ahead especially about the dying process.

They variously expressed their rejection of heroic intervention procedures at such a time as an unwarranted intrusion which would, in all probability, only prolong the dying process, and possibly, their suffering. While they would all opt for a quick, painless death, should that not be forthcoming, they wanted to be kept comfortable and to have their pain managed in a way that let nature take its course as death neared. The women who had completed EPOA and AHD documentation, which formally recorded these wishes, felt some sense of comfort and security for having taken that action. The others were interested to take some action in this regard in the near future.

In my interpretative reflections on these findings, I was mindful that a patient's right to reject or discontinue treatment is a relatively new aspect of end of life management and not without its detractors who contend it is not only bio-ethically challengeable but also open to abuse (Leming & Dickinson, 2007; Kerridge, Lowe and McPhee, 2005). There was an incipient awareness of the dynamics of this, and other, bioethical dilemmas among these participants. For example, they questioned the disparity between the rhetoric and the reality of what palliative care could offer; why there were no provisions for the limited use of cannabis and heroin for pain control by the terminally ill who might find this effective; and Lucy, Joy, Madeline and Ann had specifically challenged how decisions were being made about organ transplantation and stem cell research.

There was also an incipient awareness in the disquiet they voiced of the biopolitical implications surrounding these contentious bioethical decisions. Several of the women voiced concerns about how health care budget dollars were allocated now and about their fears for the future if services which affect quality of life outcomes for the vulnerable are no longer available. Though they didn't use the language of the 'disability burden' discourse they felt its impact and feared its consequences in fiscal decision making.

There was seemingly less awareness of the more subtle bio-politics implicit in the attitude several of them had toward their preferred role in any carer/cared for relationship, willingly identifying with the carer role, but eschewing being cared for lest they be a ‘burden’. The two oldest participants had quite a different perspective. Though they grieved the lifestyle lost to age related disability and frailty, they didn’t regard themselves as burdens either economically or personally. They were both interested in making the most of what time they had left and in this the quality of the care available was integral.

Chapter Five: Older Women Speak Out About Voluntary Euthanasia

Introduction

By having an Enduring Power of Attorney (EPOA) and an Advance Health Directive (AHD) in place, four of the women in this study had taken the precaution of volunteering information about how they wanted their terminal care managed, at least as far as they could legally do so. They were clearly saying no to the *"… 'halfway technology' … that neutralises the effects of certain life-threatening diseases without actually healing the patient"* (Hill & Shirley, 1992: 21) because they just wanted to be kept comfortable and not to suffer through the dying process. Though the other eight participants had not yet taken action to formalise a statement of their wishes, they too indicated during our discussion that they rejected any over-medicalising of terminal care for themselves.

Autonomy in decision making about one's own future is a respected value in our society but one with considerable constraints attached, especially when it comes to the human body (Cosic, 2003). For example, though suicide is not against the law, seldom is the '… *right to commit suicide presented as … self-destruction justified as an assertion of personal liberty"* (Lieberman, 2003: 39). Reluctance to talk about death, which the participants had found to be frustratingly commonplace among their contemporaries, is exacerbated in the case of suicide. People feel uneasy about someone *choosing* death and are often horrified by the thought of how it was done when extreme measures are involved (Cline, 1995). Yet suicide seems the only legal choice open to the terminally ill who seek death because they are in intolerable pain, or threatened by such a prospect, but are unable to access legal assistance to die (Magnusson, 2002).

This chapter focuses on the participants' perspectives on the idea of being assisted to die, which is essentially what voluntary euthanasia is all about. It would have been surprising if any of them had failed to form some opinion about voluntary euthanasia because it had been the focus of considerable media interest in the several months prior to their being interviewed. For the most part though, they had well formed views on the subject which this publicity did little to change.

How they perceived choices in terminal care generally will be explored as will their frustration about the many contradictions they identified in medico-legal, religious and political arguments supporting current end of life practices. The way they spoke out about rights in reference to accessing assistance to die raises several important concerns that contrast the power of hope with the powerlessness of exploitation, misuse and abuse as these positions represent the extremes in the debate around legalising voluntary euthanasia. The reflection section explores this emergent issue of a rights discourse and its potential to challenge the medicalising and privatising of terminal care. This is consistent with a view that a discursive approach to human rights "… *recognises that rights are constructed through human interaction and through an on-going dialogue about what should constitute a common humanity"* (Ife, 2001: 6).

Setting the Scene

From the late 1990s, a radicalised voluntary euthanasia lobby directed by the seemingly tireless Philip Nitschke has been courting national attention with a range of strategies designed to ensure that the issue of accessing the choice of a peaceful death at a time of one's choosing remains in the spotlight of public attention. The passion which advocates of voluntary euthanasia feel for advancing this cause has been translated into very public action in recent years. Two examples which were particularly notable in 2002 involved Nancy Crick in Queensland and Lisette Nigot in West Australia. Each had suicided, leaving behind very public statements which stressed that, their reasons for having taken this action while they were still able to do so independently, was because their preferred choice, to access assistance to die at a later date, when they might be in intolerable pain and unable to take their own life unaided, would not have been available to them in the foreseeable future. Adding to the controversy these deaths aroused because of their connection to the voluntary euthanasia lobby, was the furore created when it was revealed that Nancy Crick was in remission from cancer and that Lisette Nigot was in relatively sound health – where then was the excuse for such precipitate action!

Nancy had maintained a website until immediately before her death and entries in her diary left little doubt of the suffering she endured on a daily basis as a consequence of the effects of cancer and the aftermath of her treatment regime. Apart from the controversy surrounding the circumstance of her death, she left another legacy which had wide ramifications. She had 21 other people with her as she took her life which created a legal dilemma over whether these people would/should be charged with assisting her death just by being there with her (Nitschke & Stewart, 2005; Tulloch, 2005). Lisette had made a documentary film, "Mademoiselle and the Doctor", telling the story of what led to her decision to suicide on the eve of her eightieth birthday and why she chose to act while she was still able to do so independently. This film is a compelling example of an older woman's determination to contribute her voice in a lasting way to the on-going dialogue about the right to die at a time of one's choice (Nitschke & Stewart, 2005).

Both women's death are consistent with what the voluntary euthanasia lobby labels a rational suicide, that is, rational as opposed to depressive or other reasons of a psychological nature, which by implication, are irrational. The claim that such distinctions are in fact illusory is an important contribution to the debate because it suggests that both rational and irrational elements may be involved but to varying degrees and that it is, therefore, very possible to be of sound mind when choosing suicide (Williams, 2001). Both Nancy and Lisette consistently denied being depressed and may well have been able to demonstrate this had they been examined by a psychiatrist. The four people who had been able to take advantage of the Northern Territory Rights of the Terminally Ill (ROTI) legislation before it was overthrown by a hostile federal government in 1997 had all been given the 'of sound mind' clearance required as one of the criteria for acceptance to be assisted to die (Nitschke & Stewart, 2005).

The brief period during which the ROTI legislation was viable won notoriety for the Northern Territory which was the first jurisdiction in the world to have legalised voluntary euthanasia, but won notoriety also for the presiding doctor, Philip Nitschke, who was then, and is still, frequently pejoratively labelled by the media as Dr Death. He is the Doctor referred to in the documentary "Mademoiselle and the Doctor" and has continued to be involved in activism around voluntary euthanasia, conducting workshops throughout Australia and on the world stage. Pat, one of the participants in this study, had attended a workshop a few months before being interviewed and most other participants knew about him, at least to some degree. Most too had some knowledge of overseas activism particularly in the Netherlands.

Widespread community support for voluntary euthanasia and physician assisted suicide has been reported in national survey data in Australia over the past several decades (Nitschke & Stewart, 2005; Magnusson 2002) and in more recent and rigorous research in Queensland (Cartright et al, 2002) but this has not been reflected in law change anywhere in Australia other than the Northern Territory's bold, but doomed, attempt to lead the way. Opposition to arguments in support of legalising voluntary euthanasia is usually couched in terms either of the sanctity of life doctrine or of the dangers of an insidious slippery slope effect (Tulloch, 2005; Magnusson, 2002). According to Tulloch the latter is the leading argument against voluntary euthanasia today but is a fear that can be contested on the facts emerging from overseas experience with radical law change such as the Netherlands and the state of Oregon in the United States of America (Tulloch, 2005).

In Support of Voluntary Euthanasia and Physician Assisted Suicide

Choice and Agency

As a self selected group, the women in this study had come prepared to speak out about voluntary euthanasia and, although some of them had reservations, they were generally sympathetic to the idea that the terminally ill should have the right to access assistance to die as an end of life option. The opportunity to explore their thoughts about this contentious issue was appreciated especially by those who felt constrained in most other circumstances. This reflected the tacit taboo that generally prevailed where talking about death and dying were concerned, but it also reflected their experience of opposition to euthanasia. Judith had specifically mentioned that:

> "Most people I know won't entertain the thought of voluntary euthanasia." (Judith)

She had also commented that she was:

> "… pro-euthanasia although by the same token I do attend church regularly and that conflicts with what the church teaches but that's how I feel. I was going to go back to Darwin to live if euthanasia was introduced because I still think there's a probability I could die of cancer, it has a habit of creeping back (she had bowel cancer in 1979)". (Judith)

Gladys told a love story with a tragically poignant ending about her father's role in helping her terminally ill mother to die. Gladys learned of this some years after the event but had no doubt her father had carried out her mother's wish when he delayed calling the doctor to administer the treatment regime which had been keeping her mother alive. The doctor had accused her father of culpability and threatened to report him but because there was no real evidence, and her father had denied there was any delay, no action was taken.

> “I realized he had to tell someone and he told me. My father had to kill the one thing he loved most in the world because she’d had enough and the doctor wouldn’t do more than give her more injections. My father had huge guilt, but he had to do it. His action was done in total love. He wasn’t guilty of murder it was a kindness. It was so sad for him, all he wanted to do was die and be with her forever. When I heard about being a participant here I thought, yes I’d like to donate my father’s story.” (Gladys)

Her father’s action in delaying treatment is an example of passive voluntary euthanasia (Tulloch, 2005; Cosic, 2003). Gladys certainly thought of it in that way and was adamant it was not murder. She believed that other people were being forced to take similar action but that we don’t know about it. It is not talked about openly because people fear prosecution.

Pat too lamented this reluctance to talk about what was happening now. She had attended one of the voluntary euthanasia workshops held here in Townsville and had been interviewed by the local paper.

> “I thought it was absolutely one of the very best groups I’ve ever been to. I had lots of arguments with people about calling Philip Nitschke ‘Dr Death’. I was furious (about this). People don’t want to know about the sort of things he talked about. I seem to be surrounded by people who don’t want to talk about these things. I must be very different from them. (Pat)

When asked what they understood about voluntary euthanasia, each of the participants described it in a similar way namely that it involves a dying person asking to be assisted to end her/his life in a:

> “… peaceful manner … with some dignity … not having to endure suffering … (and it must be) the person’s real wish”. (Ann)

> "I think it applies to people who are really sick, terminally ill. I should be able to say I don't want to live any longer. I've had enough of this pain. I'm not going to get any better no matter what you give me. All you are doing is prolonging my life in this miserable state and I don't want it any longer … if we didn't have the technology and the facilities to keep me alive I'd be dead anyway." (Lucy)

> "I want no life support but I don't want to be pressured into it (voluntary euthanasia) either. I'd tell them, not today thank you. I'd like to think I'd get the call, a signal when it was time to go …" (Judith)

Participants were aware that there were legal constraints on access to voluntary euthanasia as an option currently, and all but one challenged this position as a violation of their right to such a choice. The dissenting opinion was based on a view that though voluntary euthanasia:

> "… does happen, it (the recent suicide by voluntary euthanasia advocate (Nancy Crick), sort of bothered me that they did this publicly (with twenty-one people present challenging the law and Nancy's web-diary). The media being involved for such a private thing, I think, set the cause back (and) made it like a three ring circus. The media inhibits the quietness and this can do a lot of damage to what many of us have been doing for many years. It's a private thing I think. We were able to do it informally (arrange voluntary euthanasia for her terminally ill partner). If we'd had to go legally we wouldn't have been able to do it so we had to be careful talking about it." (Marian)

Marian's position suggests choice of doctor is the crucial ingredient in being able to access voluntary euthanasia at this point in time and that some informal knowledge network is involved in locating those doctors. She had cautioned though, that care was needed to safeguard these informal networks from damage by exposure.

Most of the other participants gave no indication that they had such a strategy in mind. Indeed Marian seemed to have had access to privileged knowledge which contrasted with the general frustration and concern others expressed about the reality of limited agency in this regard.

> "I would be devastated if I asked for help to die and was ignored. I wouldn't like it but I would have to accept it and do whatever came, but I wouldn't like it. I'd feel awful, I'd feel despair." (Eva)

> "We are supposed to live in a democracy so it should cover everything, so, if you don't want to live then you should be able to get help." (Madeline)

> "It seems unjust to me that you can't have authority over your own body. You would have to be terminally ill, but if the person has made the decision when they are in their right mind and healthy, just like when you make a will, I do not believe that the state or government has the right to tell you what you can or can't do with your own body." (Alicia)

Judith did intimate that she believed it was possible to access assistance but not how this could help her.

> "I would like to get assistance to go when the time comes. Doctors have been doing this for years. But I can't get that help legally now." (Judith)

As mentioned above Judith had intended to go to Darwin to be able to access assistance to die legally when she might need it but that avenue was now closed with the demise of the ROTI Act.

Resisting the Status Quo

Marian's experience was the exception when compared with that of others in this study, insofar as she was the only one of them who had knowingly been in the presence of active voluntary euthanasia. Her brief description of the circumstances involved in her husband's death bore similarities to accounts of the approach taken by Timothy Quill, an activist in the physician assisted death controversy in the United States. The metaphor which is the title of his book, *"A Midwife Through the Dying Process"* (1996) tellingly sums up the philosophy espoused by Quill and his practice partners, who describe their work with dying patients, their families and those concerned in the treatment process, as a collaborative partnership. Marian's cautioning also seemed to reflect Quill's realistic acknowledgment that "… *current ethical thinking and restrictive laws (*make*) it unsafe for physicians to walk with their* *dying patients when their path enters uncertain terrain"* (Quill, 1996: 25). His book tells of how he and his colleagues negotiated that unsafe terrain.

Marian's family had been able to access "… *a chosen death and an end of pain outside the law* (accessible) *for those with connections …"* (Magnusson, 2002: 280). Their's was a privileged and private resistance to the legal status quo and safe, while they were "… careful in talking about it …" (Marian). Marian's opposition to the very public demonstration of resistance which Nancy Crick had organised to ensure that she didn't die alone when she took her life, and that others were challenged to think about what had motivated her action, seemed based on its being a potential threat to privileged access to assistance. Nancy's and Lisette Nigot's action in seeking publicity to promote the case for law change and encourage debate was, however, deliberately challenging such privilege.

For all that she had reservations, Marian was not unequivocally opposed to law change. Her concerns were about the direction it might take.

> "It would depend on how the law was changed and if you had to see lots of people and make it a cause celebre. It comes down to whether you want the doctors or the lawyers to decide what your end will be." (Marian)

Because of her preference to leave things the way they are it seems clear that Marian favoured doctor controlled outcomes but would have some ambivalence about a law modelled on the Northern Territory ROTI Act. Though that process was doctor controlled, it required two physicians and a psychiatrist to be consulted, and for them all to agree, in order that the process went ahead (Nitschke & Stewart, 2005; Tulloch, 2005). That would have been too much like a "cause celebre" for her.

Of the other women who were definitely in favour of law change, several expressed concerns about safeguarding autonomy in the decision making process.

> "I wouldn't like to see the law changed if it could be manipulated. It'd have to be like an EPOA. When you do your will if you could include a thing that said I believe in euthanasia and if at some time in my life I become a vegetable, or in a coma, and it's known I'm not going to recover - I don't want palliative care either - I would like someone to assist me to die, preferably not someone in the family, so that it could be done professionally and that's the end of it. It

> seems to me such an automatic thing when you can write all sorts of other things in your will." (Alicia)
>
> "I just naturally assume there would have to be safeguards in there with any law change. You can't just whack someone in a mental institution there is legal protection this could be a similar situation." (Pat)
>
> "I think the average GP understands their patients well enough to prevent abuse of the law." (Judith)
>
> "I think a reliable doctor who knows your true medical condition could save you from being popped off. I've most definitely thought about this and support law change." (Ann)

There was concern too about how the rights of patients in the current system were safeguarded and what might be happening through involuntary euthanasia as:

> "… slow death by removing tubes if someone is wanting to move that person along. That's not right." (Joy)

Marian too was concerned about the possibility of involuntary euthanasia for, although she believed in doctor control of end of life management, and her family had been able to access such assistance, she was opposed to the principle of double effect which she heard could be invoked without consultation with the patient.

Overall there was uncertainty about how terminal illness was managed outside their personal experience and, although some had an AHD in place or were contemplating completing this documentation of their wishes, there was a measure of unease about what might happen in circumstances not covered in an AHD. Speaking out, even in a small way as they were in this study, was a contribution they felt they could make to protest the silence that generally surrounds discussion about death and dying. They thought it may also open up more discussion about what may lead some people who wish to, but are unable, to access assistance to die to then choose to suicide.

Suicide

Gladys had thought that suicide was against the law in the same way as voluntary euthanasia is and was surprised to learn it was not. Her misunderstanding about the legal status of suicide may reflect the pejorative associations that suicide continues to attract. Dominant regulatory discourses in our society ensure an atmosphere prevails in which suicide is not generally sanctioned as a legitimate option. Those who succeed as suicides are likely to attract stigma and shame as their lasting memorial, those who contemplate it are to be dissuaded wherever possible, and those who attempt it are to be saved if found in time.

Gladys did not believe that suicide was morally wrong even though she had believed it to be illegal.

> “I don’t have any reason to commit suicide. I’m still enjoying myself and I don’t have a reason to, but if somebody else does that’s their business.” (Gladys)

She believed her father had not been guilty of any crime either when he supported her mother’s wish to die by taking no action to save her.

> “He broke the law, but he did the right thing. It was very hard for him to do it and he shouldn’t have had to do what he did.” (Gladys)

There are close parallels between suicide and voluntary euthanasia, both active and passive, especially in instances which can more accurately be described as, physician assisted suicide, when an individual patient is provided with the means to suicide at the time and in the circumstances of their choosing. This is what happens under the Oregon legislation. Marian had made these connections when talking about voluntary euthanasia.

> “Voluntary euthanasia is about deciding that you would like to terminate your life (and went on to add) I do not see the difference between suicide and voluntary euthanasia.” (Marian)

All the women in this study believed that ultimately the choice to suicide was in the individual’s own hands and was an especially understandable and rational choice if the person were terminally ill and confronting intolerable suffering. Some had reservations about generalising too widely beyond that, however. Joy, who is a practising Christian said about Lisette Nigot:

> “I think it’s a shame she had to do it at that stage because there would be no one to help her later. It’s a lot like MND, if you got diagnosed with that you’d have to decide when you wanted someone to step in and help you, and if you haven’t got someone, you’d have to do it earlier. That’s your decision if you know what lies ahead. If you don’t want to go there you can exit before you get there. I really think if you know what lies ahead of you - God’s got his plans of what’s going to happen to you - but if you say, I’m sorry I’ve got to exit now, I’m sure he’s going to understand why.” (Joy)

Joy could not unequivocally condone suicide outside the sort of situation outlined above but conceded it was an individual decision. She nevertheless found it difficult to imagine being in that situation herself. Pat on the other hand could say:

> “I don’t think it’s an unusual thing to think about suicide. I am surprised if people tell me they’ve never had suicidal thoughts.” (Pat)

Though informed by a different empathic awareness, these two women’s views about suicide shared the common ground of respect for autonomy in decision making and compassion for those confronted by intolerable suffering.

Lucy had despaired about what had happened to a woman she knew slightly who had attempted suicide using her car’s exhaust system but who had been found and resuscitated. This woman had planned that her two children would die with her as she didn’t want them to be taken into care but, though the mother had been saved, her children were both dead. Being ‘saved’ destined the mother to spend the remainder of her life in a mental institution, her psyche damaged, not only by the exhaust fumes and the life circumstances that had precipitated her suicide attempt, but also by the knowledge of what was:

> “… even worse - she’d killed her own children. You should never wake them in those circumstances. (Lucy added that) I feel very strongly that to suicide is a very courageous thing to be doing. It takes a lot of courage, you’d have to be down and out, totally down and out, before you’d consider doing that.

> So if you've got that many problems, would you want to be woken up again? I don't think so, the problems are going to be there again." (Lucy)

Syd as a telephone counsellor had mixed feelings about the current thinking within the organization for which she works.

> "I have a lot of difficulty because the directive is to talk them out of it at any cost. I put this against my own values and my feeling that respect for the caller is my first consideration. I try to explore options they have already run through and others they may not have thought of. If they still want to go ahead, they go with my blessing." (Syd)

Syd thought there was a veiled contradiction in being expected to 'rescue' the caller by talking them out of what was a lawful act on the assumption that the caller was indirectly seeking help by reaching out. It seemed to her that, if somebody has made the decision to suicide, they could also be saying this is the last power I believe I have and, in reaching out, they could be seeking validation of that final right to agency.

People can change their minds, of course, as an experience Inge related attests. She had contemplated suicide some years earlier after suffering a nervous breakdown.

> "I did have a handful of pills one time but I didn't take them. The face, looking at me wanting to take the tablets, in the mirror that was in the room, wasn't me. It was very interesting to me that something was still there to say life is sweet. I was not ready to die then but when I am ready, I'll be very happy with voluntary euthanasia. I wouldn't want to upset my children (whom she believed would not agree with her about voluntary euthanasia) more than necessary but what I want is more important." (Inge)

Ann was adamant that, should she be terminally ill and her condition was deteriorating past a point when she felt all quality had gone from her life, she would take her life.

> "I can do that at any time anyhow but I should be given the means to do it with some dignity. If someone could help me, good and fine, but it would have to be without them having to face prosecution." (Ann)

Lucy also was prepared to act for herself but was fearful that she might leave it too late.

> "I may be too weak or not be able to access enough pills so someone has to help me. (She therefore supports law change but with stringent safeguards.) It would have to be well documented and have several people saying it was OK to prevent bribing the doctor or others." (Lucy)

As a nurse she had more knowledge than most of the other participants about means but, sometimes knowledge alone is not enough to provide the comfort that access to assistance would provide.

Assisting Suicide

Gladys had remarked when expressing her frustration about not having legal access to voluntary euthanasia that she wouldn't know what to do or who to ask for advice about alternative options. She emphatically dismissed talking to her doctor.

> "You can't ask your doctor can you, they might think I was insane." (Gladys)

Alicia *had* talked to her doctor about writing down somewhere that she believed in euthanasia and would want assistance if she were in a vegetative or comatose state.

> "He looked at me and said no you can't do that and don't tell your children too much either because they'll end up in jail." (Alicia)

The law prohibiting voluntary euthanasia and assisted suicide was a definite deterrent to these women and, though Marian had been able to circumvent its constraints in her particular circumstances, she was nevertheless acutely conscious of what might have happened without her privileged connections.

Madeline, though she supported law change, had given thought to another important element quite apart from the legal considerations.

> "I would like the law changed although it is difficult. You don't want to involve someone else and perhaps that person will feel guilty later in life." (Madeline)

Lucy recounted a conversation in which a nursing colleague had personalised this very concern. In her colleague's opinion:

> "People who want euthanasia are very selfish and thinking only of themselves, not about what it's doing to those who have to administer that last injection or whatever. She (Lucy's colleague) would not want to be the one to feel guilty for the rest of her life." (Lucy)

Alicia had a different perspective. She believed that her suggestion of a formal declaration of a person's intention as an adjunct to their will would forestall such problems.

> "I'd like to have it written down somewhere so that no one got a conscience about it. They'd just be doing whatever it is I'd said I wanted." (Alicia)

As mentioned above she had also believed that a professional person would be the best person to provide assistance to die rather than a family member.

Gladys' father had felt the burden of guilt, although that may have been associated with having held on to the secret about his actions for so long as much as with the action itself. In Gladys' opinion his was an act "of kindness."

Ann believed she would be able to help someone.

> "I would be able to help somebody if I didn't have to go to jail. If I thought I was doing it against the law I wouldn't do it as much as I would want to. I wouldn't put myself in that position. If it was legal and all conditions met, yes, I think I probably would help someone." (Ann)

Ann's description of her feelings about her partner's last days captured the sense of compassion implicit in her willingness to assist someone wanting to die. She had said then:

> "It's not that you want to see your loved ones die but you want to see them out of their pain. I knew it wasn't going to get any better for him and the sooner it happened he would be out of his pain and suffering. I looked on it as a loving thing wanting to see the end of that." (Ann)

Assisted suicide is a crime in Australia, however, and if the person or persons providing that assistance are charged and found guilty, they face a lengthy jail sentence. Even being in the presence of someone who suicides could be construed as assisting, or encouraging the suicide. Those present at Nancy Crick's suicide had been faced with that possibility. They were not charged because there was insufficient evidence to establish that assistance was provided, but, that decision was not announced until two years later. There is still uncertainty about how any similar situations in the future would be construed because the decision not to charge was not made by the court (Nitschke & Stewart, 2005).

Ann's wish to be provided with the means to die with dignity would contravene the current law and there is some uncertainty about how being provided with information about accessing the means would be construed. This latter point is a major concern for advocates of voluntary euthanasia who believe people should have access to such information. Since January 2006, however, they have been prohibited by law from disseminating such information through the normal electronic channels they had been using prior to that date (Deliverance Exit International Newsletter Feb-March, 2006).

The state of Oregon in the US which has permitted physician assisted suicide since 1997, framed its law to permit a doctor to prescribe a lethal dose of medication to eligible terminally ill patients on their request. That of course circumvents any problems about direct assistance in administering the lethal dose or injection and is consistent with the view that to have access to the means (preferably legal access) provides peace of mind to the dying person who can plan their end and then get on with living (Cosic, 2003). Gladys had identified the potential for that outcome.

> "It'd be nice to have that law. Knowing it was there you would think I'll be right for another few weeks, or I can go on a bit longer. You might go on and on like that. It encourages you. It'd be a comfort." (Gladys)

It would also give Ann peace of mind knowing she could legally access the means to her end.

Contradictions

Media Message

It is somewhat paradoxical that though these participants, most of whom favoured law change, were expressing opinions consistent with widespread community support for access to voluntary euthanasia (Nitschke & Stewart, 2005; Tulloch 2005; Magnusson, 2002), they were more conscious of opposition to, rather than support for, such change. The media coverage of the deaths of Nancy Crick and Lisette Nigot had reinforced their perception of that opposition.

> "The media treated them very cruelly and unfairly, sensationalising it all and not looking at the real lives of the women and showing them as doing what they had a right to do. It was all negative for those women and for those who are for voluntary euthanasia. I don't see anything positive coming out of the media about voluntary euthanasia." (Ann)

> "They were made to look like silly old women who all they had to do was take a couple more tablets and they'd be all right (the implication being they were just depressed)." (Inge)

Marian was of the opinion that neither of the women was depressed or in need of friends, the latter being another explanation offered by opponents of their actions.

> "I didn't get the idea that these were women who needed friends. It seemed they were surrounded by friends. I got the feeling that the women doing what they did would be strong women." (Marian)

Most spoke of the issues being sensationalised, particularly in television coverage, and of how this evoked negative connotations not dissimilar to those inferred by Marian's reference to a "three ring circus" – too many other things vying for attention for the main act to hold the spotlight.

Madeline had a similar reaction but was concerned that, any support for the voluntary euthanasia cause, was totally eclipsed by the media's focus on challenging the women's justification for suiciding if they weren't terminally ill. She thought it was easier for the media to challenge women's motives because, it seemed to her, our society thinks of suicide as an act of weakness and of women as the weaker sex. She would rather the women had been:

> "… left alone and not made a fuss about. It was as if they had committed a crime." (Madeline)

Syd also thought the women were portrayed most unjustly and the media had much to answer for.

> "I was very concerned at the trial by media. I'm very concerned with the media generally, I see it as totally dishonest, immoral and negative." (Syd)

The 'Dr Death' labelling of Philip Nitschke had angered Pat although she had been able to say that:

> "… the people talking on Radio National seemed to be quite caring." (Pat)

With the latter sort of reporting being more the exception than the rule from these participants' perspective, it is not surprising that none of them brought up the opinion polling results about voluntary euthanasia – they would have heard little about it. Perhaps too it was cynicism given the resistance politicians have shown to these polls, evidenced most notably by the overthrow of the Northern Territory ROTI Act of 1996 by a federal government decision the following year.

Syd was one who dismissed the influence of opinion polls and other public demonstrations of feelings about contentious issues, citing as an example, the mass rallies in Australia against participation in the Iraq war which had been taking place around the time of our interview.

> "People don't want the war but we're getting it anyhow. Politicians are not prepared to act for those who want voluntary euthanasia either." (Syd)

Sanctity of Life

The war as it entailed sending soldiers off to face possible death was cited by other participants as evidence of the hypocrisy inherent in the arguments which suggest sanctity of life is the basis for denying access to voluntary euthanasia.

> “The way we are now, where are our morals? We send soldiers over there to be killed – the sanctity of life! (her exasperation was palpable)”. (Inge)

Syd had raised another contradiction evident to her in the government’s support for involvement in the Iraq war.

> “How come we are able to send an army when we can’t afford to man our hospitals or afford to look after our old people?” (Syd)

Marian felt strongly about sanctioning the war too and echoed Syd’s concerns about resource allocation.

> “That sort of thing I think is wrong (sanctioning war). That’s wrong. Keeping *food* away from people who need it is wrong.” (Marian)

Marian had a strong social conscience and believed poverty was a sanctity of life issue if anything was and she questioned signs of real commitment to that cause from those with the power to effect change and influence opinions in support of such change.

Marian had also observed that something must be very wrong in people’s lives if suicide seemed the best answer to their problems.

> “If somebody says my life is an utter pain and I want to end it all, they got a right to and, if we’re concerned about it, we should do something to make their lives more desirable, ask what we can do to change their lives so they don’t feel they want to get out of it, provide the best care possible, for example.” (Marian)

Her rejoinder to the argument that resources are scarce was:

> “Unless you want to buy a new bomber.” (Marian)

Madeline had an explanation for the incongruence she too perceived between societal attitudes which support a sanctity of life argument yet perpetuate pejorative attitudes which stigmatise those who suicide, or attempt it, and their families.

> "Perhaps it's the guilt in society. If people suicide there must be something wrong with the system." (Madeline)

For her, negative attitudes about suicide are really a form of societal projection - people would rather blame the victim than change the system.

Gladys made a different association in challenging sanctity of life arguments.

> "I get troubled about the Catholic Church saying you're not allowed to use condoms even if you've got AIDS. They can pass on death like that. That sort of thing I get angry about but I don't about people wanting voluntary euthanasia or suiciding." (Gladys)

Judith made particular mention of yet another area of concern which challenges sanctity of life arguments. She recalled the stigma, ostracism and shame she and her family had felt because she had a brother who she said was labelled in those days as sub-normal. Her parents, though advised to send him away to an institution – the "asylum" Judith had called it - had chosen to keep him with them in their own home.

> "That had a profound effect on our lives. There was always a stigma. At school I was known as having the mad brother and my parents were shunned in certain society. They don't want the odd one out." (Judith)

Madeline had been the full time carer for her daughter who had been born with a disability. There had been changes in the way people with disability were regarded in the period that separated Judith's family's experience from Madeline's but Madeline could still say:

> "It's a big challenge being the mother of a child with disability. People with disability are more recognised now where before they (the broader society) were trying to hide them. (When her daughter died Madeline said) … I was so

> angry when people talked to me about God, saying she'll be better off and she'll be whole." (Madeline)

Madeline's example of the 'better off dead' inference in such a remark stands in sharp contrast to a sanctity of life ethic. Perhaps this is another example of societal projection where it is society which is disabled: blind and deaf to its contradictions and incongruence, and seemingly paralysed when it comes to changing attitudes.

In all these examples, participants were contesting the veracity of a concept of sanctity of life that did not also embrace quality of life as an integral guiding principle, intimating that without such a principle, moral and ethical judgments that shape public policies and practices in our society are flawed. In their view this was particularly evident where a terminally ill person who sought assistance to die with dignity because of diminished quality of life was denied the right to have their decision respected. At the same time, they recognised that, were this right granted, there would have to be safeguards in place to monitor potential abuse or misuse of the power which those entrusted with providing assistance would hold.

Slippery Slope

Opponents of legalising voluntary euthanasia, however, believe it is impossible to implement safeguards effective enough to protect against the *"slippery slope to Auschwitz"* (Leming & Dickinson, 2007: 296) effect. This is an argument that suggests that if voluntary euthanasia should be legalised it may not be possible to control its interpretation and, therefore, where and how it might be used against vulnerable people (Cosic, 2003).

Inge had pointed out that suicide is sometimes a rational choice made for very pragmatic reasons, such as the survival of the social group.

> "I've read that it is an Eskimo custom, especially for the women, that when they know the end is coming, they just walk off into the snow. They just say goodbye and off they go. What strong characters they must be to do that." (Inge)

Inge offered this example more by way of an aside than as a model to emulate, but ironically, self-sacrifice is one of the slippery slope effects which, it is suggested, could be an outcome of legalising voluntary euthanasia. Feminist ethicists are concerned that older women in particular might be influenced to choose voluntary euthanasia, should they perceive themselves to be a burden on family or society, because they are well conditioned to self-sacrifice.

Madeline had, coincidentally, envisaged a tropical version of this Eskimo custom as a method of suicide which she might choose for herself although, in her case it was not being proposed as an act of self sacrifice. Rather it was a creative and pragmatic approach to the problem of not having access to assistance to die.

> "I think I would walk into the sea, perhaps a stormy sea. I would provide a meal for a shark and there'd be no funeral fees for anyone to worry about either." (Madeline)

Madeline favoured drowning because she believed it was not an unpleasant way to die and it was accessible to her. It was certainly a less violent choice than hanging which Philip Nitschke says is the most common method chosen by older people because "(*r*)*ope is always available and hanging works"* (Nitschke & Stewart, 2005: 187). Dr Nitschke believes that people should not be driven to use extreme methods like hanging (and drowning), or to fail in the attempt and be worse off than before, as Lucy's story about the woman who attempted suicide using the car exhaust illustrates.

Suicide could be perceived as an example of individual autonomy in action where the individual has a measure of control over deciding the timing and method of death. Not having access to a method which effectively ensures death with dignity places limits on choice, however, and pressures the person determined to suicide to use whatever method is available. This presents, in effect, an obverse perspective on the slippery slope effect - vulnerable people, potentially made more vulnerable, when excluded from knowledge and or assistance which enables them to die with dignity. Lucy had very real concerns about this.

> "My only fear I have is being incapacitated to the extent that I can't do it for myself any more. I don't want to be kept alive that's the one thing I know for a fact." (Lucy)

In giving voice to her fear, Lucy was echoing the sentiments which had driven people like Nancy Crick and Lisette Nigot to suicide precipitately rather than risk not being able to do it for themselves later, nor to access assistance. This together with the very strong feelings Lucy also had about over-medicalisation of the dying process could be seen as having the potential to push her down a slippery slope to a premature death.

> "There should be a cut off point somewhere. If I'm riddled with cancer and I don't want to be alive any more. I don't want that. I think we've gone too far in the medical thing when we keep people alive against their wishes." (Lucy)

Principle of Double Effect

Fears of the slippery slope which could propel the vulnerable to unsolicited assistance to die, or alternatively propel them to premature suicide has yet another potential launching pad lurking, seemingly innocuously, within the principle of double effect.

Only Joy had direct knowledge of the principle of double effect through her training as a volunteer with the local palliative care service. She had been reassured by the doctor in charge during a training session that the intention to relieve pain with a steady increase in the dosage of pain control medication was not to be confused with an intention to kill. He had given an example of what could happen if dosages were mixed up for two patients with different pain control needs.

> "Patient A would likely have an uncomfortable night, Patient B the best sleep he'd had in ages. He (the doctor) says you can't just slip in the extra dose of morphine to kill the patient." (Joy)

Voluntary euthanasia advocate, Philip Nitschke, is very outspoken about the principle of double effect which he says is also known as terminal sedation and which is really slow euthanasia. He suggests that under the cover of the principle of double effect, slow euthanasia is semantically disguised and definitionally sanitised and is the way doctors can stay "… *within our current moral and legal frameworks.* (He does concede though that it remains) *… the only means doctors have to safely skirt bad laws …"* (Nitschke & Stewart, 2005: 159–160).

Skirting the law in other circumstances as the doctor attending Marian's partner had done in providing assistance for him to die was clearly active voluntary euthanasia and a risky practice. It is a matter of speculation how often this occurs but survey data collected by the Australian Medical Association in 1994 indicated that fifty percent of its members would hasten death if active voluntary euthanasia were legal, which suggests some doctors might be sympathetic to requests for assistance (Tulloch, 2005: 119). It is also a matter for speculation how often the principle of double effect is invoked openly and with the understanding of the patient as opposed to being entirely at the discretion of the presiding doctor.

Several participants commented that they believed doctors had been helping patients to die over the years but, because it wasn't something that was talked about openly, they had no real evidence or knowledge. Those with an AHD had made the decision that they wanted to be allowed to die naturally when their time came and were in effect requesting access to passive voluntary euthanasia (Leming & Dickinson, 2007). That could of course mean there was the possibility that the principle of double effect would be invoked in managing their pain. Hopefully this would be discussed with them but there are no guarantees (Nitschke & Stewart, 2005; Cosic, 2003; Magnusson, 2002).

Critical Reflections

Parallels with the Abortion Debate – a different end of life experience

The secrecy and uncertainty surrounding how and under what circumstances euthanasia is being practised in Australia is perhaps nowhere more graphically reported than in Roger Magnusson's expose of the "*euthanasia underground*" (Magnusson, 2002: 1). In exploring the lawless environment that has evolved in the wake of the AIDS tragedy, Magnusson tellingly captures the realities of desperate people seeking an end to their misery and of their helpers, some with the skills and knowledge to do so effectively, others not so endowed. Magnusson talks about a *"knowledge vacuum"* (ibid: 269) which all too often compounds the vulnerability of the protagonists in these underground practices, and which may, therefore, lead to botched outcomes and further trauma for all concerned.

There are many familiar echoes in these stories of the recent past when women relied on backyard abortionists for assistance to terminate a pregnancy. Hurried, shrouded in secrecy and all too often beset by complications as a result of a "knowledge vacuum", these backyard operations were in effect an 'abortion underground'. Driven by desperation and fear - not only of the long arm of the law, but also of mistakes being made – there was little space for emotional comfort and support from family, friends and certainly not the 'practitioner' at a time of considerable personal trauma.

The primary goal of advocates lobbying for legalised abortion has been to ensure access to safe, affordable procedures, and, while abortion is still a contested issue from a number of perspectives, there would be a huge public outcry should there be any hint of a return to backyard practices as the only option for women today. Abortion was a reality when backyard practices proliferated and nothing, including legal prohibition, was effective in stemming the tide of demand. Euthanasia in all its forms - voluntary and involuntary, passive and active – is a present reality regardless of the law and, as Magnusson points out, must be acknowledged if we are to minimise harm. He concludes also that while legalisation and regulation are not without risk of the slippery slope predictions of misuse and abuse, if nothing is done, other risks pertain as is tragically evidenced in his research, where the slippery slope leads to the "underground".

By contrast the increasingly radicalised flank of the voluntary euthanasia advocacy movement, Exit International, which has been developing its organisational base over the past decade, has chosen a proactive strategy of publicity-attracting confrontation as it pursues its goal to provide members with real end of life options (Nitschke & Stewart, 2005). Philip Nitschke's vision is that dignity in dying is achievable through developing "… *a 'peaceful pill'* … *an accessible and reliable pill* … *possession of* (which) *would provide not only peace of mind for its owner, but the ability for them to have control over their own life and death"* (ibid: 298). Discussion of other methods of accessible, reliable suicide strategies have already been the subject of Exit's workshop and conference content material over these past several years, one very widely publicised example being, the *"Exit bag"* (ibid: 246 – 251).

> "I have no problem with Nitschke's method with the bag. I'd much rather go that way. Anyone who's had an operation knows it's nice to just fall asleep. There's nothing to it, just go to sleep." (Lucy)

Lucy had expressed the wish that she would die in her sleep but, if nature didn't take that course, she was prepared to find a way to help herself. The Exit bag to which she was not averse was an option for her it seems, especially if her fears of not being able to access enough pills are realised (see quote page 75).

Eva had also talked about death in terms of going to sleep, of how she liked to sleep and of a tablet that could achieve this end. At one point in our conversation she mused;

> "If I'm terminally ill and failing, I'd like to think I could have a party and then take my tablet. I'd do it because I'd think that's a reasonable and nice way to go. It would be in certain circumstances when you would feel that you've done enough, there's not another book you want to read and nature is taking over, and then you'd go to sleep." (Eva)

She had concerns about the Exit bag, however. Earlier in our conversation she had observed when reflecting on the publicity surrounding Philip Nitschke's visit to Townsville:

> "I didn't like the bag when I read about it, I thought I was being smothered right then, but if I was in unbearable pain I think I could say, put it on." (Eva)

There is, of course, no ready access to either an Exit bag or a peaceful pill currently, although several members of Exit have engaged in a project to create the latter in a makeshift laboratory in a secret location and reported on this at the Exit International Conference in Brisbane in 2005. This tactic was also testing the law once again as the twenty-one people present at Nancy Crick's death had done by being present when she suicided. The federal government is determined to quell activities such as the manufacturing of a peaceful pill it seems and, while no action has yet been taken against the group who were experimenting with the peaceful pill, legislation proclaimed in January 2006, casts a long shadow of uncertainty over any future similar ventures. This legislation which makes it an offence to transmit, view, copy or download suicide promotion material by fax, telephone, email and internet, has effectively curtailed much of Exit International's operations in disseminating information about right to die and end of life options through its regular electronic outlets (Nitschke & Stewart, 2006).

Exit has been consistently outspoken about its efforts to develop do-it-yourself methods for self-deliverance and has attracted a nationally distributed membership. A large percentage of these members are elderly and/or ill and many are prepared to take the risk inherent in negotiating the uncertain terrain created by ever more restrictive laws in order to access an effective, reliable means for ending their lives should they choose to use it at some future time. Driven more by determination than desperation, these advocates for autonomy in decision making about end of life options are vocal and creative in attracting attention to their cause much as the activism for choice in the abortion debate was driven by the determination of a vocal and creative women's movement.

Voluntary Euthanasia and Physician Assisted Suicide – Criminal Acts or Caring, Compassionate Acts

None of the participants talked about voluntary euthanasia/physician assisted suicide in a way which suggested they thought of it as a crime although they knew it was against the law. Marian had admitted to having been in breach of that law but most of the others were reluctant to risk the consequences of such involvement. This reluctance was, however, tempered by a sense of compassion for all those embroiled in terminal illness trauma, and they all believed it was morally defensible to provide assistance to die in these circumstances if the dying person requested it. These two examples of ambivalence highlight just some of the several perspectives from which participants viewed the legal risks.

> "No I wouldn't be comfortable breaking the law as it stands in Queensland. I am basically a law-abiding person. It wouldn't be the punishment. It is really respect for the law of the land, but I would have difficulty not helping someone like Nancy Crick. Reason? Respecting that person's decision and responding to that person's need, that would be more important to me than other considerations. If the law was different I wouldn't have any other ethical issue in helping somebody who felt I was the appropriate person, the trusted person and I felt it was really what they wanted to do and not something they'd dreamed up on the spur of the moment. A responsible decision and all other options had been explored and rejected then I would like to think that I could do it comfortably." (Syd)

> “I think it’s wrong someone reaches that stage of intolerable pain and their partner or loved one helps them and that person could be charged with murder, that is just so awful even though in most cases they’d be let off. Why should they have to face that afterwards. I don’t think that’s a criminal offence. But then I suppose if the son comes along and mum is getting to be too much of a nuisance, and he’s saying let’s give her the shove. How do you judge what’s right and wrong about allowing voluntary euthanasia when there’s all these different circumstances. How do you safeguard against someone being just sick of living or wanting to bump mum off. We need to talk more about these things, about dying and death. There needs to be more education.” (Joy)

Though she didn’t name it as such, Joy had identified one of the concerns raised in arguments about the slippery slope effect. The dilemma for her, however, with regard to law change was the lack of real dialogue about how this concern could be addressed. Indeed she wanted more dialogue about how all aspects of end of life concerns could be better managed. The protection of the vulnerable on both sides of the divide – those who seek access to voluntary euthanasia and those who need to be protected from coercion and involuntary euthanasia – would of necessity be an integral feature of such dialogue.

All participants were concerned to protect the vulnerable especially those whose pain and suffering are unresponsive to the treatment options available to them. All of them had named pain and suffering as a morally just reason for legalising voluntary euthanasia. Opponents of voluntary euthanasia argue, however, that palliative care, not hastening death, is the answer to this problem of intractable pain. Tellingly, these participants either knew little about palliative care and what to expect from it or, as Ann had, found it offered:

> “… a lot of talk but not a lot of action. Maybe their caseload is too high, maybe they don’t have enough staff to do it but it would be far better not to promise you these things and to make it clear what they could do. Palliative care didn’t live up to my expectations at all.” (Ann)

Ann’s compassion for the dying who could be released from their pain and suffering through voluntary euthanasia was directly related to her experience of the inadequacy of current palliative care provision. Her vulnerability as the primary carer for her dying partner had been exacerbated by having her hopes raised about what support to expect, then dashed as time passed and promises were broken. She was left with "lots of mixed feelings" (Ann) about her experiences.

Palliative care had featured in the impassioned rhetoric of religious and political opponents of voluntary euthanasia who argued successfully for maintaining the status quo in the lead up to the overthrow of the Northern Territory ROTI Act in 1997. These powerful voices had promoted palliative care as the appropriate and, by implication, the morally correct, way to support the dying. Yet there is little evidence of a similarly aggressive campaign mounted by these powerful voices, then and since, either in the parliament or out, demanding adequate resourcing of this valuable end of life option.

There is no doubt that models of good palliative care such as those described by specialists like Allan Kellehear (1999; McNamara, 2001) inspire hope and reassurance that we in Australia are in the forefront of activity in this evolving field of knowledge. The reality of an inadequately resourced palliative care response by contrast, inspires fear that, for some, the promise of good palliative care will be just another casualty of the health crisis and those in intractable pain left to suffer. This had been Ann's experience – the personal-political nexus that set her questioning the status quo which she found "… *full of embedded hypocrisy and covert subterfuge"* (Tulloch, 2005: 53).

Unfortunately this disparity between the reality and the rhetoric of palliative care provision is another under-discussed end of life issue. All too easily it can slip from the agenda of our death-defying, death-denying society and, for most people, assume significance only after an encounter with terminal illness. Without this sort of community conversation the tendency is, for either side in the arguments for and against the status quo, to each be convinced that their ethical position "… *is anchored to a moral rock"* (Magnusson quoted in Cosic, 2003: 264). There is little opportunity either to explore the significance of what specialists in the field of palliative care have to contribute to community conversations about the place of voluntary euthanasia in end of life care.

Allan Kellehear, for example, is quoted as saying that while "*(h)e doesn't believe voluntary euthanasia should ever be used … surprisingly … (he) also believes it should be legalised. The existential issue is that I wouldn't want people to take their* *lives* (but) *I'm not everyone, and I don't decide for everyone. And I think the multicultural, multisocial citizenship response is that euthanasia should be legalised. But I would like to live in a society where no-one used the legislation"* (Cosic, 2003: 263). He is not alone in questioning the oppositional alignment of palliative care with voluntary euthanasia, suggesting that some would value the latter having a complimentary position in their end of life care planning (Hunt, 1998; Birnie, 1998).

Emergent Concept: right to quality of life, a quality of dying concern

There was very little evidence that any of these women had seriously engaged in end of life planning beyond the completion of an AHD. Even then only three of them had done so. Given too, that the scope of this documentation is limited to the medical management of the dying process, there appear to be many gaps in their knowledge of what to expect. Most of them had more knowledge of and interest in voluntary euthanasia than of any other options. This could reflect either the success of the voluntary euthanasia lobby in rallying support for their cause or, to the effects of increased medicalisation and privatisation of dying and death which has characterised the evolution of the hospice and palliative care movement in Australia (McNamara, 2001).

McNamara is concerned to scrutinise the progress of these trends within palliative care because she has observed that, *"… palliative care has moved its emphasis from dying people to issues of symptom control and 'palliation', or the masking of the symptoms of dying"* (McNamara, 2001: 125). Her analysis of the politics underpinning this process exposes the dynamic manoeuvrings of institutionalised power through which palliative care is being mainstreamed to harden it up for survival in the competitive "… *economic and political milieu of Australian health and medical care"* (ibid: 131). The consequence has been that, rather than encouraging a greater acceptance of dying and death in society, this reversion to a medical model with its greater emphasis on medical intervention, is undermining that intention. Medicine's ascendency was relatively briefly eclipsed in end of life management when the "... *the rights of terminally ill persons began to be recognized and addressed in the 1960s"* (Hunt, 1998: 149). This was a time of major social movement activity around rights issues, and sweeping social, economic and political changes were evident in many western societies like ours.

For the dying this manifested in the emergence of the hospice alternative. Based on an holistically oriented approach to the dying person, hospice care shifted the emphasis from the "*curative mode of care*" characteristic of the acute hospital setting to a greater emphasis on quality of life concerns in which the dying person's agenda was of central concern (Hunt, 1998: 149). This approach is based on a social model of dying and emerged from a community based initiative and an innovative vision of what a good death could mean. Its evolution through to the present has not been without controversy and contention. Over time the "*… concept of hospice came to be seen as philosophy rather than a location"* (Jallard, 2006: 261) and in Australia the term palliative care is usually preferred to hospice although both are often used interchangeably. As it has become a specialised discipline and more widely recognised, some improvement in funding has occurred but as governments tighten the purse strings, palliative care is not high on the priority list of competing demands. The challenge becomes how to ensure that available resources are not insidiously channelled into the traditional medical model of clinical care at the expense of the more holistic ideals of the hospice philosophy (Jallard, 2006, McNamara, 2001; Kellehear, 1999).

Were the evolution of palliative care able to continue unencumbered by the influence of *"market populism"* (Sawer, 2005), the possibility may yet emerge for palliative care to accommodate a *"… shift from professional paternalism to …* (respect*) for patient autonomy …* (and) *acceptance of voluntary euthanasia"* (Hunt, 1998: 151). Hunt's suggestion is premised on the emphasis which both palliative care and the voluntary euthanasia movement place on quality of life as their core concern. It might also be possible to explore the use of cannabis and heroin as pain management options. The use of heroin for this purpose has strong advocates in some medical circles and, favourable reviews made of the once widely used '*Brompton Cocktail'* in which heroin was a standard ingredient, suggest *"heroin remains a medicine without superior, even after a hundred years"* (Carnwath & Smith, 2002: 151*).*

The case for legalising the medical use of cannabis was passionately argued by octogenarian author and researcher, Pauline Reilly in her book *"Cannabis and Cancer: Arthur's Story"* (2001*).* Desperate to find a way to relieve the suffering of her terminally ill husband, Pauline's research led her to try baking him cannabis biscuits. Though fearful of breaking the law, especially when she decided to grow her own supply of cannabis, the success of her efforts proved to be well worth the risk. The quality of her husband's last months of life was transformed - a transformation attested to by her husband's attending physician - and she determined it was important to tell her story to encourage legalising the medical use of cannabis.

All the participants in this study believed that, if cannabis could enhance the quality of life for someone who was terminally ill, it should be available for that purpose. Syd went on further to state that:

> "I class it along with alcohol and cigarettes and like them, it could be a source of income for the country and the quality of it could be controlled. I would like it to be made legal and to be readily prescribed for anyone who could get pain relief. I know several people who use it for that and very successfully and it's awful that they could go to jail for it. I believe that demonising anything only pushes it underground. I don't smoke myself but my concern with drugs is that we need to be better educated to the effects, and the side effects, of all drugs including things like antidepressants and we need to take more responsibility for ourselves." (Syd)

Gladys was also scathing of the drug offensive.

> "There's more people in jail in Australia for taking drugs than for breaking and entering and it's costing the country a fortune to feed and clothe them while they're locked away. It doesn't solve the drug problem. It's getting worse." (Gladys)

All participants were consistently concerned to ensure quality of life considerations were paramount in end of life care and that the terminally ill patient was the final judge of what this might mean in practice. They were also consistently concerned that there was little discussion of what to expect of end of life care and had concerns about how that "knowledge vacuum" might be challenged. Having their voices heard and being stimulated to think more about the issues that were raised in our conversations was a step in that direction perhaps, given Syd's observation that:

> "Little ways add up even though they are not seen, so if what we are doing here in this research makes a difference in one person that's important too." (Syd)

Summary

This chapter focused on the knowledge the participants had of the voluntary euthanasia debate and their feelings about current constraints on choosing this as an end of life option. In setting the scene I briefly outlined the cultural and socio-political context within which their perspectives were being shaped. This included the activities of a radicalised voluntary euthanasia lobby, under the leadership of the controversial and charismatic Philip Nitschke, which was promoting self help as a legitimate and rational choice for the terminally ill who sought an end to intolerable pain and suffering. Their activities were also a protest against the overthrow of the ground breaking Northern Territory Rights of the Terminally Ill (ROTI) legislation which had made that jurisdiction the first in the world to legalise voluntary euthanasia. This action by the Federal Government, which used its constitutional powers over Australian Territories to effect the end of ROTI, seemed to run counter to the consistent and widespread public support which had been reported in opinion polling results over many years.

The women in this study were self selected and were, generally speaking, sympathetic to the idea that the terminally ill should have the right to access assistance to die when pain and suffering became intolerable. Two of them had direct knowledge of such assistance being provided for a close relative, one was an example of voluntary euthanasia in its active form, the other in its passive form. Both felt constrained to talk about these experiences because of the possibility of repercussions, but believed that such discussions were vital to expose the double standards, contradictions and tragedies which silence covered up. And there was general agreement that this was nowhere more obvious than in sanctity of life arguments.

Several participants spoke of being unable to access assistance to die as a violation of their rights to make such a choice although they recognised that it was not against the law to choose suicide, and that this would be the obvious alternative. The difficulties of accessing the means to achieve this end, as well as the need to avoid involving anyone who might be charged with assisting the suicide, were the obstacles which seemed most daunting to them. Having an AHD gave those who had taken that initiative some small comfort that they would be allowed to die naturally but, did not ensue that should a decision be made to use the principle of double effect, they would be consulted. They believed that safeguards to protect the rights of the vulnerable should be integral to any legislative change to legalise voluntary euthanasia in order to prevent coercion and involuntary euthanasia.

Those participants who had experience with palliative care, which is often upheld as providing the answers to management of pain and suffering for the terminally ill, were critical of the inconsistencies which they had experienced between the rhetoric of what was promised from this services and the reality of what was provided. While this was perceived as likely due to under resourcing difficulties, it was suggested this should be acknowledged.

The reflections section compared the ‘knowledge vacuum’ which surrounds what is happening for many desperate people seeking to end their pain and suffering in the ‘euthanasia underground’, with the secrecy and dangers which surrounded the backyard abortion tragedies of the not too distant past. The exposure of what is happening is important to minimise harm rather than to punish those involved except for the most blatantly exploitative practices. The voluntary euthanasia lobby has been actively speaking out about the need to give good advice to people who perceive suicide as their only option to protracted pain, suffering, the most well known example of ideas they have promoted being the ‘Exit bag’. Several participants commented on this as an option which they might be influenced to consider.

The inadequacies of palliative care were highlighted as an obvious inconsistency in the arguments which promoted this service as the appropriate alternative to voluntary euthanasia. The right to quality of life as a quality of dying concern had been the foundational basis of the palliative care movement, a holistically focused approach which had shifted the emphasis from a curative mode of care to one which focused on the holistic needs of the dying person. The aim was to provide a good death. This emphasis is perceived as changing as a consequence of the economic and political influence of neo-liberalism and palliative care is reverting to a more medical than socially oriented model of care.

All participants were concerned that these important end of life issues were not more widely discussed and understood. As Ann had found, there is added trauma in feeling you have to fight the system for what you thought you had a right to by way of support from services for the terminally ill.

Chapter Six: Older Women Speak Out About Quality of Life

Introduction

The focus of this chapter is on the expectations participants had for their future. Most of them, as national demographic projections indicate, could anticipate a long life, but not necessarily one untouched by *"… an extended deteriorative decline"* (Battin in Magnusson, 2002: 37). The years after age fifty are often popularly referred to as the 'third age' although, as the average lifespan is likely to exceed that milestone by thirty and more years, it is a term with more euphemistic than descriptive and comparative value. For example, Joy, the youngest participant had just entered this third age and had observed that for her, getting older "… had been a gradual thing" with little impact on her lifestyle. Ninety-three year old Eva on the other hand, was nearing her life journey's end, and felt very differently about the ageing process. No longer able to live independently, she had consciously resolved to manage the pain of that loss by determining not "… to spoil a minute of what's left by dwelling on what I can't do." Eva was not about to waste any opportunity to savour what could give her the sense that there was still quality enough in her life to compensate for its rapidly diminishing quantity.

The changed circumstances of Eva's life, which meant she was more physically dependent than she had previously been, reflected the reality of the qualitatively different aspects of age which increased frailty and/or disability portend. It is a stage which is more realistically identified as the "*fourth age"* (Twigg, 2006: 50) and is, as yet, little discussed beyond the bodily needs of those who live that long. This fourth age, as Eva had found, lies at the doorstep of death, and though it is associated with failing health, deterioration and decline, it is not generally spoken about as a time of dying which could be compared with terminal illness.

Quality of life issues were of concern to all participants as they had been for Eva. This chapter explores their concerns about the impact growing older has had on the quality of their lives already and, as they projected it could have in the future, especially if this involved possible placement in a nursing home. Their feelings about these changes reflect the "*existential challenges"* (Thompson, 1998: 695) of old age which are exacerbated in a youth oriented culture like ours which has little time for, or interest in, learning more about the ontological concerns of older people. Where interest is shown it is more likely to be reflected in pejorative perceptions of the aged as a burden on the public purse, a perception all too often internalised by the aged themselves (Thompson, 1998). In speaking out about their projections of a future challenged by possible vulnerability, these women were helping contextualise the issues from an older women's standpoint.

Setting the Scene

Modern medical science and technology has so transformed the prospects for survival in contemporary society that staving off death appears to be the normative response whatever the age of the patient or the stage of the condition being treated (Jallard, 2006: McNamara, 2001). Increasingly, such treatment happens in an institutional setting rather than at home so that family, friends and acquaintances are distanced from the experience of living with dying and death. The impact of the increasing medicalisation of dying on the ethos of palliative care was raised in the previous chapter as an economic and political concern exacerbating the erosion of the original holistic social model of a good death. According to this model the focus should be on care and not caught up in the cure mode characteristic of a technologically advanced medical model where death tends to represent failure in "… *institutions designed to save lives rather than manage death"* (Jallard, 2006: 194).

Control over death is, of course, ultimately impossible and, despite the effects of prevailing "*death rejecting attitudes*" (ibid) which predispose many to postpone thoughts of end of life planning, most eventually must confront the inevitability of this reality as they age. It would be comforting if there were more encouragement offered to look forward with positive anticipation to the last stage of a long life as a time to negotiate the final tasks involved with achieving maturity. According to Erik Erikson's theory of human development, the reward for successfully resolving the developmental tasks associated with this last and eighth stage of life – senescence – is to achieve integrity and thus to experience "… *a sense of completeness or wholeness ... in one's self and a conviction that one's life has meaning and purpose and that having lived has made a difference …"* (Leming & Dickinson, 2007: 113).

Unfortunately, old age is more often projected as a "… *time of no future"* (Thompson, 1998: 700) as ageism takes tighter hold on the public psyche. Ageist attitudes are also evident in the pejorative inferences about providing for the needs of the aged which are projected as a sword of Damocles hanging over the economy. This not only homogenises a section of the population which is diverse in age and needs, but also demonises them in a ‘blame the victim’ approach. Obviously we all have a future until we die, but if ageist influences continue to dominate that future then, whatever its quantity, its quality is likely to reflect the emptiness conveyed by the ‘no future’ image of the quote in the opening sentence. Horror stories of conditions in some nursing homes which are passed along by word of mouth or featured in media exposes, reinforce such images of bleak emptiness and arouse fears, as the years roll past, about what could lay ahead should frailty, disability and/or the diagnosis of an extended deteriorative decline prevail (Wynhausen, 2005).

Independence Under Threat – Participants Explore Their Uncharted Futures

Fears of Increasing Frailty and Disability

Independence was an important concept to all participants in this study but was interpreted quite differently across the age span represented in this small sample. In recent years the oldest participants, Eva and Inge, had increased their reliance on family and professional caring services for assistance with daily living as frailty and/or disability had taken their toll. Inge, though the younger of the two, was the more dependent on such assistance at the time of the interviews.

> “I dealt with growing old very well until I lost my eyesight. I was proud of being young for my age. My grandchildren used to say you’re not like other grandmothers at home knitting. I hate being dependent. I can’t even read my own mail. Nothing’s private any more. I have to trust people everywhere. Sometimes I feel it’s something fighting against me.” (Inge)

Inge’s sense of self had been deeply wounded when she lost her vision. Scars from old wounds had been scratched too and the effects of current and chronic sorrow swelled to overflowing. Her dreams of studying art as a young woman had been thwarted in the turmoil and trauma of separation from family and home as a refugee forced to make a new life alone in a strange land. Those dreams had rekindled quite late in her life when an art course helped her realise her considerable talent.

Only a short time later though, she was once again forced to deny that talent expression, as blindness took hold. Her changed circumstances may have introduced her to a different experience of dependency than she had encountered in her life before then but, the resentment she felt about that was transcended by the overwhelming pain of a future lost to her as an artist. She had recently listened to a documentary about acclaimed Australian octogenarian painter, Margaret Ollie, who was living independently, still painting and maintaining a vibrant presence in the art world, an experience which inspired this telling comment:

> “If I could see *I’d* (her emphasis) be like Margaret Ollie.” (Inge)

Eva had been living with her daughter for three years at the time of our interview and she too felt the sadness of relinquishing her independence less than the sadness of physical and sensory losses which had accompanied the passage of the years. She seemed to balance, as best she could, the chronic sorrow of living with those losses by finding ways to restructure her sense of self in these changed and changing circumstances.

> “I don’t allow myself to hold on to any negativeness. I have some affirmations that help when I feel down but I believe that whatever I have to face I’ll do so with the same amount of courage and cowardice as I’ve always done.” (Eva)

Both women had sought out support services which helped them to continue to live in their own homes for as long as possible and, as discussed in Chapter 4, neither interpreted their need for assistance as a burden on society. Inge had concerns about increasing competition for funds and how this affected her experience of the service provided.

> “It’s not personal any more it’s more efficient I must say that, but the helpers used to be friendly and had time to say hello. I was told by the person in charge when I spoke about this, that they were a business not a charity so I suppose I have to get used to it.” (Inge)

Pat, in her mid sixties, feared the progression and associated pain of a degenerative back condition but, the immobilising prospect of her disability was of concern for other reasons too.

> “The getting older doesn’t worry me as much as the frailer. Earlier this year I was flat on my back for a week and couldn’t even get up to go to the toilet and

> I thought how terrible it would be to be like that permanently. I envy those 80 year olds whipping around. If you're like that it would be wonderful.
> One thing that scares me is that if I was really in a bad way with my disability and I wouldn't be able to do it myself (take her own life), and someone helped me, they would put themselves at risk for helping a suicide." (Pat)

Pat was very clear that without access to assistance to die she would be very likely to consider suicide should her fears about deteriorating health be realised. That would mean she could decide to end her life prematurely without fully exploring the options for managing her condition and the 'existential challenges' of shaping a new sense of self and, possibly, a reason to choose life. In such an exploration it would be possible to confront ableist influences which perpetuate negative beliefs about the quality of life of disabled people. These beliefs are all too often mindlessly accepted and internalised without questioning what the socio-structural and political underpinnings of such beliefs may be (Swain, French & Cameron, 2003).

The stigma and exclusion from mainstream society associated with ableist influences was a vivid memory for Judith whose family had kept her intellectually disabled brother at home against formal and informal pressure to put him in "an asylum". She had been ridiculed at school as having a "mad brother" and her parents "shunned in certain society" all of which had a "profound effect" on the family. Madeline also spoke of the pressure in years gone by to hide people with disability away and contrasted this with today's more accepting attitudes. Nevertheless, she carried the scars of being blamed by her ex-husband for their daughter's disability and had found it "a big challenge being the mother of a child with disability". She was angry still at suggestions that her daughter's death was a blessing because "she was better off with God where she could be whole" and, by implication, better to be dead than disabled (Whiteside & Perry, 2001).

Anticipation of possible dependency was very concerning for those participants not yet affected by debilitating frailty, disability or decline, and most markedly so for the two youngest participants.

> "My independence is very important. I really don't know how I would cope if I had a stroke and had to have my children caring for me. I am just so independent. I would find that very, very difficult." (Joy)

> "I'm extremely independent, always have been. It would not be easy to accept I was dependent and needing care." (Ann)

Joy and Ann seemed to associate being independent with the carer role and to place great value on this aspect of their current sense of self, a perspective in accord with cultural norms which place "*… such a high value on self reliance, autonomy and independence* (that) *shame and humiliation can result from the need to depend on others"* (Roos, 2002: 78). From this perspective, the caregiver is the *"… apparent normal state … the abnormal* (being the) *state of the person in need of care"* (McLaughlin, 2003: 85).

Fear of Dementia

It followed quite logically that both Joy and Ann had strong feelings about not wanting to be cared for should they develop dementia.

> "I do not want to have someone have to look after me if I have dementia. I have nursed people with dementia and that was OK and I would have no qualms about nursing my husband but I don't want that myself." (Joy)

> "I can only speak for how I feel myself (about dementia) but I've spoken to my girls and said that if I get like that, don't let me go on, find some way to try to do something because where is the quality of life like that if the person is just a vegetable." (Ann)

Both women were adamant that feelings like theirs would have to be made clear before the onset of dementia, however, or at least while the person making such a statement still had the capacity to make an informed decision. Alicia held similar views. It must be a personal choice and she had made her choice very clear to her daughters too. She did not want to leave her home to go into care especially if she had dementia.

Lucy was taken by surprise by the direction her thinking started to take as I asked her about her experiences with dementia.

> "I hadn't thought of dementia, I had only thought about pain when I thought about voluntary euthanasia. I suppose if it was me I'd be quite happy to have

> it done but I'm thinking of the person who would have to do something like give you a drug to kill you and to me that is murder. I couldn't do it but then again if I'm the patient I'd be quite happy to have someone do it for me. I don't want to be like a baby wearing nappies and needing someone to bath me and do everything." (Lucy)

The powerful images these women associated with dementia as a vegetative or baby like state were not the way they wanted their families to remember them. Alicia and Marian had experience of their children being totally bewildered by the change in their grandparents as dementia gradually took hold, but gentler images of the effect of dementia on the whole.

> "My mother was kind of just nodding away. Maybe you wouldn't mind just sitting, nodding away. I wouldn't want to be kept alive artificially though." (Marian)

> "My mum thought I was her sister and that we were young, and she'd talk about the dances, the races and her life then and seemed to be enjoying herself back there. The person we used to know wasn't there though. I've thought about this a lot and decided I don't want that for me. It seems pointless. I couldn't decide that for my mother but I could for me, I'd say put an end to it." (Alicia)

Pat raised other concerns about the changes that occur over time as dementia takes over someone's life.

> "It does worry me being a burden and, what's probably the worst is, you wouldn't know to put the bag over your head. Someone who worked in that area once told me you don't have to worry about it because when you're there you won't know anyway. It's the getting there though. It would be bad when you start to feel that terrible, terrible confusion. Everyone usually talks about it in a 'ha ha' way but it must be terrible to get worse and worse. Getting there must be terrible." (Pat)

Pat was aware of the insensitivity and ridicule inherent in ageist and ableist attitudes which trivialise the life changing consequences of a mind and self altering condition like dementia, and this seemed to increase her despair as she empathised, in imagination, with what that experience could be like. She also touched on the dilemma for anyone who might not have wanted to end their life living with dementia but who had not taken action before the effects of dementia took hold.

Legal constraints had overshadowed Syd's confrontation with dementia. She remembered the anguish of powerlessness as it compounded her grief.

> "My aunt had Alzheimer's. I had been very close to her and my uncle and her loss was so awful for me, a really terrible experience. I felt resentful that she had to be like that and that she was gone out of my life. I wasn't empowered to put her out of her misery. I had no way of doing it. But it was the pain of my uncle, who couldn't bear to see her like that, that concerned me most, the one who loved her best. That made me say, rather brashly, that I believe in euthanasia and that we shouldn't be allowed to get old, they should pull the plug at 60." (Syd)

She recalled how radical expressing opinions like that was twenty years ago in the rigid South African Calvinist society in which her aunt and uncle lived and was convinced that, had she spoken out publicly that she would have been "… viewed very harshly for thinking like that" (Syd). She is no longer ready to set an arbitrary cut off date for a life, but would want it to be possible to access voluntary euthanasia for those who had nominated this as their wish, should dementia take hold.

Gladys worried about dementia whenever she couldn't remember things or told the same stories over again and, as she recalled the sadness at witnessing her lifelong friend change, she reflected on what this could portend for her.

> "She was a different person, she was OK but she didn't know me. They just live in the moment. I thought at first that was all right but then I thought she's got nothing to look forward to because she can't remember what happened five minutes ago. They wouldn't know to ask to be put away. I don't know what to do about that. I wouldn't like that for myself. I thought I would perhaps like to have care for 2 or 3 years but then I'd like to be put away." (Gladys)

As she grappled with the existential challenge of an image of herself living only “in the moment”, Gladys seemed to be less concerned about having to be cared for than about life without a sense of the future.

Fears About Being Admitted to a Nursing Home

Although Gladys suggested she was prepared to accept care in a nursing home (as her friend had been receiving) should she develop dementia, she was adamant that she would want to be reassured about the quality of care offered before she would voluntarily enter a nursing home for any other reason.

Uncertainty about quality of life prospects for residents in nursing homes concerned all participants.

> “Some old people’s homes are pretty awful. Some women are still pretty alert but others are just sitting around. There should be some way for people to be sorted out so those with all their marbles could be put together. No offence, but some women aren’t educated and others are. You can’t really put them together. They might be nice and good women but not interested in much.” (Madeline)

> “I would go if I had to but I think the boredom would be hard to handle. Maybe if there were really good resources available it wouldn’t be so bad. I’ve read about some places that sound really nice where it’s more like being at home. I wouldn’t like to need total care though, even if someone is willing to do that. I don’t think any human being should have to be put in that position, really old and helpless but being treated like a baby. I know we are all different like chalk and cheese, so I suppose I can only speak for myself.” (Eva)

Ann, Alicia and Joy had no wish for total care either as observed in previous quotes. Judith, who lived in a retirement village attached to a nursing home facility, was equally adamant.

> “I see them sitting around and I say to God, don’t let that happen to me! And then if they are drugged up because they might be violent, there’s no life then is there. When there is no quality of life and people are taking up wards and nobody wants to go in there, because it gets so depressing, and there’s urine

> under the beds and on the floor and staff leave, it seems like it's just keeping people alive so the money rolls in each week. People often get exploited." (Judith)

Judith raised challenging issues which resonated somewhat with a distressing experience Pat had as a visitor with a group to a local nursing home.

> "I don't want to be put in a home. I think you just sort of give up. I don't think people should be shoved off like that. I was giving out presents last Christmas in one section of the home where they were lying on trolleys and it was the saddest thing, they were just lying there they couldn't move anything. One lady pulled at my hand like don't go sort of thing. They couldn't open their presents. The kindest present we could have given them was a shot in the arm. I think that's so sad. If we could only have 'homes' just like your own home. There are all these rules in these homes. I was just a mess after that." (Pat)

Pat hoped to be able to stay in her own home where she could still have her dog with her. Having their pets with them was so important for older people, she thought. Lucy agreed and couldn't imagine living anywhere that wouldn't allow her to have her pets with her.

Madeline and Lucy thought families should do more to keep their elderly relatives at home for as long as possible. Madeline thought more tolerance was needed and Lucy held similar views.

> "I think a lot of older women miss out on family life. A lot get shoved into old people's homes or retirement villages and they don't have the contact with the young and I think that's sad." (Lucy)

There were limits though, even for Lucy, who recounted the story of a friend's traumatic experiences of caring at home for a ninety-three year old parent with advanced dementia. Incontinence was a constant challenge for that full time carer but it was the dangerous and unpredictable behaviours which were the most stressful especially one involving a fire.

Joy had a similarly harrowing story of the dramas of home care when dementia is involved.

> “My friend was looking after her mother who would defecate and urinate behind the lounge chair. How could you put up with that! You’d be cross if your child did that but if your Mum’s doing it that’s just too hard. Every time the poor women left her mother alone, this is what she would go and do. Respite is so limited.” (Joy)

These difficulties in providing for the high care needs of a family member might not always be just about the adequacy of resources, however, as Syd pointed out.

> “Even though nursing home staff are far too thin on the ground, people living in those homes are often luckier than being with family and being seen as nuisances.” (Syd)

Madeline thought older people were often regarded as nuisances too, while Lucy’s and Pat’s graphic description of some people being too easily “shoved” into nursing homes or retirement villages intimated a similar view. There were echoes here also of Madeline’s and Judith’s recollections of the way people with disability were placed in institutions in the past as the preferred way to manage their care needs. Madeline had described the practice as “hiding” them away.

Power

Ageism, Sexism, Ableism – discourses which support disempowering practices and attitude

Judith, who had initiated her own move into a retirement village, was satisfied it had been an appropriate accommodation choice for her especially as she had her own car and enjoyed a range of social contacts outside the village as well as what was available on site. She had observed though, that some women around her were unhappy in this environment and had not come to terms with the way women’s lives had changed over the years. In her opinion this was because:

> “They expect their families to do everything for them rather than helping themselves. And, when that doesn’t happen, they feel lonely and miserable

> even when there are activities they could join the other residents here in doing. Too many now just want to sit in the air conditioning and watch TV." (Judith)

She had no patience either with what she perceived as their failure to eat properly and exercise to keep healthy.

Her description of herself as "a no nonsense lady" was in keeping with her dismissive assessment of these other women's "pride, vanity and self neglect" as the factors contributing to their unhappiness. She was impatient also with those who are "set in their ways and who close their minds". She prided herself on being perceived as "different from that norm" and was grateful that she could "run away" in her car and find things to do in the outside community. There was, however, a note of apprehension in her voice when she pondered that for her, "the telling time is still to come" when she too would no longer be able to "run away".

Although Judith's observations were from the perspective of a resident in a retirement village, they echoed concerns raised by other participants about what life might be like in a nursing home – a more restrictive setting. Her observations also suggest questions which are seldom asked about the existential challenges of end of life relocation experiences.

Could, for example, some of the unhappiness, loneliness and lack of self reliance which Judith had found exasperating among some of her co-residents, be a manifestation of the effects of chronic sorrow where the losses involved are of a lifestyle once known and of the self who had inhabited that space? Could it also be argued that these reactions would not be unexpected if, as Syd, Madeline, Lucy and Pat had suggested, some families are too ready to have their elderly relatives admitted to a retirement village or nursing home? These women may have internalised the existential reality embodied in the expression "shoved away" which, at the very least, has connotations of, out of sight out of mind and, at the worst, abandonment. Whatever the reason for the unrealised expectations of the residents in the village where Judith lived, and however reasonable and realistic the explanation, it was obvious from Judith's observation, that there were negative outcomes. Judith made no mention of avenues for addressing the emotional and psychological needs of residents other than diversionary activities.

Madeline, Inge and Eva had been mindful of the challenges presented by being confined with people like those Judith described as “set in their ways and who close their minds”. The nursing home situation would not be an environment from which one could “run away”, at least not easily, other than to retreat physically, emotionally and/or psychologically. Inge intimated that she had withdrawn in this way since losing her visual independence. Even though she still lived relatively independently in a pensioner unit in a public housing suburban development, she could no longer drive. This restricted her accessing interests which she had previously enjoyed as there were limits to the transport options she could afford.

> “I’ve been fighting Guide Dogs to do more than bingo, community singing and going on visits to the casino. I seem to be the odd one out. I don’t fit. The people around here seem to fit in with each other - they like to watch videos and the soapies. I feel guilty not joining them and I sit here being lonely because I don’t know what I could talk to them about. I miss having educated people around me. I have a coffee in the morning with one woman because she’s my neighbour but I feel so lonely. I suppose it’s my own fault.” (Inge)

Inge envied one of her friends who had also lost her sight but, who because she “belongs to a different circle, and is more well off”, has more opportunities to access, and enjoy, intellectually stimulating outings and company.

Inge felt there were definitely socio-economic differences in the way older people were regarded and treated and perhaps her attitude to her neighbours was a projection of her internalisation of that belief. From other comments she made about older people it seemed she was aware of gender differences too. She thought negative publicity directed at Nancy Crick and other outspoken women voluntary euthanasia activists was because they would have been regarded as:

> “… silly old women, (whereas) they (the critics) would have taken more notice of men doing the same thing.” (Inge)

She added by way of affirming this comment that one of her male friends, whom she valued as an intellectually stimulating companion and helper, nevertheless constantly exasperated her because:

> "… he's convinced that men's brains are bigger than women's and so they are smarter." (Inge)

Alicia identified an example of this belief as it lingers in current discourse when she suggested that making use of "the strict father authority figure" would be an effective way to educate older people about their rights, especially for women like herself whose formative years had been dominated by male authority.

The power of that father figure authority was a painful memory for Joy and Madeline who had both desperately wanted to continue their schooling. Both had similar memories of this message.

> "You're a girl and you'll just get married so why waste money on your education." (Joy & Madeline)

This was an argument difficult to refute at that time when women were required to resign from jobs like teaching, nursing and the public service if they married.

Ann believed not a lot had changed in some women's lives.

> "A lot of older women are still looked at as uneducated home bodies so what would they know about what's going on. Sexism is still rampant, very definitely and as soon as you do speak out you're labelled a feminist which is, of course, meant to be even more of a put down. Because you're a woman you don't seem to be taken seriously. I went in to get something done and was asked, 'are you sure that's the right measurement, *who* measured it'. Because you're a woman you're questioned. It happens so often I get agro and I've been known to say excuse me, I'm not dumb. Sometimes it comes from other women but mostly from men." (Ann)

The 'put down' in a different guise had incensed Lucy.

> "I find as a single woman I'm taken advantage of for simple tasks around the house. They think she can't do it herself so I can charge her what I like. I don't mind paying for things if they are going to get done but often it's a shoddy job and you have to get someone else out to fix the problem when it really should have been done properly in the first place. It wouldn't be like

> that if I was a man. I had this happen with solicitors too. Dealing with anybody as a woman is so much harder than for a man." (Lucy)

In subtle and not so subtle ways the effects of sexist, ageist and ableist influences were all too familiar to most of these participants and, as they contemplated the future, they felt they may become more vulnerable and less able to question and resist when challenged by oppressive practices and attitudes.

Autonomy and Decision Making

Syd, however, believed she had inured herself to such oppressive negativities and was adamant that it was within the personal power of women to conquer them.

> "Only we as women can empower ourselves. We have given away our power and we choose to. It's not a naughty world or society." (Syd)

Her confidence in personal power was, she thought, consistent with St Therese's 'little ways' philosophy and a strategy which enabled her to feel a sense of agency and some measure of control over how she reacted when confronted by life's challenges.

> "And we will never know what the power of these little ways adds up to because they are never seen". (Syd)

Other participants had identified a growing sense of personal empowerment with the passing years. At least that is what it seemed they were saying with words like these:

> "I think growing older has been liberating." (Marian)

> "I've never had so much freedom." (Alicia)

> "I feel freer in this latter part of my life to talk." (Eva)

The youngest participant, Joy, believed that negative attitudes to older women were of less significance today than a generation ago.

> "Little old ladies are tripping around all over the world so stereotypes are changing." (Joy)

Perhaps there should be some lingering concern, however, that in Joy's example there remains *a* stereotype of 'the little old lady' which, regardless of the activity to which it attaches, retains the hint of a derogatory taint.

These women used words like choice, liberation, freedom and rights with a familiarity echoing the social and cultural transformations brought about by the "*politics of liberation"* (McKnight, 2005: 155) which dominated the latter decades of last century in western societies like ours. Without those influences for change, they may have been less visible and more easily ignored as women now growing older.

Most still had a strong sense of personal agency evident in their criticism of and resistance to sexist, ageist attitudes. The fears they had of losing independence should frailty, illness and/or disability stalk them in their declining years, seemed to centre on threats to that sense of agency and, with it, a threat to their sense of self identity. Thus the spectre of nodding away, being bored, shut in without access to compatible company, drugged up, helpless and hopeless just waiting to die haunted their various visions of what becoming a nursing home resident portended – for them that would indeed be a sentence to do "… *time with no future"* (Thompson, 1998, 700).

This image of independence was seemingly projected to focus on physical self sufficiency as the determining characteristic. Its alternative, dependence on others for physical care, it was feared, could bring with it not only the loss of identity as an able bodied self, but "… *marginalisation in a world of able bodied persons who mostly treat …* (the disabled) *as invisible"* (Roos, 2002: 76). Dependence is not invisible however, and has become very evident and much more vigorously derided and denigrated as a location on the status hierarchy with the crumbling of the welfare state and as western cultural norms have more closely embraced individualism as a prized goal. Individualism which "… *celebrates personal freedom and independence" (*Eckersley, 2004: 45), frames dependency, especially dependency on what is scathingly referred to as the *"… nanny state* (as a domain populated by) *… child-like wards …* (rather than) *responsible adults"* (Folbre, 2001: 83).

There is though another focal angle from which to explore the meaning of independence. Social researcher, Richard Eckersley (2004) has pointed out that independence is often confused with autonomy, and that individualism confuses these concepts also. The important difference is that "… *autonomy is a matter of volition* … (of being able to act in accordance with one's own) … *internal locus of control, indicating a sense of social as well as personal agency"* (Eckersley, 2004: 89 & 178). The opposite of autonomy is heteronomy not dependence Eckersley says. From this perspective physical competence is a less significant concern for participation as a citizen than is the *"… right to be an individual …* (which) *is achieved and recognized through social relations"* (Fine, 2005: 254). This is a perspective disability activists have done much to highlight in their struggles to break down the barriers to inclusion of people with disability as full citizens.

The experience of Eva and Inge illustrate the significance of what has been called *"relational autonomy"* (Fine, 2005: 254; Hankivsky, 2004: 120). Frailty and disability had indeed increased their dependence on others for assistance to a considerable extent but neither intimated their sense of self was diminished by this. When Marian contemplated the possibility of being dependent on others for care, she identified in the substance of what would be important to her a position which mirrored Eva and Inge's lived reality.

> "As long as I am able to cope with life I'll be OK. As long as I'm deciding it'll be alright if someone is doing things for me especially if I'm able to live in my own home for as long as possible." (Marian)

All participants believed they made responsible and informed decisions about their lives, felt confidence in their ability to continue to do so into the future and saw no impediment to bringing that competence and confidence to a decision about voluntary euthanasia or physician assisted suicide were circumstances to allow them that choice.

Most were very decisively determined to resist admission to a nursing home but, their fears about their capacity to sustain that steadfast opposition should their lives be touched by *"… an extended deteriorative decline"* (Battin in Magnusson, 2002: 17*),* hung like a cloud over their visions for the future*.*

Critical Reflections

Older Women’s Standpoint

The cloud metaphor seemed an appropriate choice to reflect the language of the oppressed which several of them used in giving voice to their fears. In their descriptions of what they knew of institutional life they homed in on examples of helplessness, hopelessness, powerlessness and even exploitation. There was also a sense that the objective realities of relocation and downsizing, which would be an inevitable outcome of admission to a nursing home, would marginalise them like fringe dwellers on the edge of life “shoved” out of the way as Pat and Lucy (see quote page 106) had graphically expressed it. Lucy and Eva had touched on another potential source of marginalisation when they spoke of their dread of being treated like a baby (see quote page 103 & 105) should they need total care. According to many accounts, infantilisation is a very realistic fear for those with high care needs. With no control over their body and no choice over how, when and where it is touched, many end up being handled with no consideration for their ‘selfness’ but, as if they were only bodies and nothing else (Twigg, 2006; Fine, 2005; Gass, 2004; Swain, French & Cameron, 2003; Thompson, 1998).

Several participants had acknowledged that nursing home staff were often overextended and under resourced but did the best they could in the circumstances. This is no doubt a valid explanation for inadequacies in the quality of care offered but it is not an excuse for acceptance by the wider society of what that implies – an undervaluing of the work of caring and of the workforce who do it. That sort of environment would seem to be fertile ground for breakdowns in the quality of care provided and for neglect to be an outcome, by default, as much as by intention. It is also fertile ground for some residents to resist insensitive handling by refusing to cooperate. According to one account: *“(m)any become limp, immobilised, refusing to move themselves or help in any way even if they could. Refusing also to speak, these patients begin to seem like heavy lumps of flesh, nothing else – all body”* (Fine, 2005: 251).

Then again it could be an ultimate surrendering of the sense of self for such residents who, when confronted by the objective material reality of their situation, become, within themselves, no more than a body - self-less, an object, and the epitome of the notion that *“I am what I make of what is made of me”* (Satre cited in Thompson, 1998:

701). Gladys' summing up of this prospect was to reject many of the nursing homes she had heard about because:

> "You're just a piece of cardboard, there's no humanity." (Gladys)

while Pat had speculated:

> "I think you just sort of give up." (Pat)

The hopelessness embedded in Pat's comment was echoed by most participants. As they had experience and knowledge of it, the nursing home option had nothing to recommend it for the quality of life it offered but was rather an environment from which death would offer a welcome release.

Death doesn't always come quickly enough in the medical model culture which prevails still in most nursing home settings, however, and residents are likely to be plagued by loneliness, helplessness and boredom throughout the period of their protracted, deteriorative decline (Gass, 2004; Thomas, 2004). This is a situation likely to be exacerbated by the tendency for staff to deflect, minimise and even ignore attempts by residents to talk about death and dying (Gass, 2004; Miller in Kellehear & Ritchie, 2003) and an indictment of a system which thus denies those residents who would value it, this last opportunity to work through these issues. Pat had felt the hand of brief resistance to this disregard for the 'selfness' of residents reach out to her during a visit to one of the local homes, a well respected facility, and was deeply affected by that experience.

From the standpoint of the older women in this study, the powerlessness of the projected future of a nursing home resident seemed inevitable, and reflected dominant cultural perceptions of institutional life. To enter that alien territory was to risk surrendering control over the body and in the process, as most of them intimated, individuality as well. They perceived those who had crossed that divide into dependency differently from themselves as if they were 'the other', a perception more deeply etched where loss of control *over* the body merged more completely with loss of control *of* the body, especially its biological emissions. Judith had spoken despairingly of the "urine under the beds and on the floor" (see quote page 105) of the facility she was most familiar with and prayed not to end up in one of those beds. These images of embodiment, objectification, and dehumanisation which they feared could be their future reality were consistent with recent feminist theorising about the ageing body and with feminist insights from social gerontology which have identified the bodily character of carework (Twigg, 2006; Fine, 2005; Harper, 1997).

Feminist challenges to the dominance of male knowledge in discursively shaping cultural beliefs and attitudes tellingly argue that "*… male representations of female bodies as leaking and, draining has been … a key cultural concept behind patriarchal control*" (Kristeva cited in Harper*,* 1997: 166). As a consequence of this knowledge/power nexus, women's bodies have been constructed as in deficit compared to the male body which, because it is unencumbered by menses, child bearing and lactation, is represented as superior and in control. The politics of liberation has inspired technological attempts like the contraceptive pill to bring female bodily emission under more control, but the stigma of inferiority and denigration lingers insidiously, evident in put downs about 'that time of the month' and similar comments which reflect how female-body-emotion are linked and valued as less than male-mind-rationality in the hierarchy of binary dualisms (Harper, 1997). These dualisms, which are structured *"… as a network of strongly linked and continuous webs of meanings …* (in which) *humanity, rationality and masculinity form strongly linked and contiguous parts of the web* …" (Hughes, 2002: 17), reinforce sexed knowledge, and privilege independence and control as valued attributes.

Woven into these webs of meanings are many examples of binary 'otherness' negatively associated with the body but, of particular relevance here, are the pejorative meanings with which the ageing body is inscribed. Holding back the years for as long as possible has become the important goal, inspired by the cultural penchant for youth worship and successfully marketed by burgeoning anti-ageing commercial interests (Twigg, 2006; Harper 1997). These women were not overtly seduced by ubiquitous urgings to stay young at all costs but, the insidious and destructive influences of ageism and ableism were evident in their negativity towards nursing homes and the way they distanced themselves from the 'otherness' of residents. The nursing home as they represented it became almost a metaphor for a 'living death' of fourth age frailty and dependency which contrasted quite starkly with third age norms of healthy, successful ageing to which they were more attuned.

Among the concepts which have emerged from feminist theorising about age and the body, and myths about 'successful ageing', is one based on *"… the image of the mask, that tension which exists between the external appearance of face and body* *and functional capacities, and the experience of personal identity"* (Harper, 1997: 161). Anti-ageing discursive pressures to mask signs of how young we are not, start early for women and make it difficult to escape the consequences of internalised ageism, an example of which is the shame which can attach to failure to control the passage of time as the mask eventually slips (Twigg, 2006).

Internalised ageism prompted Eva to say about ageing:

> "I think it's worse in your forties, the shock is greater. I think you accept it but I never liked mirrors around the place. The person I saw there I didn't recognise. It wasn't the person I visualised I was. And I don't like the label an old woman either it's always a put down." (Eva)

Internalised ageism tends to individualise responsibility for failure in the anti-ageing stakes and, by default, to perpetuate denial that decline and death are the natural course of a long life. Society's failure to accommodate to this reality is part of the pattern woven into the death defying/death denying mantle of prevailing ageist influence which stigmatises and marginalises the frail, disabled and physically dependent aged (Twigg, 2006; Harper, 1997).

Learning from the disability movement

Pressures to 'mask' the signs of ageing are not dissimilar to those which influence people with disability to conceal, or disguise, their disability in order to 'pass' as normal. Disability activists have condemned this practice as perpetuating the marginalising and stigmatising of people with disability because it reinforces prejudice against difference, especially visible bodily difference (Thomas, 1999). Difference is, in that context, measured against a *"… normative gaze* (which) *locates bodies on a single aesthetic scale that constructs some kinds of bodies as ugly, disgusting or degenerate"* (Young, 1990: 11) and marks them as 'other'.

Young (ibid) describes this gaze as evidence of cultural imperialism, a form of oppression through which some groups are over visible as bodies but, paradoxically, invisible as individuals with experiences, perspectives and interests. Disability activists argue that, since the nineteenth century, the 'disciplinary gaze' of the medical profession has legitimated the perception of disability as an aberration and overseen the institutionalisation of a medical model of management. The medical gaze focuses on the deficiencies, deficits and limitations of impaired bodies which have to be cured, corrected or, if that fails, hidden away (Swain, French & Cameron, 2003). Under this regime, normalisation is the goal and able bodiedness the yardstick against which intellectual, physical and sensory abnormalities are judged.

The discourse of able bodiedness is powerfully reinforced in language which exhorts individuals to ‘stand on your own feet’, ‘stay one step ahead’, ‘stand up for yourself’, ‘walk tall’, ‘make great strides’. These and similarly evocative images reflect the taken for granted normative framework on which the socio-cultural imperative to be independent and in control rests. It is a framework which, unfortunately, also positions people with disability, who need assistance with the every day tasks of living, as dependents who are not in control of their lives, dependency being another example of binary ‘otherness’ negatively associated with the body.

In challenging these and other individualising and pathologising consequences of the medicalising of disability, particularly the way it serves to fixate the socio-cultural as well as the medical gaze on the impaired body, activists in the field have effected a paradigm shift in thinking which locates the problems associated with disability within the social environment rather than in the individual (Twigg, 2006; Swain, French & Cameron, 2003). The social model of disability which has emerged has refracted the pejorative normative gaze through a civil rights lens and, in so doing, has provided space for the successful politicisation of personal experiences of discrimination and prejudice. Rights education and rigorous advocacy has strengthened the foundations of this social model and, reflective review and re-visioning has facilitated its evolution.

One particularly significant, albeit contentious, direction this reflective process has taken has been to reclaim space for the inclusion of the subjective experience of impairment in the complex dynamics of disability politics (Twigg, 2006; Thomas, 1999; Morris, 1989). Feminist disability advocates argue that this development is not regressive, as some critics protest, but a timely intervention by the primary stakeholders who have demanded the right to explore this terrain for themselves using the insight of lived experience to guide the way problems are defined and confronted rather than having them defined for them. The slogan ‘nothing about us without us’ nicely sums up their passionate commitment to making visible the individual inhabiting the over visible impaired body, their aim being to inspire respect for the integrity of the whole person - mind and spirit not just body (Twigg, 2006; Morris, 1998).

There are clearly parallels between the oppressive consequences of ableism and ageism. Both operate at a directly bodily level which individualises, pathologises and effectively obscures the social, emotional, rational and spiritual diversity within both populations (ibid). Activists, particularly feminist thinkers, from the disability sector and from social gerontology, have identified the need to explore the existential challenges arising from engagement with the physiology of impairment and/or frailty, as well as those arising from the disabling impact of an insensitive, non-inclusive environment. This will provide insights into the body/self nexus and the dialectical relationship which forms and reforms both throughout the life journey (Twigg, 2006; Thomas, 1999).

Challenging the dependence/independence construct has featured prominently in this struggle, especially the way dominant discursive definitions of dependency portray disabled care recipients, regardless of age, as helpless, passive, pitiable and childlike wards who are not fully responsible adults (Folbre, 2001). Disability activist, Jenny Morris (1998) tellingly challenges such a perception arguing from a disability rights perspective that "*Independence is not about doing everything for yourself but about having control over how help is provided*" (Feminism, Gender and Disability, text of a paper presented at a seminar in Sydney), an interpretation which reflects an expectation that care recipients should be respected as citizens with social and personal agency in making decisions about their lives.

Marian had spoken about the importance to her of retaining her sense of control should she need assistance with daily tasks of living.

> "As long as I'm deciding that'll be alright." (see quote page 113)

Emergent concept – end of life care: social or medical domain?

Memories of institutional care and control regimes remain fresh in the minds of many disability rights advocates who warn that we should not be complacent about the care people with disability receive, especially in a residential setting. Their concern is that hard won individual rights could easily be submerged in the routines of hierarchically organised residential systems providing care, tipping what should be experienced as an enabling and supportive living arrangement into a regime of institutional care and control (Swain, French & Cameron, 2003).

Most of the women in this study feared they would experience nursing home life in this negative way. They feared the inevitability of losing not only their identity and sense of agency but also a way of life never likely to return, and the prospect of living with such losses into a bleak, empty future of unknown length was daunting. This anticipation of the pain of chronic sorrow which is the "… *pervasive*, *profound, continuing and recurring grief responses resulting from a significant loss or absence of crucial aspects of oneself* (self loss) *…"* (Roos, 2002: 26) brought with it concerns about being a burden and a nuisance to others (Thompson, 1998). They seemed unaware of the possibility of working through these existential challenges to achieve some sense of their life's having integrity, and a future, until that last breath. To be in care is a negatively construed experience across the life span and would be no less so as a fourth age dependent confined in a nursing home, seemingly destined to be punished in this way for living too long, and longing for death as a release.

Prominent academic and political philosopher, Iris Marion Young (2005) raises issues about the loss of privacy experienced by many who move into nursing home because of high care needs. From the range of ways in which privacy may be affected she singled out the loss of personal space as the one most likely to impact on the sense of self identity and the integrity of the nursing home resident. The trend in many high care facilities is for shared room accommodation which, even with the best of intentions on the part of management, constrains what residents can have around them of their memories and other items of importance which could make their surrounds more homelike. Young calls for a reordering of the standards for public spending priorities and service provision to include what she refers to as 'decent' options for frail aged and their families but, she concedes, if economic expediency dictates the collective nursing home as the most just way to meet demand, then as a trade off, every nursing home resident should have a room of her or his own. The expectation presently seems to be that residents will adjust with some encouragement, and given time, are unlikely to challenge the underlying politics of the taken for granted practices and attitudes characteristic of the hierarchically structured medical model of management in the nursing home environment (Young, 2005; Thompson, 1998).

A poignant anecdote from a collection of stories from dying Australians (Kellehear & Richie, 2003) tells of the nursing home experiences of a woman who attests to the despair of lack of privacy and the 'shedding of her life' as she described having to give away her cherished books and other treasures for lack of space. There is no good nursing home she lamented, and told of not even being able to talk about her wish to die. In the course of a monthly discussion group when the topic invited ideas about what to do with a one million dollars windfall, she had ventured the vision *"I'd get a ticket and go to Amsterdam. And I'd pay to have euthanasia …* (which she said) … *went down like a lead balloon …* (and was reported back in the minutes as) … *one lady said she would take a trip to Holland"* (Miller, 2003: 33). Reflecting on the nursing home life she was leading, she regretted her lack of foresight in not having taken some action to prevent her being in such a position, action which it might be conjectured, could have involved taking a trip to Holland.

This story resonated with the sentiments of several participants in this study and with the fears most voiced about ending their lives as a nursing home resident, fears which could well have masked anger at the projected powerlessness of an existence which promised to render them virtually homeless as well as selfless. Few had firm ideas of the means they would take to avoid such an exigency but the idea of suicide was tacitly implicated in the vehemence with which they rejected the nursing home option as they perceived it at that time. It was a reaction which left the impression that they would rather be dead than face the 'living death' of the nursing home as they understood it to be.

Home care is not without its constraints, of course. Spatially, the bodywork involved is usually evident in a very material way in the presence of care paraphernalia and reorganised living space as mobility and movement deteriorate. Temporally too, timetabling for meals, bathing and other daily care needs may be readjusted to fit within the schedule of the care providers. Nevertheless, being surrounded by possessions and the various signs and symbols which reflect the individuality, past and present of the person being cared for, has the advantage of creating a sense of their territorial rights, and provides something of a buffer to the possibility of being treated only as a body (Twigg, 2006). Social freedom is less vulnerable in one's own home environment where personal-space-decisional privacy is not constantly under threat of possible violation from benevolent surveillance or deliberate prying (Young, 2005).

The high care needs of the fourth age frail and or disabled, the majority of whom are likely to be women (Twigg, 2006), are emerging as another important frontier on which the struggle for social justice is being played out. The very valuable lessons which could be learned from the disability movement, about the disempowering consequences of over reliance on a medical model of practice, do not seem to have guided policy and planning decisions about how this bodywork focused care work could be more appropriately delivered (Swain, French & Cameron, 2003; Young, 1990). This may be because the social model of disability, and the way it is evolving especially through feminist influence, is little understood outside the ranks of the disabled and their supporters (Thomas, 1999).

It is not that medicine doesn't have an important place in fourth age care work as it does for many people with disability but what is challenged is the privileging and dominance of the medical discourse in care work (Twigg, 2006). It might be more useful to explore how the social model of palliative care could inform care work for those debilitated by fourth age frailty and/or disability (Hunt, 1998). Descriptions of good palliative care suggest it embraces responsibility for the total well being of the individual whose bodily needs are interwoven with the existential challenges of every day life. Within such an environment relational autonomy, which respects all parties in the exchange processes involved in care, could flourish (Fine, 2005; Hankivsky, 2004). In such an environment also, whether it is residential or home based, as the end of life approaches, it would be hoped that the emphasis could remain on the quality of life that is left rather than its quantity.

Summary

The women in this study faced their future with some trepidation about what would happen should they become more dependent than they were at the time the interviews were conducted. The prospect of requiring care met with mixed response with most voicing concerns about not wanting to be a burden should they ever be assessed as in need of high care. There were general concerns about developing dementia, most declaring they would rather be dead than demented. There was also a very strong rejection of the prospect of life in a nursing home about which they had very negative images. They were aware of the many socio-cultural and political changes affecting women's lives over the past several decades and had felt the impact of rights discourse in their lives which had raised their expectations about being treated with respect and dignity.

In the critical reflection section I have explored the literature for evidence which validates and further explains the fears these participants hold for their future. From their standpoint, nursing home life would marginalise them by allowing them to be ‘shoved’ away out of sight while at the same time rendering them over visible as a cost burden to the economy. People with disability, whose struggles to overcome the problems of institutionalisation, have blazed a trail which has much to teach planners and policy makers responsible for fourth age care provision. There are also valuable lessons to be learned from palliative care models which focus on quality of life concerns rather than quantity of life for people nearing the end of their lives. Fourth age high care needs as another frontier on which to engage in the struggle for social justice, offers the potential to challenge the pejorative and oppressive normative ‘gaze’ of cultural imperialism which denigrates the ageing body, over medicalises it and denies it socio-cultural and political significance.

Chapter Seven: Concluding Critical Reflections

Introduction

The use of theory triangulation as an heuristic research tool was very productive in this exploratory study. I had set out to hear the voices of older women (who like myself, were confronting the final stage of our lives - our fourth age as it is known) as they spoke out about end of life challenges, focusing especially on how they thought and felt about voluntary euthanasia and physician assisted suicide. I had a particular interest in older women, not only in terms of ageist-sexism and other socio-political influences on their lives, but also because of the concerns feminist ethicists have raised about older women's vulnerability to coercion to volunteer for euthanasia, were it to be legalised, rather than choose it voluntarily.

I used a conversational style for the interview process which was purposeful insofar as, while the focus overall was always on the broad areas I had identified as relevant to addressing my research questions, I had also used it as a means to open up insights, develop perspective and to allow for interruptions which happen in conversation as contextually relevant ideas emerge. Overall I believed it would have a constructive outcome given that *"(t)he conversation format illustrates how knowledge is socially constructed, tentative and emergent"* (Reinharz, 1992: 230), and would be a way to move beyond polarisation in the debate which often restricts the focus to the two conflicting positions and leaves the terrain between unexplored.

I brought a feminist post modern standpoint perspective and a critically reflective edge to the interaction and to the interpretative analytical process which was used to explore the power dynamics of the situations, ideas and relationships which we discussed. I was looking for common problems as a more realistic possibility than expecting common outlooks to emerge, given the differences evident even within this small sample (McLaughlin, 2003). This was an approach consistent with the heuristic process of discovery which has as its goal *"… utility rather than certainty …* (and which) *is used to make problems manageable"* (Poulter, 2006: 335). This creates the potential for the knowledge thus produced to be *"good enough to generate political activism" (*McLaughlin, 2003: 67).

One of the unexpected findings from my analysis of the data was the fear most had expressed about becoming a resident in a nursing home. The care needs of fourth age frail and/or disabled people is an issue which I came to realise had as much, if not more, relevance in the lives of many older women like these participants than questions about the right to access voluntary euthanasia, although they are not necessarily unconnected issues. This chapter explores the social, economic and political dynamics which seemed to underpin their fears and uncertainties about the dying process as they project it may unfold for them. It also visions a different future and tentatively suggests strategies to realize that vision.

Voices – whose and how are they heard in the voluntary euthanasia debate?

Though these women believed they had the right to have their opinions about voluntary euthanasia heard and respected, they feared the more powerful and privileged voice of what Philip Nitschke has called the *"Unholy trinity – Medicine, Law and the Church"* (2005: 68) would not make this easy. Several of them cited the demise of the Northern Territory Rights of the Terminally Ill Act as evidence of the power of this lobby in the face of reports from national public opinion polls which, over many years, have consistently registered widespread support for such legislative change.

None of them saw any virtue in suffering unnecessarily when death was immanent preferring to *"… go gentle into that good night …* (rather than to) *rage against the dying of the light"* (Dylan Thomas, The Poems, 1971). This latter stance does seem to have normative status, however, if the much lauded 'heroic' model of dying is any indicator. The readily recognizable characteristics of this model are: a brave face, positive thinking and a determination to maintain the fight against the ravages of illness or disease till the very end. There is little convincing evidence that this model has any particular influence on survival, according to a review of different coping styles reported in the British Medical Journal in 2002 (cited in Bone, 2007: 106), but few voices are heard challenging its ascendancy.

Judith had witnessed how intrusive and insensitive the expectation to fight to the end could be when, in reality, the person needed to get on with the business of dying and to be encouraged to do so as he chose (see quote page 49). The model's populist appeal may be yet another manifestation of the death defying ethos which has burgeoned alongside advances in medical technological sophistication. It does tend to marginalise those who don't conform for one reason or another, however, and may pressure some to 'mask' their reality in order to 'pass' as living up to societal expectations which, in the process, perpetuates the silence that silences resistance to the status quo.

Each of the women had some experience, query and/or uncertainty about the medicalising of dying as it had touched their lives, but most had felt constrained against discussing the practical and existential implications in any depth because of the seeming reluctance they had encountered, not only from their contemporaries, but from the community generally. Lucy, for example, had voiced concerns about the dominance of the technological imperative to push death back at all costs rather than let it take its natural course. It seemed to her this was sanctioning the prolonging of dying rather than prolonging life and her plea was for the naturalness of dying to be respected.

Dr Tom Preston, an American cardiologist and long time advocate for both better palliative care and increased choice for terminally ill patients to access assistance to die, argues in a similar vein. Extending lives beyond their natural end, in his view, is to risk *"… sanctifying unnaturally created biological existence rather than meaningful human life … Physicians who use curing but not caring to the very end are the primary agents of excessive end-of-life suffering. We must remember to sanctify death as the natural conclusion to life"* (Preston, 2006: Preface, xvii).

He was concerned to dispel any disquiet that his support for *"patient-directed dying"* (the title of his book) was promoting this practice for everyone and believed that the emotively powerful language in which his opponents denigrated his position fuelled such fears. He argued that words like *"suicide"* and *"kill"* were misnomers when linked with patient-directed death if they are not similarly invoked to describe situations involving terminal sedation and the principle of double effect. He believes that the option of legalised patient-directed dying would be less open to abuse than current practices especially when the community is fully cognizant of how this can and should be managed. He cites Oregon where physician assisted suicide has been legal since 1997, as an example of a regime which has not been subject to abuse – annual compliance reporting is required under the Oregon Death with Dignity Act (Preston, 2006: 139–141).

The women in this study were not familiar with the Oregon example but it is a model not inconsistent with their ideas about how accessing assistance to die might be managed when suffering was intolerable and death was immanent. They believed that quality of life, not sanctity of life, should be the priority. Gladys had speculated that she may not take up the option because just knowing it was available might be enough for her to keep going just one day at a time. She and others had also commented that knowing it was there might prevent premature suicide for anyone who thought they had better act while they still could rather than risk future suffering. Joy related this specifically to a condition like motor neurone disease where decline could be slow but inevitably, and progressively, would be very incapacitating. The Oregon model still requires the patient to self administer the lethal dose, however, which would discriminate against anyone physically not able to manage such a feat.

A very vocal lobby group within the disability movement called *“Not Dead Yet”* has quite a different perspective on discrimination and aid in dying which vehemently opposes legislative change. This group is particularly active in the United States and United Kingdom and concerned voices from within Australian disability lobby groups argue similarly against legislative change (Meekosha, 2000; Parsons & Newell, 1996). Their fear is that those whose lives are already vulnerable to discriminatory perceptions which imply that it would be better to be dead than disabled (or old), would feel pressured to take the voluntary euthanasia path, or have that decision made for them if they are unable to speak for themselves (ibid).

The disability movement is not of one voice in this matter though. An organisation based in the United States called *“Autonomy,”* which advocates for adults with disabilities who seek control in all areas of their lives, includes assistance to die at the end stage of terminal illness as one of the important issues it addresses (cited in Preston, 2006: 167; and personal correspondence from Chair of Board of Directors). And although there is no similar formally organised movement in Australia, individual stories have been featured in the media, or on the various voluntary euthanasia websites, over recent years which concur with the principle of self determination (for example, see: http://www.exitinternational.net/; http://www.saves.asn.au/). It is important to note that both opponents and proponents of voluntary euthanasia have argued the importance of ensuring the right to die does not become the duty to die but differ on how to guard against such an outcome (Preston, 2006; Battin, 2005).

Older women, who not only tend to outlive their male cohorts but are also likely to live longer with disability (Twigg, 2006), are another population vulnerable to pressure to volunteer to die rather than choose it voluntarily. Feminist ethicist, Susan Wolf (1996), is one who cautions against too hasty endorsement of legislative change on the basis that gender is ignored in the debate when it is clearly significant from several perspectives. She argues that sexist influence in western society particularly devalues women who are old, disabled or ill and that this, and other socio-structural and cultural determinants of health which differentially affect women, may predispose the most vulnerable to seek assistance to die, to escape the oppressive consequences of their life circumstances, as much as to escape physical pain and suffering. Poverty, poor pain control, inadequate access to appropriate medical care and vulnerability to depression are among the factors she mentions as characteristics of gendered disadvantage which may motivate women to request assistance to die. Wolf argues that without change in these circumstances, women offering themselves as candidates for assistance to die are vulnerable to physicians making decisions to either grant or refuse assistance on the basis of internalised gender bias. On the one hand this may result in their too readily acquiescing to such requests which would affirm women's historically valorised self sacrificing proclivities. On the other hand, they may ignore or dismiss such requests as evidence of women's emotionally labile tendencies. Either way, selfless sacrifice or selfless suffering, the circumstances of disadvantage which precipitate them, would (and do) continue to go unchallenged.

Wolf concedes the seeming paradox of her cautioning against support for the right to self determination and autonomy, the core arguments of proponents of voluntary euthanasia, when these issues are very much at the heart of feminist politics but, she believes, it is with good reason if there is no concomitant analysis of gender and other historic bases of subordination which may be involved. She believes that all decisions and requests from patients about their end of life management merit *"… conversation and exploration …* (because, she explains), *I am not arguing that women should lose control of their lives and selves, instead I am arguing that when women request to be put to death or ask help in taking their own lives, they become part of a broader social dynamic of which we have properly learned to be extremely wary"* (Wolf, 1996: 308).

Knocking on heaven's door

From what they were saying to me, most of the women in this study were already locating themselves within that broad social dynamic, taking up a position from which the future of fourth age frailty and/or disability was being ever more clearly, and negatively, projected onto their awareness, especially when the image in focus was of themselves as a resident in a nursing home. They had good reason to be fearful of the prospect because according to Allan Kellehear (2007) all too many nursing home residents are subjected to a *"shameful …* (dying process which reflects a) *… moral and social failure to provide satisfactory models of social care for dying people at the economic margins of our world"* (ibid: 248). Admission to a nursing home would likely place them in a *"holding location"* (ibid: 217), symbolically signalling the beginning of the dying process, but with little overt acknowledgment of this existential reality, as if the preparation for dying and death were on 'hold' too.

There was an imperative undertone to their insistence that we should talk about these end of life issues more as a community, and tacit affirmation that we must hear from the dying themselves what it is like otherwise, *"… the dying have no idea how other people die, and like them* (as we will eventually become them) *we will want to know"* (Kellehear & Ritchie, 2003: 120). Nowhere is this more relevant, it would seem from this study, than in hearing about all aspects of aged care residential living. Admission to such care was referred to in the previous chapter as like a 'shedding' of one's previous life in order to downsize to the available accommodation. As there are many of us for whom this could be the reality ahead, there is a real urgency to learning how this transition is to be prepared for, managed and monitored. This is especially important if the 'shedding' process could devolve further to become a shedding of the role of citizen as dependency increases and the body needing care assumes more of a presence than the person to whom that body belongs.

Left unexamined and unchallenged, the results of this depersonalising insensitivity so poignantly epitomised in the poem *"See Me"* (Anon) (see Appendix 6) will continue to oppress vulnerable people, like the author of the poem, unable to articulate her sense of powerlessness, marginalisation and 'otherness' openly and directly. It is the sort of environment which resonates with the conditions Susan Wolf warns about as providing fertile ground in which to sow the seeds of support for voluntary euthanasia. For the women in this study, especially those who adamantly rejected the nursing home option, voluntary euthanasia could be a realistic and rational alternative should their residential care experiences manifest as their projected visions predict.

Most of these women had no experience or knowledge of palliative care, and none questioned if it could or should be integral to the care provided in a nursing home setting, but there are those who perceive the residential setting as *"… an arena of meaningful care … within which the principles of palliative care take their place … to provide for the dying person a sense of community rather than the isolation so often feared"* (Hudson & Richmond, 1998: 292 & 300). In such a community of support it is envisaged that residents could be sensitively, creatively and non-judgmentally encouraged to explore and express their innermost feelings as they confront the existential challenges of ageing and dying. This concept is not unlike a model of "*health promoting palliative care"* developed by Allan Kellehear (1999) in his book of that title. Kellehear's model is as an innovative, practical and inspirational action plan which addresses dying from its earliest stages. It explores ways for end of life care to evolve which would challenge the privileging of the physical aspects of symptom management and pain control over psycho-social concerns. His vision for the adoption of a health promoting palliative care philosophy is that it would renew *"… our practical commitment to the social side of life …* (and offer) *opportunity to deepen our understanding of the finer distinctions of human need that go beyond the body …"* (ibid: 177).

This is just the sort of vision which is likely to have reassured the women in this study to agree to the nursing home as an end of life option. Unfortunately, there seems faint chance of this vision being realised within the current economic climate and without a groundswell of protest against the body/burden nexus thinking which is an insidious product of the commodification of care as it has emerged under market populist influence. Instead there is the very worrying prospect that legalising voluntary euthanasia might be perceived as a pragmatic political solution to the increasing challenge of meeting the costs of fourth age dependency – it would be by popular demand after all, ease the health care crisis and perhaps even provide usable organ and tissue donation material. There are those for whom that selfless sacrifice would be gladly, and quite rationally, made even were they able to access optimum conditions of aged care provision. The worry lies in legislative change proceeding without concurrent development of such optimum conditions, the slippery slope outcome Susan Wolf warns about.

Leading advocates for aid in dying like Tom Preston, Timothy Quill, Phillip Nitschke and, a more recently published Australian voice, Rodney Syme (2008), are just as outspoken in their advocacy for the very best of palliative care as they are for access to patient-directed dying. If, as it seems from this study, this is not reflected in common knowledge and, more is known about voluntary euthanasia than about palliative care – all participants had an opinion about the former but most had no real knowledge of the latter – there is real urgency for more effective community education about what to expect from, and how to access, good palliative care, as well as for urgent encouragement of community conversations about all aspects of end of life care, as these women were advocating, to increase awareness of what is lacking and why.

Ethics of care

I have already argued that the reason there was so little awareness of palliative care, either as a supportive option for the terminally ill and their families or, as an integral aspect of nursing home life, is that it is so under-resourced that it cannot meet the demands made of it as it is, let alone as it might be. Families struggle as Ann had with what is available but feel let down by the system. She had observed:

> "I had to seek out doctors to give me some idea of what was to happen. It's not a synchronised system. You need someone who will sit down beside you. I'm sure they can give you some ideas. At a time like that you do not need to fight the system." (Ann)

Ann's experience does, however, help illustrate the moral dilemmas about the provision of care and the caring relationship which have been a source of tension for many years within feminism (McLaughlin, 2003; Sevenhuijsen, 1998). She had spoken of her lifelong desire to be a carer and nurturer (see quote page 44), and her great unease about being cared for (see quote page 102), but seemed unaware of any socio-political significance which might attach to privileging the role of carer over that of the cared-for and, thereby, implying the latter is the devalued, dependent position in which to be placed. On the contrary, she gave the impression that her desire to be a carer and nurturer was based on a genuine and willing acceptance of the responsibilities of that role and not on some sense of having, or wanting to have, power over anyone, or of self sacrificing duty, or of compulsory altruism (Sevenhuijsen, 1998). Feminist thinkers, who have struggled to unravel the complexities of these various possible orientations to the role of caregiver as it has traditionally been ascribed to women in the private sphere of family and home, have been confronted with the dilemma of exposing the potential for exploitation in the status quo without diminishing the value of the care provided, or of the role of caregiver.

This dilemma has been particularly evident as women have moved in greater numbers into the public sphere where questions about the place of care in our society have revealed the inadequacies of systemic responses. Ann had felt the injustice of having to “fight the system” for what care she and her partner were entitled to access from public sector sources, of which palliative care is a part, and had felt most strongly about the lack of consistent affective response from the system. Ann prided herself on being independent and self sufficient and, in assuming primary responsibility for nursing her very ill partner, had demonstrated her competence to manage that complex challenge under difficult circumstances. She had been grateful for the medical and nursing assistance the system had offered because it gave her some respite but, in this situation, she had also felt the need to have someone within the system to be with her and for her emotionally as well: someone to talk to, to provide information, to discuss what was happening and to explore options which would have helped her feel that she and her partner were fully involved in decisions being made about the management of his care. She had been vulnerable and needy as well as self sufficient and independent. And while she had been dependent on the system, the system had also been dependent on her too because, had she not taken on the carer role, her partner would have had to be accommodated in the public system somewhere – hospital, hostel, hospice or nursing home.

This is an example of the interdependence which feminists, who have taken the ethics of care standpoint forward beyond the pioneering work of Carol Gilligan, have argued reflects the reality of the human condition (McLaughlin, 2003). Selma Sevenhuijsen (1998), is one who advocates that the privileging of self sufficiency and rationality as morally superior attributes to vulnerability and emotional neediness, not only obscures the reality of the uncertainties of human existence, but is also potentially harmful. That is because patterns of interaction which locate needs in ‘others’ encourages the *“… externalization of morality* ... (which in turn) *means that care figures in politics as a handicap, as a burden or as a ‘necessary evil’ …” (*ibid: 28), and constructs a perspective which reinforces the association of the norm of self sufficiency and needing nobody with the “*‘ideal’ standard for citizenship”* (Hankivsky, 2004: 110). As an abstract ideal, this positions the vulnerable, needy and dependent as less than full citizens and, by default, marginalises and disadvantages them, thereby exacerbating their vulnerability. It also tacitly justifies the perception and labelling of the costs of their care as a 'disability burden' on the public purse – language consistent with the 'externalisation of morality' and the commodification of care.

Sevenhuijsen argues that treating care in this way is *"privileged irresponsibility"* (1998: 132). She believes that feminist energy has been misdirected as it has followed the discursive track signposted *"… in the language of individualism, independency and 'equality-as-sameness' …* (in which the world of care is) *a 'traditional' barrier to freedom and equality"* (ibid). A consequence of this has been tellingly articulated by feminists with disability who point out the political, ethical and theoretical problems arising from focusing exclusively on the carer in the struggle to achieve equal rights for women, because no allowance is made in that analysis for the rights of all those women who require care, other than to suggest they be institutionalised. This is an approach which diminishes and devalues not only those with high care needs but also diminishes and devalues the care givers, effectively stripping *"… care of its full significance"* (McLaughlin, 2003: 87).

Ethics of care feminists believe that to give care its full significance requires recognition of its centrality to social functioning and to everything we do as humans in order not only to survive, but also to thrive (Sevenhuijsen, 1998) – the *"invisible heart of care"* without which the *"invisible hand of the markets"* would wither (Folbre, 2001: 1). Sevenhuijsen argues that focusing on care as a social practice provides scope for examining the dynamics of care and the subjective experiences of all involved across the boundaries of the public/private divide, reframing the analytic process to work within a political rather than a psychological discourse. This is particularly relevant in reflecting on what Kellehear has so graphically identified as the 'shameful dying' which occurs for many in the nursing home environment and on the very possible slippery slope reality projected for their future by the women in this study.

Visioning a different future

One telling aspect of this 'shameful' situation is the failure to officially acknowledge that residents in nursing homes are in the dying stage of their life (Kellehear, 2007). Dying may or may not be immanent when they enter that environment but, to tacitly reclassify what is happening at this stage of their lives in terms of failing health effectively medicalises and *"… debases longevity by translating advanced old age into a litany of defects, injuries, and illnesses …"* (Thomas, 2004: 200). It also reinforces the association of the vulnerability of fourth age frailty and/or disability with dependency and the 'shameful' body/burden baggage which dependency has increasingly accrued under neo-liberal influences.

Allan Kellehear (2007) argues that we have a moral and social responsibility to find ways to change this model of what to expect at the end stage of life, and find other models which encourage those who are there to explore the meaning inherent in their experience of this final chapter in their lives. American geriatrician, William Thomas, who has been working with such a model, has inspired a movement called the Eden Alternative the aims of which are to de-institutionalise the culture and environment of long term institutional age care facilities which he describes as *"… the backbone of a contemporary old-age archipelago"* (2004: 157), a label he deliberately imbues with connotations of punishment. The alternative he has founded is based on a developmental model of ageing which identifies care needs as more than body focused. Several of the women in this study would have been interested to explore the Eden option had they known of it and its philosophy, because it values the notion of relational autonomy, a concept consistent with their ideas about what was desirable in a caring relationship.

This relational understanding of autonomy has emerged from recent feminist work on the dilemma of how to politicise the care discourse while continuing to value the ethical principles associated with caring (McLaughlin, 2003). It is an understanding which pays *"(a)ttention to the social and contextual factors that facilitate meaningfully autonomous actions … a view that seeks meaningful self-direction within a context of interdependency"* (MacDonald, 2002: 194). Eden Alternative organisations are focused on ensuring the vulnerable frail aged, with the support of their care providers, are able to direct their own lives and participate in meaningful exchange with those around them. The Eden environment is typically filled with plants, animals and frequent interactive opportunities with children and others whose presence adds to the variety, interest and spontaneity of daily life. This is an arrangement described as creating a habitat for human beings rather than a facility for frail aged, based on a rationale which argues that habitats nurture, institutions control (http://www.edenalt.org).

The social orientation of this model would seem to align with the social model on which palliative care was founded and, because it purposefully challenges institutionalisation, resonates also with the concerns of the disability movement for recognition and protection of the rights of individuals with high dependency needs. Professionals working within these fields – aged care, palliative care and disability support – have much to learn from and with each other about the mutual benefits of a perspective on care which challenges 'privileged irresponsibility' and the marginalisation of both the cared for and their carers. Care, wherever it is provided, when regarded as a social practice can be judged in terms of whether it is good or bad, is adequately resourced or not, and whether it is consistent with the principles of relational autonomy (Sevenhuijsen, 1998). A politicised ethics of care model which embraces this approach and which recognizes the centrality of care in everything we do as individuals and as a community, would provide a platform for action to expose the injustice of failures in the system.

The absence of widespread engagement with these issues by those on the threshold of fourth age vulnerability is, therefore, a serious concern. I asked the women in this study for ideas which might stimulate such engagement with other women like themselves and which might also nurture serious reflection on concerns that arise along the way. They thought the dissemination of information was always important and, most likely to find an audience, if presented in creative non-threatening ways. They especially favoured humour and interactive approaches in face-to-face situations but noted also that television 'soapies' often focus their storyline on controversy, and that lots of people talk about their favourite programmes and characters when they meet socially. Above all they stressed the need to talk, but just how to develop discussion further and nurture serious reflection on the most sensitive and controversial aspects of fourth age frailty, dying and death, was considered a real challenge.

There are advocacy groups whose role it is to educate about rights, and to stand with and for the older population, but their voice continues to be a whisper within a culture dominated by a privatised and depoliticised ethos which fosters disinterest in collective concerns and the common good. The Older Women's Network (OWN) keeps raising its voice and has a history of successful activism and advocacy in promoting the rights, dignity and wellbeing of older women. Their theatre group, for example, uses satirical humour to excellent effect in confronting controversial issues and is much in demand. The multi-faceted OWN model is an ideal vehicle for stimulating more widespread discussion but, unfortunately, the network has shrunk over the past decade as funding for the developmental work needed to keep the network strong has been withdrawn – the fate of several other advocacy oriented peak feminist women's groups (Summers, 2003).

The still very vibrant Sydney based OWN group continues to provide examples of what can be done with the little they have. Their theatre group activities is a creative example, as is their very successful and inspirational use of Study Circle principles and guidelines to listen, learn and understand how to cultivate better relationships (http://www.ownnsw.org.au). OWN has also found the Speak Out format a useful tool to work with in situation where disparate views of the world need to be aired in non-threatening environments. Speak Outs, according to a very successful Older People Speak Out activist organisation here in Queensland, are a form of action research on a specific issue in which a range of positions are raised in the first part of a session, and possible solutions discussed in the second (http://www.opso.com.au/index.htm). These examples of strategies for exploring sensitive topics open up possibilities for points of agreement to emerge which enable the debate to be carried forward into a less divisive space, and hopefully, into a more creative and productive one as well.

They are strategies which might work to start a dialogue between the disability movement and the voluntary euthanasia lobby. Neither is an homogeneous group – I have already mentioned the dispute within the disability movement between *'Not Dead Yet'* and '*Autonomy*' over the right to access aid in dying but, even within the voluntary euthanasia lobby there are quite strong divisions about strategies and goals. These divisions and differences could provide room for dialogue and negotiation. Both groups have significant vested interests in how the 'death rights' discourse is shaped if they are to ensure legalisation of the right to die, if it happens, is never translated into a duty to die. Were they able to reach agreement in that regard, they might move to a different space where it would make sense to form an alliance to stand for and with each other to guard against misuse and abuse of power, that is, a strong advocacy stand for aid in dying to always be patient-directed and never other-directed. In the process of negotiating how such an alliance would work, it would also make sense for the disability movement to share its experience with rights and advocacy education, particularly about self advocacy.

The more we have community conversations using formats which aim to bridge gaps in understanding about important issues and concerns, the more it is possible to nurture the *"… idea of active citizenship. Here the public sphere is seen as a meeting ground where people shape identities through action and interaction, through the exchange of narratives and opinion, through deliberation and debate … and continually revise and transcend their images of 'self' and 'other'"* (Sevenhuijsen, 1998: 14). With effective facilitation in these discussion groups, respect for difference can be maintained as the dialogue about contentious and contested issues proceeds. It would certainly seem to be important to practice the skills of active citizenship well in advance of fourth age frailty in preparation for confronting the tendency for older people to "… *enjoy a lesser form of citizenship …* (and the way this), *underwrites a variety of discriminatory practices within the service system"* (Twigg, 2006: 54).

A strategy which has been used to engage individuals in contributing to policy decisions which affect their lives, especially in the health care sector, is the citizens' juries concept. This is a form of participatory democracy which lends itself to a more valid assessment of what an informed public is thinking than *"… opinion polling or superficial 'consultation' …"* (Mooney, 2007: 1). It is an approach which involves randomly selecting groups of a relevant population, asking them to put their *"citizens' hats"* on, providing them with good information about the issue being debated, offering opportunities to consult experts in the field for clarification and additional information, and then asking the groups to reflect on what they have learned in order to make recommendations about what action should be taken. They are asked to suggest solutions which would be in the best interests of as many as possible of the wider population. Participants report they find the experience rewarding and learn more about what is involved in making informed decisions as responsible citizens (ibid). This citizens' juries approach has wide application for informing policy decisions at government level (ibid) and would certainly seem very appropriate, and timely, to be used in the voluntary euthanasia debate as politicians in several legislatures are likely to be called on in the near future to vote on bills currently being processed in the Federal Parliament, as well as in the Parliaments of South Australia and Victoria (http://www.vesq.org.au).

Despite their use of the language of a rights discourse to frame their support for the easeful death which voluntary euthanasia or physician assisted dying promised, the women in this study knew little, if anything, about strategies like these which encourage active citizenship. They knew little, if anything either, about models like the Eden Alternative, Allan Kellehear's Health Promoting Palliative Care, or any of several other models from around the world which take a holistic approach to end of life care needs and planning (see, for example, http://www.beaconhillvillage.org). Were they and their peers to be engaged in more widespread discussion about such ideas as an active citizenry, it could be easier to recruit support to demand an end to 'shameful' dying. Planning for fourth age challenges well ahead of time should become as routine an exercise as planning for the lifestyle changes of third age retirement, with more in mind than Advance Health Directives and Enduring Power of Attorney preparation.

Actioning the Vision

Whose responsibility is it though to begin the process of catalysing active citizenship and the political activism necessary to ensure as wide a constituency from the aged population as possible confront these important and complex end of life issues? Grassroots organisations like OWN, which is dedicated to keeping the interests and concerns of older women on the political agenda, depends largely on the volunteer efforts of its members to maintain the high standards of leadership in its activist role. OWN is, as previously discussed, constrained by scarcity of resources in how far the network can extend. It is though, the sort of organisation which is more likely to encourage discussion of the existential aspects of fourth age challenges from a feminist perspective, providing a standpoint from which the gendered nature of the bodywork of care work would be more obvious (Twigg, 2006). As a feminist organisation, OWN is concerned to highlight all forms of discrimination against women, and is currently focusing on the increasing feminisation of poverty within the ageing population and the impact this has on health, well being and the breakdown in social networks (OWN Matters, May & June, 2008). Poverty, as Wolf has warned, is among the reasons women may be predisposed to 'choose' to support voluntary euthanasia. OWN is an organisation which also openly discusses voluntary euthanasia. Its May 2008 newsletter featured an article about a woman who asked for her story about taking control of her dying to be told, and understood, as an act of self determination. With such broad based interests and well established strengths in using developmental principles, practices and processes to hear women's voices and encourage activism, OWN offers a valuable model to emulate for those concerned for older women's future welfare.

Recent social work literature which proposes a body-centred framework for practice (Cameron & McDermott, 2007) is making an important contribution at the academic and professional level to understanding and confronting the challenges of fourth age frailty and/or disability. This approach brings insights about ageing from bio-medical, critical and post modern perspectives, and confronts the gendered nature of ageing evident in the way ageing is perceived and provided for. As an approach based on understanding the relationship between the biological and the social lived experience of embodied beings in the world, it challenges the mind/body dualistic thinking which has reinforced the perception within social work that the body belongs to medicine (Twigg, 2006). It is also challenging the perception that social work with older people is *"… low status employment dominated by medicalised constructions of old age"* (Hughes & Heycox, 2005: 344). The need to be sensitive to the interconnectedness of body and mind as socially, culturally and politically located, requires the development of a paradigm shift in thinking about, and understanding, human behaviour at all points along life's journey, not least at its ending phase (Cameron & McDermott, 2007). Social work has the potential to become an important ally and advocate for exposing the injustice of failures in the systems of care of which 'shameful dying' is a result.

It would appear that doctors are also inclined to perceive work with older people as low status. Harvard professor and surgeon, Atul Gawande, writing in The New Yorker (2007), raised concerns about how the undervaluing and under resourcing of geriatricians, and the work they do, acts as a disincentive for doctors to take on this specialty, despite research evidence which indicates the considerable benefits which being in the care of a geriatrics team has on the quality of life outcomes for the elderly. He argues this is a consequence not only of the privileging of the technological imperative in medicine but also of the influence of prevailing ageist fantasies of agelessness. Because the focus of geriatrics is on care over cure, and on lifestyle and living situations throughout the course of our decline, in Professor Gawande's view, this makes us uncomfortably aware of the reality and inevitability of our mortality.

He is not alone in protesting about ageism in the service of managerialism especially as it threatens holistic practice with people who are at the end stage of their lives (Holloway, 2007; Twigg, 2006; Harper, 1997). Being pitted against one another in competition for the scarce resources available to meet the needs of end life care, aged and palliative care professionals tend to retreat behind the barricades of defensive protection in their individual specialty domains rather than to seek opportunities for collaborative practice. Not only does this run counter to the foundational philosophy of palliative care which stresses the importance of the complementary skills of a multi-professional team and the process through which this collaborative effort achieves its outcome vision of *"… a death which is as dignified and peaceful as it can be and accords with the wishes of the dying person and their family"* (Holloway, 2007: 26), it seems also to predispose palliative care to accept a more medicalised approach to care management in which the focus is on the bodily manifestations of pain and suffering at the expense of the socio-cultural and existential dimensions of its practice model (McNamara, 2001).

The social injustice of entrenched ageist and gendered oppression evident in this and other examples of the commodification of end of life care and the tolerance of care practices which, as Kellehear (2007) has identified, manifest all too often in 'shameful' outcomes, is not likely to yield easily to change. But there are ways, as I have already suggested in visioning a different future, to encourage others to engage in the dialogue necessary to initiate that change and recover a sense of citizenship and *"… of public responsibility based on an ethic of interdependence – a notion fundamental to what we mean by social justice"* (Preston, 2006: 236). By not recognising the interdependence between the invisible heart of care and the invisible hand of the market we are perpetuating an increasing, but dangerously false, dichotomy between individualism and community. The Eden Alternative originator, William Thomas believes older people have a vital role to play in initiating the paradigm shift in thinking necessary to accommodate a politicised ethics of care and its core belief in interdependence. Nancy Folbre agrees arguing that the benefits of high quality care spread out far beyond the immediate recipients. *"When elderly folks enjoy a good quality of life, the community as a whole feels more cheerful about its future"* (Folbre, 2001: 50).

Thomas (2004) compares the passage through old age to life's end with the passage into the world at birth and suggests old age needs a 'midwife' to help negotiate the passage through to journey's end. Eva had made a similar connection although she was talking specifically about being assisted to die.

> "… birth is a journey for the baby and the mother and I have a feeling death is a journey in the other way. I see it as being in a beautiful, peaceful place, with beautiful music playing and someone you trusted and had given permission to give you this cocktail …" (Eva)

Timothy Quill (1996) has used the ‘midwife’ metaphor to illustrate the significance of the relationship between the person who is terminally ill and those involved in her/his care. He talks about the importance of nurturing an atmosphere of trust and respect over time, of free and full discussion of, and planning for, what is to come. He also believes this preparation for dying should include provision for an easeful death when life is no longer tolerable. In his view to be ‘midwifed’ through the dying process is to feel totally supported in exploring options, making decisions and dealing with outcomes, an approach which resonates with the concept of relational autonomy. Timothy Quill has extensive experience as a palliative care specialist and is an advocate for physician-assisted dying who has survived the challenge of litigation as a result of speaking out publicly about his views and practice.

Australian urological surgeon and long time advocate for physician-assisted dying, Dr Rodney Syme (2008), has recently published a very candid, compassionate and courageous account of the assistance he has provided to many terminally ill persons who asked for his help to die over the past thirty years. By speaking out in this way, Syme has challenged the law very openly and he too now risks prosecution. His belief is that this may, however, prove to be the catalyst for the decriminalisation of voluntary euthanasia and a substantive move forward in the debate. He is very clear that his support for physician-assisted dying is sensitive to the holistic and contextual reality of pain and suffering from the perspective of the terminally or hopelessly ill individual. This is bourn out in his descriptions of the challenges he has faced over the years in dealing with the moral and ethical dilemmas arising from the choices he has made as he, and those he has helped, have negotiated this difficult terrain There seems little doubt that his is a ‘midwifing’ approach.

He takes issue with opposition to his support for physician-assisted dying from palliative care specialists who argue that palliative care is able to adequately manage pain and suffering so there is no need to hasten the end. Their arguments may have strategic value in the politics of competition for scarce resources if they attract attention to the need for the best possible palliative care to be made available to all who need it, but the result, Syme argues, is that it also gives false hope and obscures the facts (ibid). He cites Professor Michael Ashby as saying *“Palliative care is a model of care, not a moral crusade, and should not be used as a strategic weapon in social debates”* (ibid: 229). Syme does not dispute the importance of palliative care and its vital role in terminal illness but, he stresses, it isn’t a model which works for everyone. There should be alternatives which complement, not compete with, the dying with dignity goal of palliative care. He believes that legislative change must have safeguards with penalties for abuse and very clear guidelines similar to the Oregon legislation.

There has been no evidence of the ‘slippery slope’ effect according to the monitoring processes which are integral to the operation of the Oregon Act, a finding supported by research conducted by internationally acclaimed bio-ethicist, Margaret Pabst Battin and colleagues, which looked at the impact of legislative change on vulnerable groups in both Oregon and the Netherlands (which legalised voluntary euthanasia in 2002) (Battin et al, 2007). Nor, it seems, has there been any reduction in the demand for palliative care, in fact Syme comments about the outcomes in both Oregon and the Netherlands, that *“… since legalisation, palliative care has flourished”* (2008: 180).

If Rodney Syme’s purposeful and optimistic decision to challenge the law is successful in precipitating legislative change – a realistic possibility in his home state of Victoria where a Bill, the Medical Treatment (Physician Assisted Dying) Bill 2008 (http://www.dwdv.org.au/) has been drafted and circulated for discussion and debate – and there is a concomitant flourishing of palliative care as a result, the experience of being ‘midwifed through the dying process’ to an easeful death may be more widely available for those who choose that end.

The outlook for better quality of life outcomes in the nursing home setting seems far less optimistic despite the best attention and care that many offer. As Syme (2008) observes, the out-of-sight-out-of-mind, shut-away-from-the-world atmosphere of institutional life has a depressing prevalence in those settings. Unless and until there is more widespread demand for the sort of change embodied in the Eden Alternative habitat philosophy (and/or other success stories of care models which have improved the quality of life for the vulnerable aged), the fears of such a future will linger in the minds of many like the women in this study.

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Appendix 1 – Letter to Women of U3A

Dear Women of U3A

Let me introduce myself for those who do not know me. My name is Madge Sceriha and I have been a U3A tutor since 1989 working with the *Women Beyond 2000* group which meets at The Women's Centre where I was employed until my retirement in February of this year.

I have subsequently enrolled as a candidate for a Masters of Women's Studies (Honours) at James Cook University and am about to submit my application to the JCU Ethics Committee seeking approval to undertake research which I believe will help inform the Voluntary Euthanasia debate.

I am writing in connection with that research to invite expressions of interest from women who would be prepared to be interviewed about their attitude toward Voluntary Euthanasia and related issues.

I am interested to hear both positive and negative viewpoints.

The timing of the interviews will depend on when I receive approval from the Ethics Committee. At this stage I anticipate I would be starting to interview early in the New Year and will be following up any expressions of interest as soon as I receive them to discuss the possibility of arranging an interview.

I am able to be contacted by:

- phone on 47 793013 and should I not be home at the time of your call, I have an answering machine and will return any calls if you leave me your contact details
- by e-mail at this address madge@austarnet.com.au

I look forward to hearing from you.

Sincerely
Madge Sceriha
28.10.02

Appendix 2 – 2nd Letter to Women of U3A

Request to Women of U3A

As I wrote in a letter published in the last U3A Newsletter, I am looking for women to assist me with my Masters in Women's Studies research by agreeing to be interviewed about their attitude to Voluntary Euthanasia and related end of life issues.

I have been very pleased with the response I have received to date but would welcome a few more women to volunteer to be interviewed. I am interested to hear both positive and negative viewpoints.

I can be contacted by phone on 47 793013 or by e-mail on madge@austarnet.com.au.

I look forward to hearing from you.

Madge Sceriha
4.2.03

Appendix 3 – Letter to Participants

Madge Sceriha
33 Sabadine St
Aitkenvale 4814
Ph 47 793013

Re: Interview arrangements for your interview for my research project: “Death Rights: Hearing Older Women’s Voices in the Voluntary Euthanasia Debate.”

Dear

Many thanks for volunteering to take part in this research. I hope you will find it an interesting and worthwhile experience.

I am writing to confirm the arrangements for your interview and to let you know that I will phone the day before the interview to check that these arrangements are still satisfactory for you.

Date:
Time:
Venue:

I have also enclosed a copy of the Information Sheet and Consent Form which I spoke to you about. Please feel free to contact me if you have any questions or concerns.

Sincerely

Madge Sceriha
5.2.03

Appendix 4 – Participant Information Sheet

INFORMATION SHEET

For research topic: Death Rights: Hearing the voices of older women in the Voluntary Euthanasia (VE) debate

The purpose of this research is to hear older women's opinions about this very controversial and topical subject. Several older women advocates for VE who have taken their own lives in recent months have been the focus of widely publicised and heated debate. How have you made sense of the arguments raised by both sides in the debate? What might you have done in a situation such as these women faced? What if you were asked to be with someone when they took their life, how might you respond?

You may have been the carer for someone with a terminal illness and have first hand experience of finding out about end of life options such as palliative care, hospice, advanced directives, enduring power of attorney … while also coping with the pain of knowing someone you care about is dying.

These are some of the sorts of issues I hope to discuss with you.

It is hoped that the outcome of this research will help establish what information is most useful for older women faced with managing end of life challenges. It is also hoped it will contribute to practice wisdom and to policy formulation around the allocation of scarce resources.

What is involved in becoming a participant in this research?

- A guided discussion taking about 2 hours.
- For greater accuracy in reporting I would like your permission to tape record the interview.
- You may choose a pseudonym to be used in any reporting of your words if you wish.
- I will contact you by phone the day before the interview to confirm arrangements and answer any queries or concerns you may have about the research process.
- You will be asked to sign a Consent Form before we begin the interview.
- You will be free to withdraw from the interview at any time should you wish to do so, you may choose not to answer some questions or you may ask that certain information is not recorded or used.
- The interview is semi-structured based on broad subject areas the aim of which is to allow ideas and themes to emerge from the discussion.
- I will be transcribing your interview as soon after we complete it as possible. I will feed this back to you and invite your comment and/or to hear anything more you would like to add.
- Your confidentiality is assured. No identifying information will be stored with the data collected and it will be stored securely.

Should you feel the need to talk with someone about any issues which come up for you as a result of this interview these counsellors may be contacted:

- Ruth Oldfield or Janet King
  The Women's Centre   47 757555 (by appointment, no charge)
- 24 hour crisis support
  The Women's Centre   47 757555 (telephone counselling)
- Suzie Dormer psychologist in private practice
  47 716005 (by appointment, a fee applies reclaimable for those with health fund insurance)

Should you have any concerns about the interview process you may contact:

- My JCU Supervisor

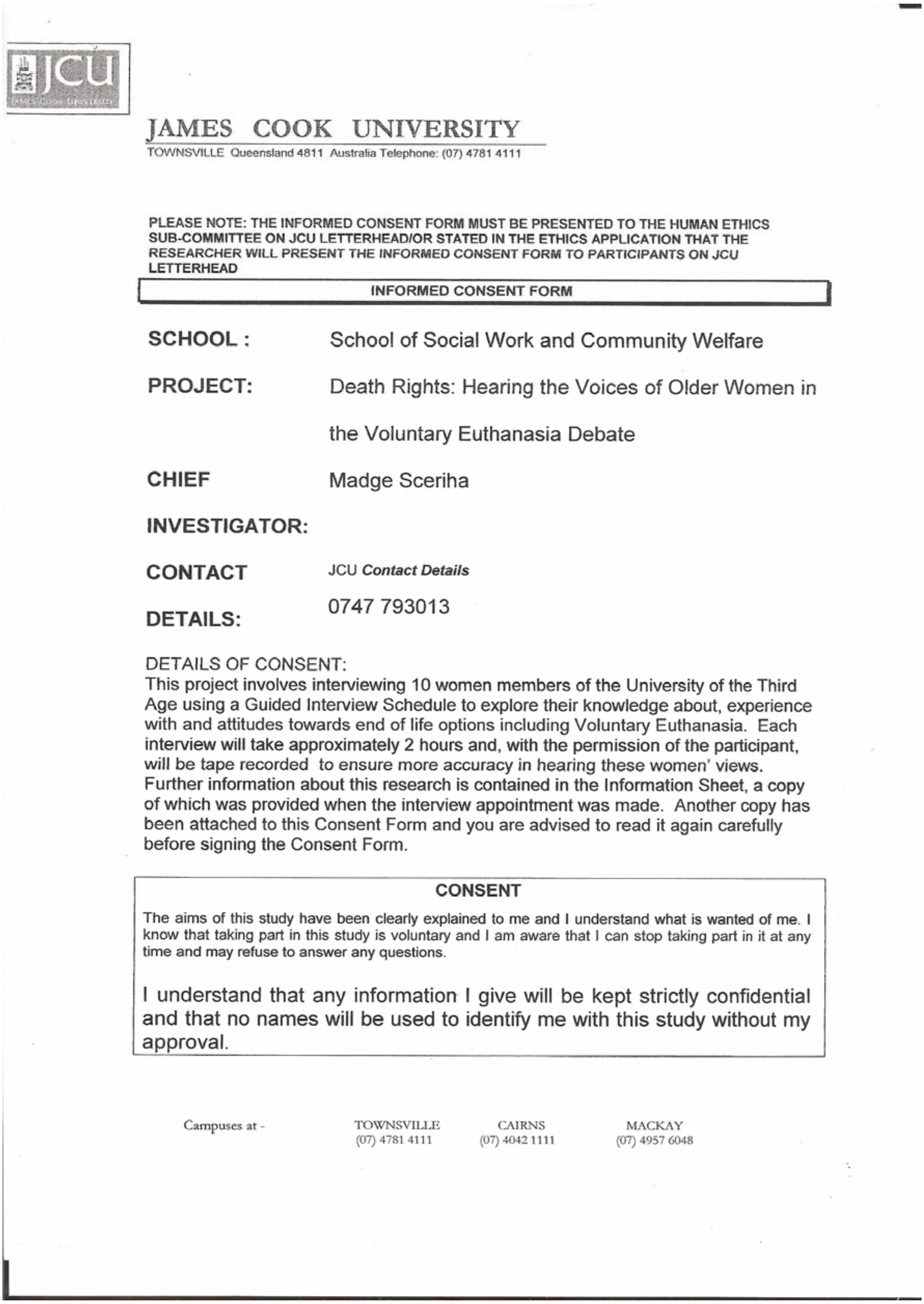
  Prof Ros Thorpe
  School of Social Work & Community Welfare
  James Cook University
  Ph 47814192

- The Ethics Administrator

  Tina Langford
  Research Office
  James Cook University
  47814342

I look forward to working with you and finding out more about this confronting subject

Appendix 5 – Ethics Consent Form



JAMES COOK UNIVERSITY

TOWNSVILLE Queensland 4811 Australia Telephone: (07) 4781 4111

PLEASE NOTE: THE INFORMED CONSENT FORM MUST BE PRESENTED TO THE HUMAN ETHICS SUB-COMMITTEE ON JCU LETTERHEAD/OR STATED IN THE ETHICS APPLICATION THAT THE RESEARCHER WILL PRESENT THE INFORMED CONSENT FORM TO PARTICIPANTS ON JCU LETTERHEAD

INFORMED CONSENT FORM

SCHOOL :	School of Social Work and Community Welfare
PROJECT:	Death Rights: Hearing the Voices of Older Women in the Voluntary Euthanasia Debate
CHIEF INVESTIGATOR:	Madge Sceriha
CONTACT DETAILS:	JCU *Contact Details* 0747 793013

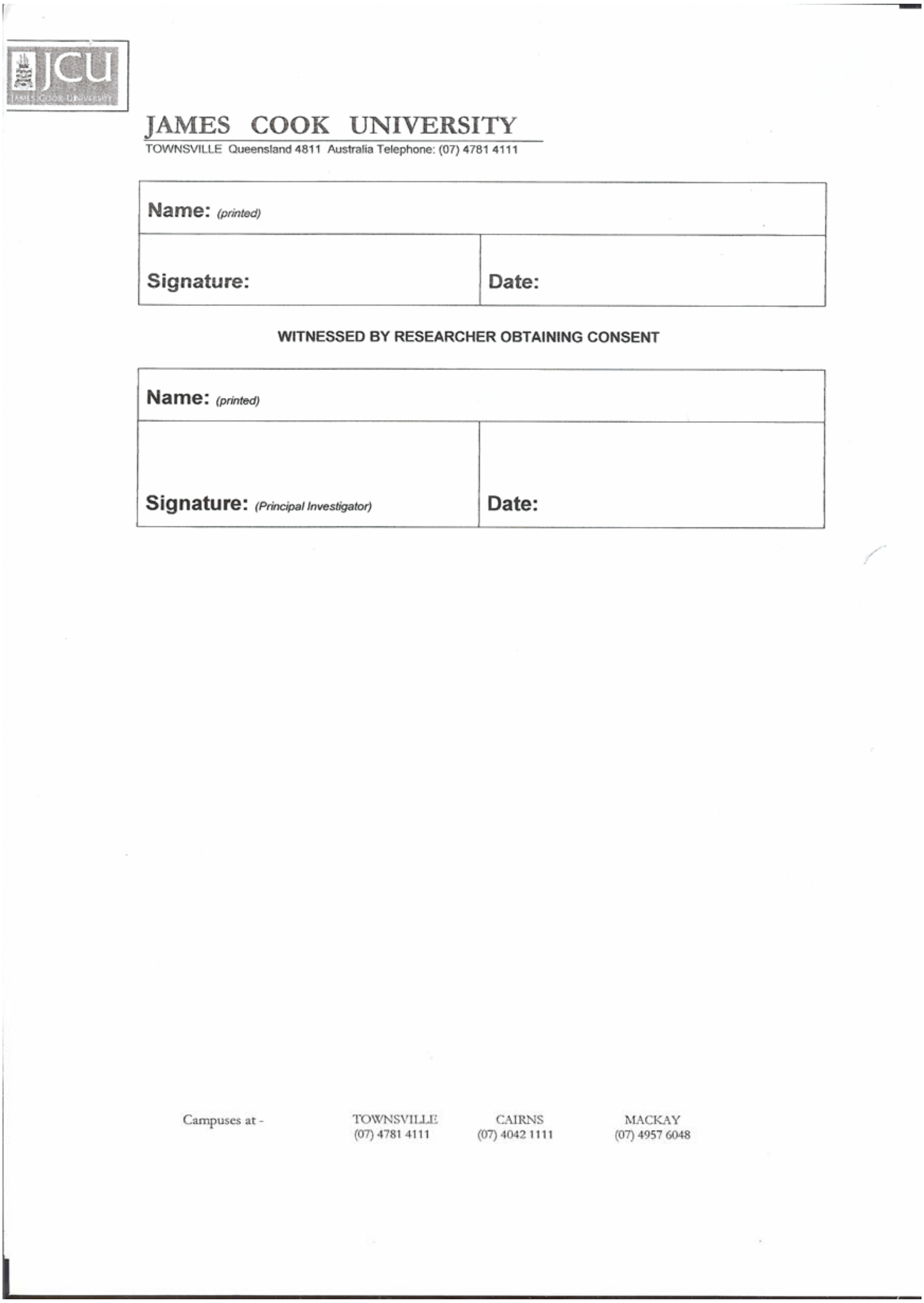
DETAILS OF CONSENT:
This project involves interviewing 10 women members of the University of the Third Age using a Guided Interview Schedule to explore their knowledge about, experience with and attitudes towards end of life options including Voluntary Euthanasia. Each interview will take approximately 2 hours and, with the permission of the participant, will be tape recorded to ensure more accuracy in hearing these women' views. Further information about this research is contained in the Information Sheet, a copy of which was provided when the interview appointment was made. Another copy has been attached to this Consent Form and you are advised to read it again carefully before signing the Consent Form.

CONSENT

The aims of this study have been clearly explained to me and I understand what is wanted of me. I know that taking part in this study is voluntary and I am aware that I can stop taking part in it at any time and may refuse to answer any questions.

I understand that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval.

Campuses at -	TOWNSVILLE	CAIRNS	MACKAY
	(07) 4781 4111	(07) 4042 1111	(07) 4957 6048



JAMES COOK UNIVERSITY
TOWNSVILLE Queensland 4811 Australia Telephone: (07) 4781 4111

Name: *(printed)*	
Signature:	**Date:**

WITNESSED BY RESEARCHER OBTAINING CONSENT

Name: *(printed)*	
Signature: *(Principal Investigator)*	**Date:**

Campuses at -	TOWNSVILLE	CAIRNS	MACKAY
	(07) 4781 4111	(07) 4042 1111	(07) 4957 6048

Appendix 6 – Poem

See Me

What do you see, nurses, what do you see?
Are you thinking, when you look at me –
A crabby old woman, not very wise,
Uncertain of habit, with far-away eyes,
Who dribbles her food and makes no reply,
When you say in a loud voice – “I do wish you’d try.”

Who seems not to notice the things that you do,
And forever is losing a stocking or shoe,
Who unresisting or not, lets you do as you will,
With bathing and feeding the long day to fill.

Is that what you’re thinking, is that what you see?
Then open your eyes, nurse, you’re looking at ME …
I’ll tell you who I am, as I sit here so still,
As I rise at your bidding, as I eat at your will.

I’m a small child of ten with a father and mother,
Brothers and sisters, who love one another,
A young girl of sixteen with wings on her feet.
Dreaming that soon now a lover she’ll meet,
A bride soon at twenty – my heart gives a leap,
Remembering the vows that I promised to keep,
At twenty-five now I have young of my own,
Who need me to build a secure, happy home,
A woman of thirty, my young now grow fast,
Bound to each other with ties that should last,
At forty, my young sons have grown and are gone,
But my man’s beside me to see I don’t mourn,
At fifty once more babies play ‘round my knee,
Again we know children, my loved one and me.

Dark days are upon me, my husband is dead,
I look at the future, I shudder with dread,
For my young are all rearing young of their own,
And I think of the years and the love that I’ve known,
I’m an old woman now and nature is cruel –
‘Tis her jest to make old age look like a fool.

The body is crumbled, grace and vigour depart,
There is now a stone where once I had a heart,
But inside this old carcass a young girl still dwells,
And now and again my battered heart swells.

I remember the joys, I remember the pain,
And I’m loving and living life over again,
I think of the years, all too few – gone too fast,
And accept the stark fact that nothing can last –
So open your eyes, nurses, open and see,
Not a crabby old woman, look closer nurses – see ME!