

“The Readiness is all”: Anticipating Death in the U.K.

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ABSTRACT

This thesis explores some of the different ways in which people anticipate their dying in the U.K. Through an ethnographic exploration of an arts initiative, a social movement, a legal case, and a new law, this thesis asks the question: how do people seek to gain recognition for their dying in the 21st Century? It is argued here that this recognition is deemed important because it is the last opportunity for people's unique identity, as they perceive it, to be reflected back at them in the faces of those who witness their dying and who stand alongside them. This witnessing is often performed in public spaces, for example: a hospice day centre; in the media spotlight; at a right-to-die conference; or in a court of law, and it is in these places where people hope that their individualised dying self will be authenticated. This thesis focuses on what happens in these public spaces and asks whether recognition is always possible. It concludes by suggesting that there are some things which are perhaps too private, too particular, and too uncertain to be recognised or authenticated in the way in which people might wish.

Section One of this thesis focuses on the activities of an arts charity which works in hospices in the U.K. and tries to elicit testimony from dying patients. Section Two focuses on the right-to-die movement: its history, politics, and the activists which bring it to life. Section Three focuses on the legal regulation of death through careful examination of a legal challenge and a new law which both involve people making anticipatory decisions about how they wish to die. As this thesis shows, people's dying testimony can take many different forms (artistic, legal, bureaucratic), and it can be represented in terms of suffering or transcendence. But the overwhelming desire of the people who feature in this thesis is to have the particularity of their lives, which is mirrored in the particularity of their deaths, publicly recognised.

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CHAPTER ONE

“One of the characteristics of modernity is that people like to feel they can anticipate their own experience.” (Sontag 2003:98)

March 17th 2008. I switch on the T.V. to catch the news. It is reported that two people of note died today: Anthony Minghella, the British film and theatre director responsible for the Oscar-winning film *The English Patient*, and Arthur C. Clarke the science fiction writer. Minghella's death at age 54 is reported as “sudden” and “shocking” for family and friends. It is only later in the report that it is mentioned that he had been living with cancer of the tonsils and neck for some time. Clarke was older. At 90 years old, one might imagine that his death would not even necessitate any explanation. But the newsreader states that he died of “respiratory complications and heart failure.” Why did such a reason need to be given? Had he not just died of old age or mortality? At the height of my anthropological research project into what it means to “be ready” for dying in the U.K., what it means to prepare and anticipate one's demise, it struck me that death today is always, to some extent, unexpected, even at the age of 90 or even after living with cancer for many years. This news bulletin about these two celebrity deaths also signals the entrenched way in which death is now medicalised. As Bauman (1992:138) writes, the late modern trend is to see death as resulting from disease, rather than from mortality. Identifying a cause is an attempt to make the unreasonable reasonable, to make death subject to preventable human action and to bring it symbolically under human control. Yet despite an attempt to rationalise death through scientific explanation, it often escapes such determination and manages to retain an element of surprise; to remain unexpected.

This thesis is about the different ways in which people in the U.K. try to make death familiar and expected once again. It is a discussion of how people try to “anticipate their own experience” (Sontag 2003) and prepare for their dying. Over the course of the 20th Century, in Europe and North America dramatic shifts occurred around the causes of death, the places of death, and the involvement of priests and doctors in

overseeing death. These shifts have been well discussed in the literature, some of which I review in this Introduction. The arts initiative, social movement, and legal principles that are the focus of this thesis have all sprung up in response to these historical shifts in the way we die, and they are all in their own way devoted to facilitating our preparedness for dying. Preparedness can inhere in attention to the pragmatics of where and how one wants to die, to addressing existential questions about the loss of ‘self’ and of relationships (in this world at least), and to the question of securing one’s legacy, the remnants of oneself in this world. In the different locations or contexts I describe in this thesis, it becomes clear that the anticipation of dying does not necessarily engender dread. Indeed, if death can be anticipated (as opposed to dying suddenly in a car crash, for example), then it can be prepared for. And often the threat of death can be annulled through preparation.

The thesis is divided into three distinct sections, each describing different fieldwork sites. Section One describes some of the activities of a charity called *Rosetta Life*, a national arts based organisation which runs creative projects in hospices around the U.K. Working with people who have life-limiting illnesses, *Rosetta Life* artists ‘give shape’ to their testimony, trying to unlock the potential for transcendence as they face death. This can be testimony about their life with illness, about their lack of futurity, or about their thoughts on ‘the good life’. The charity also attempts to find witnesses for people’s testimony. This has echoes of Derrida’s view: that testimony only becomes such when witnessed (2005:68). Here, the charity tries to engage with the ‘public’ world which Arendt (1958) describes as that part of the world which is common to all of us and which transcends the lifespan of mortal men. *Rosetta Life*’s work suggests that by witnessing the testimonies of the dying, the public can be rehabilitated to the fact of mortality and be better prepared in its collective ‘being-towards-death.’

Section Two describes what has become known in recent years as the “right-to-die” movement. This is a social movement that holds individual autonomy to be the overriding principle when it comes to preparing for death. If my suffering at the end of my life becomes “unbearable”, then I alone should be able to request that a doctor

help me to die. So runs the argument of right-to-die campaigners. Whether a person is preparing for dying through planning a trip to *Dignitas* in Switzerland, or by learning the techniques of suicide, or by politically agitating to change the law, they view the “civilised and certain” death as the ‘good’ death. Rather than harnessing the transcendent power of testimony at the end of life, as *Rosetta Life* seeks to do, the people I met during this part of my fieldwork have a sense that the dying process is dominated by physical suffering and existential anxiety, which they would like to bypass or transcend. Like the *Rosetta Life* artists and participants, they also feel that in approaching death, one can gain a heightened awareness of ‘self’ or individuality. But in their case this manifests itself in a reluctance to compromise their personal sense of dignity in the face of diminishing capacity and increased dependency on others. For right-to-die campaigners, it is the pragmatics and aesthetics of the preparations for death that are key and collective acceptance of our mortality will only be improved when we accept that suffering in dying has no meaning and when we are granted the right to artificially procure our own death.

Finally, in the Third Section of the thesis, I give examples of two contrasting legal avenues for securing an ‘expected’ death which I categorise as the ‘extraordinary’ and the ‘ordinary’ routes. The ‘extraordinary’ route I describe is a legal case brought by a woman called Debbie Purdy and her husband Omar Puente. The couple sought clarification of the 1961 Suicide Act which makes assisting in a suicide a criminal offence. Debbie wanted to know what “factors” the Director of Public Prosecutions would take into account when deciding whether to prosecute her husband in the event that he accompanies her to the organisation *Dignitas* in Switzerland for an assisted suicide. As the couple’s case is laid before the judges in a fanfare of media attention, the question is whether Debbie’s desire to gain certainty about her future death will be legally recognised and what this would mean for other people’s death decisions. Like the public audiences that *Rosetta Life* seeks to secure for its testimonial art, Debbie too asks that her dying testimony be witnessed by the judges, as well as by the public at large through her media appearances. What is less prominent in discussions of the case is her husband’s pivotal role in her preparations. This case clearly shows that preparations for dying involve relations, a feature that is

often lost in the existential focus on the ‘self’ and the heightened sense of individuality that, according to the German philosopher Heidegger (1962), one’s ‘being-towards-death’ is supposed to bring. The ‘ordinary’ route I describe is the new option to make legally effective advance decisions about our deaths in the event that we no longer have mental capacity i.e. we can no longer make decisions for ourselves or express our wishes. This legal option again assumes that the planned or expected death is the ‘good death’ and that it is incumbent on each of us to anticipate our future needs and circumstances to relieve the state or our families of the burden of making our death decision for us.

These three research sites were chosen because they are all spaces where people are preparing for and anticipating dying. As such, there are many cross-cutting themes. All three sections highlight the different forms that people’s dying testimony can take and the conflict over how that testimony is represented. For example, for some the focus is on suffering, for others transcendence over suffering, and for others still, transcendence through suffering. The Christian roots of many of the ways in which we continue to talk about death, including both suffering and transcendence, are discussed in relation to how they emerge in each of the sites. The question of who is in charge of representations of dying, given that death is deemed to have become ‘professionalised’ over the last century, is also addressed in all three sections. The importance of finding witnesses or securing recognition for people who are facing death is a theme which runs throughout, linking to the common desire to leave a legacy, a trace of oneself, or to be memorialised in some way.

In this Introduction, I want to offer a brief summary of some of the relevant and recent literature in Anthropology that theorises late modern dying. Death and its rituals have been the subject of anthropological investigation from the earliest days of the discipline. As Fabian (2004[1973]:55) writes, the “folklorisation” of “primitive” cultures has produced an impressive number of detailed reports on human reactions to death. A vast canon has thus been built up. But my aim here is not to give a systematic review of the anthropology of death and dying, as this would take me too far away from my central concerns, and could easily amount to a thesis

in itself. Rather, my interest is in briefly tracing some of the themes arising in this vast body of literature which link to ideas that have emerged from my own research and that have informed my analysis. As Fabian (2004 [1973]:53-5) suggests, I want to place the problem of death back into the context of a “we”, not relegating reactions to death to “the others”, or at least “to the other that has survived in us”. The perspectives on dying which I describe and contextualise in this thesis are all expressly Euro-American. Before embarking on a review of the relevant literature, I want to outline the Heideggerian concept of ‘being-towards-death’. Heidegger’s philosophical ideas can help to illuminate some of the assumptions which are at play in *Rosetta Life*’s arts projects, as well as the beliefs of other people who feature in this thesis.

Being-Towards-Death

How do we live life as a dying person? What happens in the time between being diagnosed with a life-limiting illness and death itself? Can this period of time evoke any special insight or awareness? The critical concept here is Heidegger’s ‘being-towards-death’, which states that it is our anticipation of our future death that is the fundamental structuring element in human existence. Becoming conscious of this movement towards obliteration or the “possibility of the impossibility of existence” (1962:307) enables us to attain an “authenticity” of existence. For Heidegger, it is only when we escape the concealment and evasion of death encouraged by “Das Man” or “the they” that we can attain this “authenticity”. It is only awareness of our own death which brings this authenticity and enables us to escape the clutches of “the they”. Since dying is something we must do on our own, death individualises us and confers on us a strange type of freedom (1962:310-11).

Bodily deterioration or the final stages of organic life, which Heidegger calls *Ableben* or “demise”, does not interest him. He is concerned with the metaphysical aspect of death (*Sterben*) as a “limit concept”, the horizon of existence which structures our lives. Authenticity, which is called forth by anxiety in the face of our finitude, brings forth our “ownmost possibility” and the possibility for transformation, a new openness and a new form of self-understanding (Carel 2006:107).

Freud (1961) also believed that death was a primary force within life. For him the “death drive” was the metaphysical principle that recognised and unified the negative aspects of human life: ambivalence, aggression and self-destructiveness. Becker (1973) continues where Freud left off, asserting a psychoanalytic model for what he considered to be our universal “denial of death”. Becker considered that humans have embarked on an “immortality project” in which a person develops a “cultural hero system” in order to foster the belief that the products of their “heroism” will outlast the person’s death. For Becker, this is the ultimate source of life’s meaning, but it is nonetheless an “illusion” which we would be better off without: “man lives by lying about himself and about his world” (1973:51). Bauman (1992) also thinks that social life aims to deny the transience of the individual by seeking to secure some form of effective immortality. In a similar vein to Heidegger, Bauman sees death as the “goal to which all life tends” (1992:19), accounting for many of the crucial aspects of the social and cultural organisation of societies (1992:11). The threat of death fosters cultural creativity, he states (1992:4). For example, the abundance of health magazines, television fitness shows and private health clubs are, according to Bauman, strategies for staving off death. Such things amount to the “countless little daily prescriptions and prohibitions that do not for a moment allow one to forget [that death is present among the living]” (1992:140).

Throughout this thesis, it will become clear that many of my research participants believe that their ‘being-towards-death’ gives shape to their lives. In choosing to collaborate with a *Rosetta Life* artist, a patient implicitly accepts that they have something insightful or “authentic” to say by virtue of being at the end of their life. The *Rosetta Life* artists encourage this view in patients and try to secure audiences who will listen to the voice of the dying and recognise the authenticity of their reflections. For the right-to-die activists, their relationship with their anticipated death is more ambivalent. On the one hand, they seek not “freedom towards death” but freedom from the dying process and the avoidance of the suffering they envisage awaiting them in their dying. Yet on the other hand, a preoccupation with the pain and suffering they associate with the dying phase actually heightens their anxiety in

the face of death. Despite comments from right-to-die activists, such as: “something meaningful might happen in spite of dying, but not because of it”, people’s uncertainty and fear of future disintegration means that the death they envisage for themselves ontologically comes to structure their present lives. Debbie Purdy and her husband Omar Puente’s legal case and the institutionalisation of Advance Decisions, are the subject of Section Three of this thesis. Both anticipate death in the sense that they encourage people to make practical plans for their death and to bring death decisions into life. ‘Authenticity’ here exists in the expectation of possible “bad encounters” (Deleuze 1988:12) in the lead up to death, and making preparations to deal with those in advance.

This thesis is not about death *per se*: it is not about the materiality of dying, or about the rituals around death. Instead, it is about our relationship with our death and the way this relationship is mediated by professionals (artists for example), activists, and the law. Heidegger’s philosophy was very much one of examining the structural and ontological effects of this primary relationship. But throughout the thesis, I show that there are detractors to this philosophy. For example, I describe people in the hospice day centre who decline *Rosetta Life*’s encouragement towards “authenticity”. I also describe people who are trying to go to the assisted suicide organisation *Dignitas* who are absorbed in the practicalities of planning for their deaths and who admit no existential consideration of their future non-existence. Heidegger was the first philosopher to suggest that “the they” was intent on avoiding and concealing death, “tranquillizing” the public against the certainty of death by “talking the ‘dying person’ into the belief that he will escape death” (1962:297). The idea that modernity is fixated on concealment and evasion of death eventually became theorised as the “death taboo” or the “sequestration of death” thesis, and unavoidably becomes the starting point for any new research on dying. It has been crucial, therefore, to keep Heidegger in mind throughout this thesis, but at the same time question his omission of the role of the Other (relatives and friends) in anticipating death and his omission of the role of direct experience in structuring our present actions (rather than an overriding orientation to a future non-existence).

Death Anthropologised

There has been considerable output from Anthropology in recent years on the biopolitical and institutional aspects of dying in Euro-American societies. This work can be distinguished from studies which look more at the attenuation of personhood at the end of life and the distinction between the social and biological death of the person (Kaufman and Morgan 2005). In fact, my own research straddles this division, but the distinction provides a useful way to categorise the literature and assess the past and present anthropological interest in death and dying.

1/ Personhood in Dying

This area of interest began with Hertz's now classic study of the double burial in Borneo. Hertz identified that in many parts of the world, death is not considered a "matter of an instant" but is rather a long process of separation from the social group (1960[1907]). Among the Dayak, "natural" death was not enough to sever the ties linking the deceased to the world of the living, which explains why corpses often remained in houses for up to ten years before full funeral rites were completed. As Kaufman and Morgan (2005:319) assert, endings depend on the culturally acknowledged transformation of a living person into a corpse, a non-person, a spirit, or an ancestor. This period is often characterised by "provisionality, indeterminacy, and contestation as social relations are reordered." It is about the Anthropology of the margins of life and Turner's (1974) concept of "liminality" has been put to good use here. It is a time when a person is betwixt-and-between social statuses and can be both vulnerable but also dangerous to the community. For example, before the Dayak's second burial, the deceased is a malicious being, an object of fear because it has not transitioned fully into the afterworld and, unaccustomed to solitude, tries to draw the living to it (Hertz 1960[1907]:36).

Hertz's now taken-for-granted insight was that death, only partly a physiological matter, reveals how the 'person' is a social being grafted upon the physical individual. It is death that disassembles the constituent parts of the person. Death also reveals the relationship of the individual to society. Individual death must be ritually dealt with in such a way that there is no threat to the continuity of the social order

and the conception of that order as eternal and unchanging. As Bloch and Parry argue, one means of negating individual death that is common across cultures is the equation of death with rebirth and the depiction of ancestors as a source of fertility for the living (1999:11). The impermanence of individual flesh contrasts with the permanence of the ancestral tomb. The 'good death' symbolically involves handing over an individual's vitality which is then able to be recycled and regenerate the social group. In many cultures, the deceased are also identified with pollution, which devalues their loss for the living and reaffirms the continuity of the social order.

The most threatening quality of death is its contingent character (Bloch and Parry 1999:12). The 'good death' in many cultures is typically the one that implies some degree of control over the arbitrariness of physiological deterioration. Bloch and Parry (1999:15) suggest that all deaths should ideally conform to the prototype of the controlled and foreseen 'good death' that ensures the continued reproduction of life. The Hindu 'good death', for example, involves the conscious and voluntary renunciation of life. But this is a prototypical good death and not all deaths conform to such prescriptions. 'Bad' deaths are deemed to be those that are unforeseen and uncontrolled.

The cross-cultural insistence on preventing unpredictable or unmanageable 'bad' deaths certainly reflects the conceptualisation of the 'bad' death in both the U.K. hospice movement and in the right-to-die movement. Both movements place great emphasis on acceptance, preparedness, and controllability. 'Bad' deaths that involve a lot of unrelievable pain are destabilising for all concerned. One major point of difference between the two movements, however, is in the treatment of suicide. Bloch and Parry (1999:16) emphasise that suicide is considered one of the most extreme 'bad' deaths in a great many cultures. The soul is often presumed to be excluded forever from the place of the dead and to wander betwixt and between as a malignant ghost while the corpse may not be accorded the normal rites of disposal. While the hospice movement would certainly consider a suicide a 'bad death', the right-to-die movement (inasmuch as one can generalise about whole movements)

would argue that 'rational' suicide from unbearable suffering can sometimes be the only way of achieving a good death in bad circumstances.

As a rejoinder to Hertz's now classic text, Bloch (1988:13) argued that Hertz never went far enough in challenging the concept of "biological death" which Hertz assumed was a termination quite unlike what happens at any other stage of life. For Bloch, being born, ageing, dying, and burials should all be considered episodes within the same sequence. This is why the image of the journey is used in many cultures, he argued, not least, I noticed, in hospice culture. "Dying", in some parts of the world, is thought equivalent to when the soul goes "travelling" during sleep, when ill, when possessed by spirits, or when under the influence of hallucinogenic drugs (Bloch 1988:15). In every culture there are complex exchanges between life and death where the dead seem to live and the living seem to die.

While there are contemporary discourses in the U.K. which stress that dying is a "journey" beginning at birth, these have to fight against the dominant biomedical paradigm that regards death as a matter of an instant. When can a person be considered dead or alive? Such determinations are always a matter of human interpretation. The Western biomedical definition of death, since 1968 at least, is "brain death" i.e. no upper or lower brain activity. As Wartofsky (1988:219) points out, even "brain death" requires to be *declared* by two doctors, proving that it is always a socially-constituted judgment. But generally speaking, bio-medicine is saturated with a Cartesian understanding of consciousness as *the* individuating, critical feature of human life and personal identity. According to Cartesian logic, once the biological machinery for cognition and self-direction goes, there is no more 'person'. Anthropologists have disputed this time and again, emphasising that a person continues as long as he or she is recognised as a person by others. Personhood may be diffused throughout the body, not just located in the mind, or may extend outside of the body to social relations. No biomedical 'condition' highlights this ambiguous zone between 'life' and 'death' more starkly than the cases of people who

exist in what is known as the Permanent/Persistent¹ Vegetative State (PVS). The lack of neocortical brain function and assumed lack of consciousness of these people might suggest that these people are no longer socially recognisable as ‘persons’. And yet Kaufman’s (2000:70) ethnography of this type of medicalised “hybrid” existence shows that an “uncommon kind of personhood” takes hold that shapes action *around* the comatose body. The moral and social relationships of nurses and relatives with these non-sentient beings, according to Kaufman, *confers* subjectivity and personhood on these permanently passive bodies which themselves have no possibility of autonomy, freedom, or expressive intentionality (2000:77).

Since Kaufman’s study, the 2005 case of Terri Schiavo hit the headlines and became one of the most litigated, public, and contentious end-of-life cases in the recorded history of the United States. Schiavo, a woman from Florida, existed in PVS for 15 years before her husband, after a seven year legal battle, was granted the legal right to have all life-sustaining treatment withdrawn. She then died from dehydration after a matter of days. Her parents resisted his rights-claim because they believed she was still conscious. The central tension in the case was between Terri’s past relationship with her parents and how they constituted her personhood, and her relationship with her husband and the subjectivity he ascribed to her. Although the case was exceptional for the media coverage and political grandstanding it generated, the challenge faced by Terri Schiavo’s family in reaching a consensus in their substituted decision making is a lot more common. Much of the same language about values and rights circulates in the assisted dying debate in the U.K. Equally, the politicisation of a very personal story of illness, disability, and dying is also a theme which recurs in this thesis. In the end, the Terri Schiavo case only further highlights Hertz’s insistence on a processual view of death. This is shown explicitly in the inscription on her headstone: “Departed this earth February 25th 1990. At peace March 31st 2005” (Green 2008:57). Death, always and everywhere, is not self-evident.

¹ There is disagreement about what this ‘condition’ should be called. “Persistent” leaves room for the condition changing, as in people emerging from coma. PVS is on a spectrum with various other ‘conditions’ such as the “minimally conscious” or “locked-in syndrome”.

One final area of the anthropological literature that further emphasises the way in which ‘life’ and ‘death’ are phases of a person’s total existence includes those studies that are concerned with memory and hauntings. Death can end a life but not a relationship. Vitebsky (1993) in his ethnography of the Sora of Eastern India, shows that Sora “dialogues with the dead” evidence a close relationship between the ‘dead’ and the ‘living’. The recently deceased are called *sonum*, which is a relationship concept. The state of mind of the *sonum* affects the state of mind (and body) of the living. Vitebsky translates *sonum* as a Memory, not the Western idea of ‘a memory’ which is firmly located in the mind, but rather as a Memory (a ‘memorial’) which has its locus of existence outside of the person whom it affects, a Memory which is part of Sora people’s objective reality (1993:14). Francis *et al*’s (2005) study of the intense personalisation and memorialising at gravesites in the U.K. also contains some great examples of the continuing bonds or dialogues with the dead where memory is both relational and affective. Headstones exist alongside other material objects as a focus for continued relationships. Obituaries, spontaneous roadside memorials, and commemorative websites are all aspects of the same phenomenon and have all been subject to anthropological investigation. Just as the *sonum* in Sora villages can be beckoned by a shaman, so the dead can be summoned in cyberspace by the click of a mouse. While all these sites promote public recognition, they are also increasingly personalised and individualised expressions of the dead person’s biography, a remarkable difference from earlier epitaphs, for example, the cenotaphs erected to mourn the dead of World War I & II.

What becomes clear in this brief analysis of personhood-in-dying and personhood beyond “natural” death is that the Heideggerian view of death as something which structures one’s whole life should not be taken for granted. The processual view of dying is that it happens in episodes across the life course at uneven intervals (occurring during sleep or trance, for instance). This does not fit with Heidegger’s existential view of death as a ‘limit concept’ that exists as a fixed point on the horizon to which one inevitably moves. The examples of continued personhood after biological death similarly subvert the ‘being-towards-death’ model, exemplifying the importance of a “being afterwards”. The liminal beings that exist betwixt and

between occupy a different time and space with very different modes of *possibility* to those envisaged by Heidegger.

The other theme which I have highlighted in this brief and selective literature review is the idea that death can be revealing of an individual's relationship to society. Whereas Heidegger thought that the anticipation of death utterly individualised people (1962:310), anthropologists like Bloch and Parry (1999) have argued instead that death de-individualises people, revealing their constituent relationships as they are 'disassembled'.

In this thesis, I explore how being diagnosed with a life-limiting illness is expected to change an individual's personhood. I examine how my participants' constitutive relationships play a part in either the continuity or the disruption of their sense of personhood. And finally, in Section Two and Three of this thesis, I suggest that for some people, their sense of personhood exists in their ability to act autonomously and to control the aesthetic shape of their life. Dying in a way that runs contrary to their expectations or plans is considered to be an assault on that person's sense of personhood and sense of personal dignity.

2/ Bio-political Analyses

Related to the long and ongoing anthropological interest in personhood at the end of life and in endings that are not yet over is the discipline's more recent interest in the way that scientific practice shapes late modern understandings of life, death, and the person. Such studies often focus on medical settings and discuss how life can be sustained and ended via the application of ever more complex human 'technique'. I have already touched upon this type of commentary when I mentioned the case of Terri Schiavo. Her case sparked a far-reaching political controversy about the role envisaged for biomedicine in sustaining such liminal beings and the moral value ascribed to these new forms of life. Kaufman & Morgan (2005:328) name Foucault as the locus of this interest, identifying his concept of biopower, that is, politics that is tied to the task of managing life itself, as central to the state's strategies and procedures for governing the end of people's lives. Where the state used to be

focused on its power to take life or to let live, since the 19th Century, its power has resided in making live and letting die (Foucault 2003: 247). The comatose, the demented, the neomort, and the “cadaveric” organ donor can all be seen as bio-political subjects, brought into being by biomedical regimes of power where “making live” or “letting die” is a political decision (Kaufman & Morgan 2005:329).

It is not the idea that definitions of life can be and are manipulated that is novel here. What is new is the array of medical apparatus that facilitates such radically new ways of doing this and the new categories of persons which come into existence as a result (and the new relationships and obligations they foster). These biomedical technologies, which were unknown even forty years ago, have destabilised and transformed previous conceptions of “natural facts” about the cessation of life (as such “facts” were held in the U.K.) (Strathern 1992). The idea of a pristine Nature that exists outside of human history and human context has long been questioned in post-Enlightenment theory. But the unprecedented interventions into molecular biology mean that we are living “after nature” (Strathern 1992) to such a degree that the categories “nature” and “biology” no longer have any commonly held referent and can no longer be used as a moral base line for decision-making:

Nature has been replaced by the right and the obligation to choose, by the spectre of litigation, the desire for control, the pressure of time, the quantification of disease and dying, and by debates about futility (Kaufman 2005:326).

New technologies test ethical boundaries. Lock’s (2002) ethnography on brain death and organ transplantation in America and Japan was seminal in exploring the new grey zones between life and death “the likes of which we have never seen before” (Lock 2003:166). Lock (1997:219) writes that whereas in the U.S. there has been surprisingly little questioning of the medical “brain death” definition, the Japanese have been much more hesitant about “harvesting” organs for transplantation. The reasons for this are multifarious, but include resistance to “technological imperialism” and to scientific efforts to assign death to a specific moment (2002:8). People in Japan are fearful that if the criteria for “brain death” is accepted then the

disabled, the mentally impaired, and the disadvantaged, will be at risk of being counted “as-good-as-dead” in order to “harvest” their organs. Such is their concern about the commodification of the body (1997:226). Such concern is echoed in similar calls to reject proposals for legalised assisted dying in the U.K.

On the one hand, for my participants who oppose assisted dying, anyone who is biologically vulnerable or socially isolated may be in danger of being counted as-good-as-dead. On the other hand, the contingency of the dying process left many of my pro- participants fearful of continuing an unwanted life in a deteriorating body and/or mind. But this thesis does not deal directly with the liminal lives of the “brain dead”, neonates, people in PVS, or those with dementia. It is dedicated to examining how people who still have mental capacity anticipate the possibility of succumbing to those states. Certain liminal states exist on that “being-towards” horizon of burdensome life that many of my right-to-die participants would like to avoid. This is the context in which these liminal beings enter this thesis.

As I noted earlier, the “good death” in many cultures is considered to be the accepted, planned, and controlled death. But when bio-politics take hold, who becomes the agent of control? Lock contends that organ donation represents a reassertion of control in response to uncontrollable accidents (2002:10). But the Japanese view this argument as a *post factum* justification for allowing technological determinism to define our deaths. Technological and institutional control of our bodies runs counter to the control that most individuals want to exert over their own bodies. Control of the human body has long been a focus of Foucauldian research: how bio-political subjects are created, moulded, treated, disciplined, and normalised or pathologised depending on the needs of the state. But we are not only subjected to strategies imposed from above. As Foucault’s notion of “governmentality” and Rose & Novas’s (2005) concept of “biological citizenship” make clear, it is through “regimes of the self” that we come to shape our own bodies, just as we co-opt medical language or technologies to create our own aspirations and affiliations. This tension between the technological or medical control of our lives versus the desire for self-control and self-determination forms the central paradox of the right-to-die

movement: that in demanding the freedom to ‘choose’ the timing of one’s own death, bureaucratic regulation still requires the medical profession’s consent to and application of the lethal dose. This paradox is discussed at length in Section Two and Section Three of this thesis.

Given that 60% of us die in hospitals in the U.K. and many more are involved in “revolving door” scenarios where we are continually admitted and discharged in order to free up beds, the majority of us in Britain will be subjected to this minute medical and institutional management at the end of our lives. Whereas in the Victorian era the family took care of the dying, with wives, mothers and daughters undertaking the most demanding work of terminal care at home (Jalland 1996:12), this role has now been devolved to institutions like hospitals and care homes. Historians and social commentators since the 1960s have identified this trend and have alternately studied it in terms of medicalisation, institutionalisation, professionalisation, secularisation, or sequestration. More commonly it has been given the catch-all heading of the “death taboo”. It is to this literature that I now turn.

The Death Taboo Thesis

Throughout my fieldwork, people often commented that they thought there was a taboo on death in the U.K. The unrelenting human desire to perfect the scientific technique which prolongs life has diminished the regenerative element which was essential to the ideal ‘good death’ (Bloch & Parry 1999). Rapidly expanding knowledge of the human genome, advances in tissue engineering, the bioengineering of drugs, and the ability to manipulate cellular aging genetically all fuel societal expectations about medical treatments that can eradicate disease and continually postpone death (Kaufman 2005:322). According to Baudrillard (1993), death’s call has been exterminated by science and our refusal to symbolically exchange with the dead makes death irreversible, a “myth”, and a “scandal”.

But where did ideas of concealment originate? Put simply, the ‘taboo’ thesis argues that once death became secularised and confined to medical institutions where it was dealt with by paid specialists, it was no longer available to public witnessing and was

cut off from the rest of social life. This destroyed its regenerative capacity and our ability to exchange with the dead. Sequestered in this way, death also became invisible in everyday life and a taboo steadily grew around it, eventually extinguishing the rituals and shared public practices that made it collectively meaningful.

Let me begin with secularisation. Christianity was historically considered a defence against death, offering devotees a safe passage to the afterlife and a guaranteed place in heaven at God's side where one would live on in eternity (Bowker 1970). The Christian paradigm posited that while the material-temporal world would be reduced to dust, the spiritual world was eternal and incorruptible. Death, for the pious, was therefore not to be feared, but to be embraced. However, religious scripts about how to approach death have never remained constant. Aries (1974, 1983) offered an ambitious model of five stages of differing attitudes towards death over the centuries, beginning with the "tame" death of the Middle Ages and ending with a damning critique of the "wild" death of the 20th Century. By the end of the 19th Century, religious affiliation was declining and this, according to Aries, precipitated a new social compulsion to conceal death because it had lost its religious or otherworldly meaning and had become an object of terror, banished to the private realm (1983:614).

Illich (1976:3) also condemns the technological imperative to conquer death, calling it the "disease of medical progress." Homes are inhospitable to birth, sickness and death, he rails, while doctors are agents of "outright dissimulation" (Illich 1976:103). Elias (1985) found that repugnance characterised the attitude towards the dying in Western modernity. He observed that people felt embarrassed around the dying and even the use of ritual phrases had come to feel inappropriate (1985:27). Dying reminds us that we are animals and fills us with shame and repugnance to the extent that we want to confine it with "civilising barriers" (1985:11). Even the word "death" is avoided:

Never before in the history of humanity...have corpses been expedited so odourlessly and with such technical perfection from the deathbed to the grave (Elias 1985:23).

Lawton's (2000) ethnography of a U.K. hospice deals precisely with what she views as the myth of odourless bodies. If death has become a "scandal", confined to medical establishments, then what of the modern hospices that have sprung up in the U.K. since the 1950s to take care of the dying? Lawton's (2000:16) ethnographic research revealed that the realities of patients' bodily deterioration are "glossed over", even within the hospice model which has historically championed the virtues of awareness and acceptance on the deathbed. People may want "odourless" deaths but, in Lawton's hospice at least, the smell of vomit, excreta and general bodily decay ubiquitously emanated from "unbounded" bodies (2000:77). This is the reason that death is 'sequestered', she argues, because the non-dying population are quite content to ignore the messy realities of dying and to be convinced by the hospice rhetoric that it is possible for everyone to "live until they die" (2000:182).

In many ways, this thesis supports Lawton's findings that the impetus to conceal death remains. But it is also important to note that for commentators such as Aries and Illich, our past responses to death were often depicted as more therapeutic than our current responses which they unequivocally condemned. As Hockey (1996:11) notes, this undoubtedly involved some romanticising of the past. People in small-scale societies elsewhere in the world have also been consistently attributed with a 'healthier' response to death, helped by stronger community structures and rituals.

The invention of such "death utopias" is more a reflection of dissatisfaction with our current reactions to death in the U.K. than an endorsement of the way in which people died in other historical times or in other cultures. Hockey suggests that trying to evidence ethnographically more 'natural' ways of dying and of approaching death in other cultures is part of a misplaced nostalgia and the result of a new impetus to prioritise emotion around dying. The trend towards emotional openness has been strongly influenced by the rise of the hospice movement. Walter (1994) calls it

“revivalism”. The Evangelical ethic of the hospice movement led to a new era which encouraged the disclosure of emotions in dying (although as Section One of this thesis shows, this is still highly regulated). Since the 1960s, people have been informed of their prognosis, and funerals in the last decade have become more personalised (particularly Humanist funerals). It is the dissonance which exists between the continuing impetus to conceal and this new “revivalism” with its pleas for emotional openness which this thesis seeks to explore.

The Professionalisation of Death

Revivalism was supposed to take individualism to its logical conclusion by enabling the individual to claim authority over the medical technologies and paternalisms that had sequestered death in the first place (Walter 1994:185). In that sense, revivalism has also contributed to the rise of the right-to-die movement. However, at the same time, it has also ushered in a new paradigm: that of the professionally managed death. In 1969 an American psychiatrist, Kübler-Ross, wrote a seminal “guide” to dying well in which she diagnosed a five-stage model of how people normally respond to a terminal diagnosis. These stages were: denial, anger, bargaining, depression, and finally, acceptance. Although she stated that not everyone goes through all five stages or goes through them in the same order, her neat, memorable five-stage model became a favourite of students training for the caring professions (Walter 1994:72). This type of dying script can be considered a modern version of the *ars moriendi*, a text written by monks in the Middle Ages which offered detailed instructions about how to prepare for dying and for entering heaven. Kübler-Ross (and before her Cicely Saunders, the founder of the modern hospice movement) were pioneers for what was known as the “death awareness” movement. They wanted to give professionals the diagnostic tools and the language to normalise and speak about dying without the fear and embarrassment identified by Elias (1985). But Kübler-Ross’s meta-story, a landmark at the time, ended up establishing a new norm prescribing the “right way” to die and grieve. Doctors continued to draw a blank when dealing with people who did not conform to this prescription (which was modelled specifically on people dying in hospital of cancer prior to old age). Although Kübler-Ross’s framework did establish a language for the dying to

articulate their feelings, some critics argue that this only encouraged people to intellectualise their feelings in a way that was self-alienating. Certainly her guide “On Death and Dying” was responsible for spawning a whole genre of self-help guides and a new therapeutic emotionalism around death.

These types of models and manuals bring to mind Foucault’s observation that expertise implies power. Rose’s (1999) view, for example, is that the psi-sciences (Kübler-Ross was a psychiatrist) are used to make governable subjects. Through the regimes of injunction, prohibition and judgment they inculcate, people come to understand and act upon their daily conduct (Rose 1999:xx). We reconstruct our sense of ourselves in tune with the experts’ language and advice. A therapeutic culture is also hugely individuating. Collective grievances are transformed into personal problems amenable to therapeutic intervention. Arnason’s (2001) ethnography of *Cruse*, a U.K. bereavement counselling organisation that purports to cast the griever as the “expert” of their “ordinary” grief, uncovers governmentality at work in psychotherapy’s power to produce a conditioned ‘self’. He found that counselling offered people a chance to “recognise, isolate and act upon their own subjectivity” (Cruikshank 1993:331) and that this is a form of subjectification (Arnason & Hafsteinsson 2003:57-9), albeit one that casts people as ‘experts’ of their own emotions. *Cruse* has clearly tried to become reflexive in its use of Kübler-Ross-type tools, but as Arnason’s ethnography shows, it is still caught up in modes of governmentality that simultaneously emphasise liberty and responsibility (2003:59).

My ethnographic research picks up similar themes. *Rosetta Life* artists are akin to *Cruse* bereavement counsellors in the sense that they try to authenticate people’s unique and individual testimony and emotions. But they are also caught in the ‘double bind’ of Arnason’s (2001) counsellors in that they want to both normalise dying people’s experiences, while at the same time celebrating their uniqueness and justifying their role as a professional mediator. This is one of the conundrums that I deal with in Section One. In Section Two and Three, I show that the professionalisation of dying also presents a conundrum for the right-to-die movement. The movement sprang up in opposition to the medicalisation and

professionalisation of dying, casting the individual (and not the oncologist or psychiatrist) as the sole arbiter in reckoning their death. But the acceptance of any request to end one's life "artificially" is to be made by medical professionals. In trying to empower themselves to make their own autonomous death decision, advocates of assisted dying have to appeal to the professional expertise of the medical establishment to legitimise their claim. This takes suicide out of the hands of individuals and places it under medical authority (Tierney 1997:72). In Section Three, I describe Debbie Purdy's appeals to the legal establishment to legitimise and witness her rights-claim to have certainty in her dying. People are caught up in both rejecting professional determination over their lives and wanting the legitimacy that an official diagnosis or legal judgment brings. Professionals have a special position in the political economy and, however we try to rationalise their services, professional ideology is suffused with a "transcendent value" (Friedson 2004:122) that people want conferred upon their decisions.

Dying in the Public Eye

The three sections of this thesis all highlight the limits to people's efforts to make dying a public event. Arendt (1958) and Sennett (1977), whose ideas I discuss throughout, both argue that the once-glorious public realm has been corrupted by the compulsion to air one's private concerns in public, which has forged the end of "civility" and caused the "unnatural growth of the natural" (Arendt 1958:47). This trend can be recognised in the mass public reaction to the death of Princess Diana, whose life and death were personalised to such an extraordinary degree that people mourned her death as they would a family member using the same private register but in public settings. The picture of evasion, concealment and denial of death which was given by Aries and Illich does not fit with media responses to the death of celebrities like Diana. During my research, the anticipated death from cancer of Jade Goody, the "Big Brother" reality TV star who stated that she wanted to "die in the public eye" broke new boundaries in terms of airing private (anticipatory) grief in public. Celebrity magazine *OK!* even published its tribute issue to the star, advertising Jade's "last words", while she was still alive! The woman who had been turned into a celebrity by the show that epitomised the very blurring of the

boundaries between the public and the private, blurred the two again in death.

According to one obituary:

...like a working-class Princess Diana, Goody became the object of strangers' intense feelings, and she became a sacrifice, a woman whose suffering and death made it possible for people to ritually cry for someone they scarcely knew (Jeffries 2009).

By this journalist's account (and his was not a lone voice), Goody was a surrogate victim, a substitute for people's collective virtues and wants and eventually a substitute for their dying. The same could be said for people who travel to the Swiss organisation *Dignitas* for an assisted death, inviting the media to accompany them and record their journey. Anne Turner, a G.P. from Glasgow, invited the BBC to record her journey to die at *Dignitas* in order to publicise her plight. In doing this, she became a right-to-die celebrity. Such people become surrogate heroes for right-to-die activists, lauded for their bravery, their contribution to the 'cause', and envied for their chance to procure the kind of death which others would wish for themselves. The question is this: how does watching T.V. programmes about Jade Goody's preparations for her death² compare with watching Debbie Purdy appearing on breakfast TV outlining her legal case for a right-to-die? And how does a documentary on Purdy or Goody's life compare to a *Rosetta Life* "celebration event" showing someone's life on film to them before they die? All are ways of preparing, but all show the influence of Debord's "society of the spectacle" (1977). Today, the real experience of death is often the experience of the image of death (Noys 2005:122). But more than this, we also experience our own death in advance through using and watching images of our own lives projected before us.

Although preparation for death seems to have long been the mark of a 'good death' experience across many cultures, the emotional and highly personalised register in which we now (individually) prepare in Euro-American societies is new. Through descriptions of an arts initiative, a social movement, a legal challenge, and a new

² Living TV's *Jade*, aired on the 19/02/09.

law, I hope to examine what is new and what is old in our anticipation of death and to describe how the private process of dying is turned into a public event.

What all of the social processes (art, activism, law) that I describe have in common is that they purport to offer a form of transcendence and public authentication of an individual's unique life. *Rosetta Life* wants to 'reawaken' patients to the possibilities of transcending their illness and to consolidating their unique legacy. People compelled to travel to *Dignitas* or learn the techniques of self-deliverance want to transcend their suffering and to die in a manner which is in accordance with their own sense of personal dignity. The right-to-die campaigners use death activism to transcend the particularities of their own individual death and align themselves with a collective belief in the transcendent value of autonomy. And finally, Debbie Purdy's appeal to a human right-to-die attempts to enlist the transcendent power of human rights symbolism to bring legitimacy and irrefutability to her wish to have certainty in death. In all of these different ways, I argue, people are trying to transcend (or are encouraged to transcend) the particularities of their own existence and their own death through the application of dying scripts or templates or through adherence to overarching values. But, as this thesis seeks to argue, there are some occasions when transcendence or authentication fails precisely because of the particularities of individualised existence. Some aspects of our lives and deaths are just too private, too individually specific, and too uncertain to be publicly authenticated in the way that people might wish them to be.

Chapter Summaries

All of the people whom I introduce in this thesis are either anticipating, waiting for, or preparing for their own death, or are facilitating or preparing for someone else's death.

Chapter Two details my research design and some of the access and ethical issues my research raised, all of which are pertinent to debates within the discipline more generally about how we locate our subject and how we position ourselves in relation to our participants.

Chapter Three introduces the reader to *Rosetta Life* and its modus operandi via an examination of the activities of one artist-in-residence working in a hospice day centre in South London. The artist, Chris, works with patients to try to “re-awaken” their imagination and a sense of transcendence over their illness through encouraging them to participate in his creative projects. While some patients are keen to be “shepherded” towards this heightened sense of ‘self’ or towards “authenticity” in their ‘being-towards-death’ (as Heidegger would put it), others are not interested, are too sick, or just want to be left to ‘take it on the chin’. As people live longer with chronic illnesses, so that ‘dying of’ becomes ‘living with’, they also have a longer period in which they can anticipate their death. This chapter is therefore about how people can and cannot or do and do not talk about their own dying. I also seek to highlight the tensions between what is individually specific in our anticipation of death and what we can make general assertions about or plans for. This relates to a broader tension in hospice care between emphasising the uniqueness of each individual’s story (encapsulated in the motto “you matter because you are you”), while also trying to create a meta-story around universal processes and stages of adapting to life-limiting illness (Walter 1994:69). This discord between the specific and the general or the individual and society is a theme that runs throughout the thesis.

Chapter Four of Section One moves from a discussion of private transformations to one of public recognition. I explore more fully within *Rosetta Life*’s ‘retelling of the self’ the desire to initiate recognition from those who have witnessed that telling. If testimony requires to be witnessed, how does *Rosetta Life* go about eliciting responsible witnessing from others, both within the hospice movement and beyond, for example, at an event at London’s City Hall? I examine two “celebration events” where filmed testimony is shown to an audience of hospice day centre patients. Where one falls flat and draws an awkward silence, another elicits welcome recognition. I also examine a National Theatre Project and its outcomes, and the making of a film intended to be shown at a person’s funeral. What are the benefits and what are the pitfalls (sensationalism, intellectualisation, moralising?) in trying to

translate the private experiences of people's intimate lives into a public discourse around dying? What does it mean to bear witness to the other's 'being-towards-death'? Ultimately, I respond to Sennett's (1974) arguments about the "tyranny" of allowing the intimate register to dominate public life by exposing some of the problems *Rosetta Life* faces when trying to convey public messages through revealing details about people's private and specific lives.

In Section Two I explore the right-to-die debate as it manifests itself in the U.K. The desire to choose the exact timing and manner of one's death stems from a common desire to control death. Chapter Five looks at the ways in which people reject professionalisation and medicalisation of dying, either through learning the techniques of 'self-deliverance' or planning a journey to *Dignitas* in Switzerland for help to die. Self-deliverance is compared with the act of assisting someone else to die in terms of engaging different ethics of freedom and responsibility. Religious narratives also feature heavily in this chapter as I look in turn at the Christian proscription of suicide, religious views of 'natural' and 'unnatural death', and Christian narratives about sin, redemption, and the meaning of suffering. The aesthetics of death are revealed to be very significant in how people envisage their death and how they personalise it to make it fit with their general view of 'self' and of the 'good life'. Right-to-die activists aspire to a type of "negative" liberty (Berlin 2006[1958]) premised on non-interference, but for those wanting help, there will always have to be other parties involved. This conflict presents serious problems for formulating legislation that does not involve making judgments about another person's life. Generally, this chapter is about how contemplation of one's dying, particularly the practicalities of how one wants to control one's own death, can enhance one's entire life by bestowing on it a shape appropriate to one's values and sense of 'self'.

Chapter Six discusses the history of the euthanasia debate, from its beginnings at the end of the 19th Century to its current manifestation and the split between the activities of FATE and *Dignity in Dying* (DID) which both campaign for legalisation. The debate about assisted dying raged long before the existence of intensive care

units, life-sustaining technology, and a state run health service. This shows that it does not just engage anti-technology arguments, but touches on broader debates about individualism and the desire for self-determination. For most of the 20th Century, the euthanasia movement was embroiled in the campaign for eugenics. The history of the movement has been used by opposition factions to discredit it in recent years. DID has responded by trying to break free of its past and enter the ‘mainstream’ by fitting physician-assisted suicide into a now well-established rhetoric of patient choice and patient rights. Freely chosen death in this model would become just one more life choice.

Chapter Seven continues the examination of the political campaigning around attempts to legalise assisted dying in the U.K. I analyse the arguments that repeatedly surface, including those of the disability rights movement which is particularly vociferous on this issue. I investigate the ways that ‘emotion’ and ‘rationality’ are conceptualised and valued, and the ways in which suffering is instrumentalised on both sides of the debate.

Chapter Eight examines the nature of conviction in its discussion of FATE activists. Here, I use my ethnography of a devoted core of right-to-die activists as a springboard into a discussion about the relationship between activism, conviction, and belief. I describe the ways in which the activists talk about their desires and their fears about dying. Why did they choose death as a focus for their activism? How far does their passion reside in their treatment of ethical principles and concepts of ‘societal good’ and how far in an authentication of their own ‘self’? Do activists play a role in making death more public by acting as conduits for people’s personal stories about dying? The types of convictions expressed and the manner of their expression reveal something about these right-to-die activists’ conceptions of their ‘self’. And this ‘self’ is then mirrored in the principles for which they are fighting – self-determination and autonomy. Like the hospice users involved in *Rosetta Life* projects, they want to claim public recognition for themselves. Once again, testimonies are elicited and the public is asked to witness them. And in the

witnessing of these activists' conviction, heroes are made and are potentially immortalised.

Section Three considers legal recognition of dying and comprises just one chapter. Chapter Nine argues that although Debbie Purdy and her husband Omar, in their “extraordinary” legal challenge, presented their case as one of demanding certainty about the application of the law, what they were really requesting was certainty in death. This the law cannot give, as yet. The Mental Capacity Act 2005, on the other hand, now formally recognises as “ordinary” the right to make preparations for one's dying. Advance Decisions have the potential to confer anticipatory certainty. Whether they will be respected by all healthcare professionals in all institutions, however, will depend on a more generalised cultural acceptance that the ‘good death’ is now the death that is to be determined by the individual alone.

CHAPTER TWO

“No other intellectual discipline combines dispassionate observation and personal ordeal in the way fieldwork does” (Jackson 2002:262).

Marcus’s (1998:122) view is that Geertz’s insistence on “disinterestedness” (1968:156) when undertaking anthropological fieldwork no longer stands because of the complicated ambiguities of contemporary fieldwork ethics. Marcus equates ethnography with a kind of “circumstantial activism” (1998:98) whereby the anthropologist is forced to negotiate an involvement with the topic and with research participants beyond previous “disinterest”, continually having to manage cross-cutting personal commitments and to adapt to circumstances. This “complicated ethical compass” of contemporary fieldwork (1998:122), he argues, is accentuated in fieldwork where inequality of power relations between ethnographer and informant can no longer be assumed and where “both are engaged in the pursuit of knowledge with resemblances in form and context that they can recognise” (1998:125). In other words, sharing the same social world as one’s research subjects and an interest in the same types of knowledge production heightens the ambiguous and complicated ethics involved in fieldwork. As Maurer writes of his own fieldwork:

“critical distance” became impossible...as a means of generating “new” knowledge that hadn’t already been conjured, argued over, or dismissed by the field itself (2005:34).

This was certainly true of my research into how we anticipate and prepare for dying in the U.K. ‘Disinterestedness’, ‘not taking sides’, or “dispassionate observation” (Jackson 2002:262) was difficult for me throughout, although I will resist adopting Marcus’s “circumstantial activism” because of the political connotations of the term “activism”. Suffice to say that the “research imaginary” (Marcus 1998:9) that I strove to create in my multi-sited fieldwork involved an *exchange* of perspectives and positions between myself and my participants, which continually destabilised my “ethical compass” but ultimately influenced the direction of my research. My research participants’ interrogation of my motivations sent a signal to me that they were not willing to be objectified, if only for the fact that we share the same social

world. They also had trouble believing my “disinterested” position and one of their pre-requisites for divulging information to me was an equal exchange of information about my own background, views, and knowledge.

In this chapter, I describe how I collected the information on which this thesis is based. I started my research in October 2006. I then moved to London in January 2007 in order to be nearer the centre of the debate. I returned to Edinburgh in January 2008 to begin writing up my data, but continued to attend relevant events throughout 2008-2009. In this chapter I discuss some of the benefits and challenges of multi-sited fieldwork, how I accessed my different fieldwork sites, and how I negotiated personal relationships once embedded in those sites. I also discuss the utility of my work for participants and the problems of maintaining a neutral stance in a highly polarised and contentious debate. My aim in this chapter is to make my methods visible and myself accountable. I also hope to link my own experiences with broader methodological debates within Anthropology.

Multi-sited research

Marcus advocates against over-determination in ethnographic projects that instead “must be allowed to “breathe”... before the theory kicks in” (1998:18). Equally, I would counter, ethnographic discoveries do not happen via “immaculate perception” (Woolcott 1999:69). There is always some prior knowledge by which we decide what to look at. Ethnography cannot proceed without purpose and, when in the field, ethnographers are “already comparing what they know, or what they think they know, with what they are discovering” (Woolcott 1999:87). For Marcus, multi-sited projects generally work against over-theorisation because of the sheer empirical challenge of making connections not obvious to the theoretical stipulations that initially inspired the project (1998:19). So while, for the sake of cohesion, my multi-sited project required an abstract or “theoretical” imaginary to ‘join all the dots’, once in the field, empiricism took over as I responded to relationships and connections which could not have been foreseen because they were outwith the “naturalised nominal categories of social space” (Marcus 1998:19).

In studying the right-to-die debate, I followed the “chains, paths, threads, conjunctions, locations” (Marcus 1998:90) where the very terms of the debate were decided. I was not interested in the dying process, but rather in the process of anticipating death. This was intended to rule out researching bodily disintegration (see instead Lawton’s (2000) ethnography or Seymour (2001)) or the intricacies of medical decision-making, procedures, and bureaucracy (see Kaufman’s American Intensive Care Unit study (2005)). Needless to say, these aspects of modern dying feature in this thesis to the extent that they shaped participants’ anticipation of death, but I did not study them directly.

With the addition of *Rosetta Life* and the hospice day centre, along with a high profile right-to-die legal case and the *Mental Capacity Act*, I had to develop complex linkages between the various elements of my project. I moved between the different spheres and ‘scales’ of my assorted sites as much according to serendipity as deliberate enterprise or design. I often felt afraid to forsake any *kind* of data for fear that it would provide the key to the whole, or at least shed light on some other aspect. I wanted to be open and flexible and follow my participants wherever they led me, while at the same time going ‘deep’ into the issues affecting people’s lives. In aiming for both depth and breadth I was faced with the challenges of ever-widening scope and multiple and increasing foci. This left me with a sense of what Strathern calls “increasable complication” (1991:14). It also presented the danger of “ethnographic thinness” (Ortner 1995:190) or the loss of depth of interaction warned by Clifford (in conversation with Marcus 1998:245).

These warnings of “thinness” did ring in my ears throughout my time in the field. The “snowballing” technique, whereby people I interviewed would suggest other possible interviewees, while slow at the outset, eventually proved very effective in securing me endless new contacts. By the end of my fieldwork, I found I was short on time and often had competing commitments in my diary. Each new participant offered a new perspective on the topic, new avenues of research, additional contacts and the inevitable follow-up time. As Strathern (1991:13) comments, “the more closely you look, the more detailed things are bound to become”. Of course, all of

these rapidly proliferating research questions were legitimate and genuine, but the difficulty lay in perceiving the links between them, which in many instances, did not truly become apparent until the writing-up stage.

While Strathern thinks that embracing complexity by studying multiple elements is one of Anthropology's strengths because no single element can allow one to grasp the entire phenomenon (1991:14), I found it very difficult to hold multiple "scales" (as she calls them) in my head at the same time. Whenever I was overwhelmed by details, or felt I was not doing justice to each of my sites, I took comfort in Carsten's (1995:1) comment that completeness is never a "proper aim" for anthropologists. This is reiterated by Strathern when she comments that connections remain partial because they are never subsumed with the ethnographer's knowledge of them – there are always things which remain beyond (1992:16, 27). From the very beginning of my project, my interest and emphasis lay with the juxtaposition of different aspects of the public discourse on dying, not with representing in a *complete* way individual participant's lives or every single alternative perspective in the assisted dying debate. It was the "thickness" of the juxtapositions, rather than the "completeness" of the life stories told which would hopefully offer the insights I was after.

Access

Access was a key determinant in the kinds of information I was party to and each of the discrete areas of my research required a different approach in order to gain access.

In my original proposal I stipulated that I wanted to volunteer for the charity *Rosetta Life* so that I could encounter "people privately contemplating death to contrast with those who seek death publicly through the courts". When I moved to London to embark on my fieldwork, I met with the charity's Artistic Director, Lucinda Jarrett, and asked her if I could use their involvement in hospices as a case study for my PhD. Jarrett was initially receptive to my proposal. As the director of a cash-strapped charity, she was grateful for all the help they could get, and considered that my filmmaking skills would be useful. She subsequently wrote me into a funding bid for

a project called “The Dynamics of Dependency on Camera” and my research was to constitute a large part of this project’s evaluation. However, after waiting some months, I heard that the funding bid had not been successful and that the project was to be shelved. I then petitioned *Rosetta Life*’s Head of Video Production, Chris Rawlence, to allow me to shadow him at his residency at Greenwich and Bexley Cottage Hospice in South East London. He agreed in principle, and I wrote a research proposal to be submitted to the Hospice’s Clinical Governance Committee (see Appendix 1).

There were a number of delays in submitting my proposal, not because *Rosetta Life* was reluctant to engage a researcher or was wilfully neglectful of my interests, but simply because my research was not a priority for the charity and it was desperately overstretched. I eventually received authorisation a full nine months after first establishing contact with *Rosetta Life*. This goes to show that negotiating access to one’s fieldwork site can be a very long and frustrating process which needs to be accounted for in the planning stages. Researchers are dependent on the goodwill of those they wish to study with and have to work to their timeframes. Prior to the formal authorisation by the Clinical Governance Committee, I was only permitted to attend the day centre on those days when Chris was working there (on average once a fortnight, beginning in March 2007). Once my proposal was formally accepted in September 2007, I was permitted to attend the day centre without Chris’s supervision, and my visits increased to (on average) twice a week for the remainder of my time in London (two and a half months).

Gaining access to the activist networks proved more difficult than anticipated. I applied for internships at *Dignity in Dying* (DID), the main organisation campaigning to legalise assisted dying in the U.K., and at *Care Not Killing* (CNK), the newly established (2006) organisation opposing legal change. Both of these organisations are based in London. However, neither application was successful. DID refused my request for an internship citing “lack of space”, while CNK never responded to my (multiple) requests. It would be unfair for me to speculate as to why these charities could not accommodate my research. However, what can only be described as a lack

of enthusiasm for my project highlights a recurrent experience throughout my research that people were generally wary of allowing me access to confidential discussions and information. The assisted dying debate is highly contentious and politicised and the media is always quick to pick up on controversial stories emerging from it. The main lobbying charities on both sides could quite understandably have viewed me as an unknown entity whose outputs they would have no control over. In an audit culture where there is a rhetoric of public inspection, submission to scrutiny, and accountability (Shore & Wright 1999:558-9), I had not anticipated any reluctance on behalf of the organisations to grant me access. Ginsburg (1991), in her research into the abortion debate in small town America, had succeeded in building up relationships with activists on both sides of the abortion debate which had led me to expect that I could reasonably do the same in the assisted dying debate. As my research progressed, it became clear that it was naïve of me to expect the two main campaigning organisations in a polarised debate to open their doors to me without significantly limiting my access to information and my ability to freely document their activities.

Inevitably, in the modern world of research, people expect to be convinced, cajoled, and nigh on harassed into contemplating the research proposal in front of them. The question is simply one of whether the researcher is prepared both to jump through the requisite hoops, and to wait for a decision to be made. Because of the breadth of my research interests, I had room to manoeuvre when one line of enquiry became blocked. But constraints of time and frustration (endlessly waiting to hear back from people) ultimately affect how long or how hard a researcher will work to gain access before seeking alternative routes to examine the same issue/ people.

I proceeded with my research by independently requesting interviews with every high-profile person associated with the assisted dying debate. Initially, I approached people and organisations with a prominent media presence. These interviewees would then advise me about other possible contacts (commonly known in research terms as the “snowballing” effect). In 2004, cross-bench peer Joel Joffe had introduced to the House of Lords his *Assisted Dying for the Terminally Ill*

Parliamentary Bill. A Select Committee had been set up to investigate the proposed Bill and submitted a call for evidence from over 100 organisations, as well as inviting calls from individuals who wished to air their views. This evidence was summarised and evaluated in the 2005 House of Lords Select Committee Report³. This report offers a thorough summary of the assisted dying debate (up to 2005) and its *Appendix 3: List of Witnesses* offers a comprehensive list of all the organisations and individuals who gave written and/or oral evidence to the Select Committee. While I did not interview every organisation listed in this Appendix, it provided me with a valuable guide to the organisations which are understood to have a vested interest in the outcome of any proposed legislative change.

In lieu of working ‘inside’ the main campaigning organisations (DID and CNK), by interviewing people affiliated to the debate I hoped to work the other way round – from the outside in. I interviewed politicians, pressure group campaigners, doctors, and lawyers all of whom were advocating for or resisting legislative change. A full list of the people I spoke to, the organisations they are affiliated to and the nature of my contact with them is included in my Appendix 3. Not all of these interviewees appear in the final thesis, but their comments have all informed my understanding of the context of the debate. The process of securing these interviews was very time-consuming and much of my time, especially during the first six months of my fieldwork in London, was spent devoted to this task. Over the course of the year, I would, on average, conduct two interviews a week. I also attended numerous public events about end-of-life issues. These are also listed in Appendix 3.

However, after some time, I began to feel that my research lacked the ‘embedded’ ethnographic insights that come from full immersion in people’s activities. The immersion archetype is still strong in Anthropology, despite more recent questioning of how it is practically achieved. According to Okely, it is commitment to total social immersion which makes ethnographic fieldwork anthropological (1992:8). I eventually achieved this immersion with *Friends at the End* (FATE). FATE is a pro-

³ See: <http://www.parliament.the-stationery-office.co.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm> (accessed 10th January 2010).

assisted dying organisation, with bases in Glasgow and London, that focuses on serving the interests of its members by dispensing advice about developments in self-deliverance techniques as well as information about travelling to *Dignitas* in Switzerland. By researching FATE I was able to access a specifically ‘activist’ mode of being and address the question of whether activists embody the crossover between the public and the private death.

My relationship with FATE began with interviews with key board members and progressed to attending regular meetings, single events, and travelling with members of the organisation to the European and World Right-to-Die Conferences. FATE also put me in contact with people wanting to travel to *Dignitas*. Although I made a concerted effort to continue interviewing anti-activists, my inability to become fully ethnographically immersed in anti-activities led to my research becoming heavily weighted towards exploring the debate from the pro-perspective. I continue to feel uncomfortable about this lack of balance. Without trying to make excuses for the direction my research took, it is always the case that those agitating for change are likely to be more ‘active’ than those defending the status quo⁴. The opposition spokespeople whom I contacted also tended to be more suspicious of my motives and more resistant to my attempts to get involved. These reasons to some extent explain the imbalance in my thesis between the two ‘sides’.

Accessing the lawyers representing Debbie Purdy and Omar Puente’s legal case also proved a challenge. Convincing lawyers, who are notoriously to-the-point and task-orientated, of the value of anthropological research was very challenging. The merits of anthropological modes of enquiry are hard to impress on a time-strapped lawyer who seeks precision, facts and ultimately a resolution. In addition, lawyers have a heightened awareness of client confidentiality operating as they do in a litigious atmosphere. When I finally managed to meet with the lawyer responsible for the case, I was asked explicitly what my involvement could offer her. Having given the response that my research was “in the public interest”, I was granted very limited

⁴ The anti-assisted dying organisation *Care Not Killing* has become much more organised and active since the completion of my fieldwork in London. It now regularly puts spokespeople forward for media interviews and regularly urges members to write campaigning letters.

access to some of the witness statements and offered some basic administrative duties on the case. I was never party to any critical meetings about legal strategy. The break-through in terms of access came just before I was to leave the field, after almost a year of negotiating and waiting.

This is what happens when one “studies up” and carries out research on powerful decision-makers. As Marcus points out, in the world of multi-sited ethnography, the ambiguity of unspoken power relations is greatly increased because the fieldworker often shares with subjects the same broadly middle-class identity and fears or, alternatively, has to deal with persons in much stronger power positions who manage both the terms and limits of the ethnographic engagement (1998:121). In conversations, I remember feeling lost in the jargon the lawyers used and experiencing a clear disconnect between the way I envisaged my involvement playing out with their fears about who would be responsible for me and what my credentials were exactly. Would they be able to control what I wrote? How would clients respond to my presence? What would be the benefit for them in granting me access? I needed to ingratiate myself with these important gatekeepers because they held the key to the discussions about rights-claims and the use of ‘rights-talk’ which were of primary importance to my research. However, my lack of power in “studying up” and the constant quizzing about what was in it for them often undermined my confidence in my own project. Unlike Riles, who found that anthropologists working with human rights lawyers were often surprised by their unlawyerly behaviour and the fact that they seemed more interested in critical theory than the technical details of law (2006:58), I found the lawyers I encountered to be very “lawyerly”. Ultimately, the most I felt I could hope for was a professional relationship based on mutual respect and very limited access to their legal world.

Formal Consent vs. Ethics as a personal relationship

There is a difference between fulfilling formal consent requirements and engaging ethically and sensitively with research participants. In my research at the hospice day centre, although my formal proposal to the hospice ethics committee was accepted, I still had to negotiate with the head nurse about how my research should proceed. She

told me that I could only approach people identified by her as ‘suitable’ participants. By ‘suitable’, she meant emotionally stable people who were not in denial about the nature of their illness (Stage One in Kubler-Ross’s five stage process of accepting a terminal diagnosis). After all, I was not a designated ‘expert’, had no counselling or medical qualification, and did not have experience of managing people’s emotions, as she saw it. The restrictions placed on the terms in which I described my research to people (to not use the words ‘death’ or ‘dying’, for example) and the pre-selection of ‘suitable’ patients were deemed necessary pre-conditions in order to protect patients from a potentially distressing intrusion by a researcher into their lives.

However, I often felt that there was an element of suspicion in the way some of the nurses in the day centre regarded my presence there. I think this in part had to do with their relationship with Chris and personal feelings about *Rosetta Life*’s mission there, which I discuss in Chapter Three. It was also suspicion arising from my status as an outsider as well as a non-‘expert’. They were understandably protective of the patients in their care. When my confidence dipped, Chris encouraged me to retain a sense of my own purpose there, reminding me that I was a professional researcher and that despite some ‘frosty’ encounters with staff, my research had been authorised by the hospice ethics committee and thus deemed to be valid and worthwhile. This self-examination of my own claims to presence, authority, and the *value* of my research continued throughout my fieldwork.

In an insightful article about conducting participant observation in a hospice, Lawton (2001) writes about the impossibility of being assured of a patient’s continued consent as they deteriorate mentally and physically. It is because of the “emotionally fragile” nature of palliative care populations that researchers shy away from engaging directly with the critically ill and instead substitute their voices for those of physicians, nurses, and families (Rier 2000). The unobtrusive nature of participant observation, which on the one hand made Lawton’s research viable (she worked as a hospice volunteer performing various ‘caring’ functions), on the other hand left her wondering if patients kept in mind that she was first and foremost a researcher in

their day-to-day interactions with her, rather than relating to her simply as a volunteer. She writes:

Although few ethnographers would be willing to admit that they have intentionally deceived their informants (by conducting covert research), most would agree that some of the most rich and interesting data are gained on those occasions when informants have seemingly forgotten that the research is taking place (Lawton 2001:699).

This is an honest reflection on a serious methodological dilemma. It was very difficult to tell whether day centre patients were confiding in me as a friend, a volunteer, a *Rosetta Life* associate, or an academic researcher. Although I tried to remedy this confusion by periodically referring to “my research” I could never tell how prominent this aspect of my identity featured in their impressions of me. This was compounded, in my view, by the restrictions imposed on my revealing my research intentions. While I appreciated the reasons for these restrictions, they did add to the ambiguities surrounding my presence in the day centre and led to a less open approach than I would have chosen for myself.

I also found that the consent forms that I had authored and which I had agreed to ask participants to sign (see Appendix 2) became an awkward encumbrance. The final wording of the form had taken several drafts to settle on, after encouragement from Chris to remove all the academic phraseology. The wording may appear vague, but it was designed to be suitably open-ended so as to allow for the iterative development of my research project. Both Harper (2007) and Kelly (2003) have argued that “informed consent”, a regulatory procedure transposed from the biomedical sphere into anthropological practice, is more difficult to be assured of in the ethnographic enterprise because of its “exploratory and indeterminate nature” (Harper 2007:2240). The research imaginary is altered by the interactions between the anthropologist and her participants and, within limits, it is the participants who determine the direction of the research. Unlike in doctor-patient interactions where the consent form is designed to redress a perceived imbalance of power between the doctor as ‘expert’ and the patient as recipient by guaranteeing the patient the power of choice, in the

ethnographer-participant relationship it is the participant who is the expert and the gate-keeper of information, so the power dynamic is very different (Kelly 2003:189):

To describe the interaction between these politically situated subjects [the anthropologist and his “informant”] in terms of a one-way transit is clearly reductive (Kelly 2003:190).

In this way, Kelly stresses that it is self-reflexivity on the part of the anthropologist and respect for the “complex dialogic” at work that is more important for ensuring equality in research relationships than a written consent form which “requires a translation of human interaction into code” (2003:192). Informed consent, she writes, is useful only in that it signals a gesture to a commitment to maintain an open-ended collaboration (2003:189).

In the hospice day centre, the problematic question for me was when to ask my participant to read and sign the form. Was I to do it during the first conversation, so that they did not feel deceived if I brought it out later on? Then again, this might make them suspicious at a point when no bond of trust had been established. As Kelly points out, consent forms can make participants nervous (2003:192). They also formalise relationships which are often fluid, and benefit from being so. In the event, I asked people to sign the forms just before I left the field. All participants were happy to do so, yet this did not relieve my own awkwardness when presenting the form to them.

One final point about ethical encounters in the hospice day centre is that I found it very difficult to maintain a balance between being sensitive in my use of the words “death” and “dying” while at the same time not internalising day centre “jollification” (see Chapter Four for an explanation of what this is). Patients have different levels of acceptance of their disease and indeed, many people’s diseases were not “terminal” in a strict sense and so they could not be classified as “dying”. Equally, patients are clearly visiting the hospice day centre for a reason. Eventually, my self-consciousness with regard to abiding by the restrictions placed on my research and the extreme sensitivity required in talking to patients veered

dangerously close to becoming my own form of denial. For example, on one occasion I caught myself attempting to “jolly along” a patient by asking him about his Christmas plans. His terse response of “it’s difficult for me to make plans” jolted me into a realisation that I too had fallen into the trap of “jollifying” patients.

This is also the problem of familiarity, as identified by Marcus (1998:16). I remember when I first attended the hospice day centre, the unusually welcoming atmosphere, the constant games of Bingo, the topics of conversation etc were strange and unfamiliar. But as my familiarity with the environment grew, things started to seem routine and I stopped noting, for one, the strange absence of talk about dying. Just as Marcus (1998:16) insists on “defamiliarisation”, Hastrup urges anthropologists to move beyond the home world “where frames and events are seamlessly and imperceptibly fused” (Hastrup 2004:468). Instead, anthropologists have to get in touch with a world that “cannot be taken for granted.” Recalling this actually became the key to unlocking my own outsider’s perspective. I realised that my inexperience of the hospice world should not paralyse my interactions, but rather help me to make connections and to see things in a way that people who have been working in that environment for years might not. The hospice day centre, the Court of Appeal of England and Wales, or the *World Federation of Right-to-Die Societies* bi-annual conference, were not part of my “home world.” It was important that all of these sites continued to appear strange to my eyes despite the length of my immersion in those worlds. To my mind, this can only be achieved through reflexive assessment of each day’s interactions and challenging one’s own responses to situations.

Formal consent again became an issue in my interviews with people wanting to travel to *Dignitas*. In total I interviewed six people (one man, five women) who were planning to travel to Switzerland for help to die. Four of these interviews were conducted in person, and two by phone. At a certain, FATE asked me if I would be interested in actually accompanying someone to *Dignitas*. The Swiss organisation stipulates that people coming from abroad for help to die need to have someone with them for their “accompaniment.” Some people have no one suitable they can ask to

perform this role, so members of FATE have been known to accompany such people. The question was whether I could be this “accompanier”. This raised a whole host of ethical questions, not least whether I would be “aiding and abetting” a suicide, illegal under the 1961 Suicide Act. I had never anticipated that my research would take this direction, but actually making the journey with a person and recording their experience a day or an hour before their death, I decided, could offer very different insights to hearing them speak about their wishes and expectations in the abstract while still on British soil. Being present myself could therefore provide an illuminating juxtaposition to the person’s earlier anticipation of the experience.

Having made the decision to go, I sought ethical and legal clearance from the University. The legal restrictions on accompanying a person who intends to commit suicide in another country were unclear at that time, as my discussion in Chapter Nine highlights. The University Ethics Committee eventually endorsed my trip on the condition that I unambiguously established myself as a neutral, detached observer by not being the sole accompanier and therefore not being in a position of having to give direct support to the person travelling. It is worth quoting the comments of one member of the Committee at length:

If a person is on their own with no other support... if anything goes amiss e.g. later resentment from a family member, NR is the only witness (apart from the film of the actual death) of what happened between her and this person. I think this could leave her vulnerable to possible accusations of influence, heartlessness, over-involvement etc. These allegations would be hard to deal with. I believe that the tension between being a researcher and supporter (albeit limited) could confuse her observations. Would it therefore not be far better to accompany someone who will have a relative or friend with them? NR's role would then be unambiguous.⁵

In the event, a suitable opportunity for an “accompaniment” did not arise, and I did not make the trip to *Dignitas*. Yet the experience of navigating unknown legal terrain, reading the insightful comments of the ethics committee member about the

⁵ Email to Dr. Kelly, from Juliet Cheetham, lay member of the University Ethics Committee, 28th August 2007

dangers of leaving myself open to various accusations, and of the many hours of fraught deliberation I gave the matter, sharpened my insight into the ethical dilemmas facing those relatives and friends who act as “accompaniers”. Ethical issues seem to become particularly pointed when discussing death or when dealing with the dying. This may be because of society’s sensitivity to the fact of death (the denial of death thesis, as discussed in the Introduction). It may also be because our sense of who we are and our substantive relationships are envisaged as becoming heightened as we die (see Section One). A third possible reason is that, as Section Two and Three of this thesis argues, many people seek certainty in death and with this, they also demand ethical certainty. If death is considered irreversible, then there is no leeway to ‘get it wrong.’ As regards to my own possible trip to *Dignitas* and the ethical dilemmas involved, I never felt comfortable about my decision to go to Switzerland, despite ethical approval from the University. I only hoped that by thinking critically about the ethical risk involved and anticipating the emotional risk to myself, I would stop a dilemma turning into a disaster. As Garner emphasises, feeling uncomfortable about the ethics of your research is probably a good sign that you are engaging directly in the issues that people feel very strongly about⁶.

Maintaining Neutrality & Utility of My Research to Participants

As mentioned previously in my access discussion, making myself useful to an organisation was one way that I could ‘sell’ my project to them. For example, *Rosetta Life* was interested in my filmmaking skills. Originally I envisaged that my research could contribute to the charity’s auditing requirements, but Chris was more interested in my contributing to their creative output. However, as my interaction with *Rosetta Life* increased, I realised that I could not feasibly make films with patients while also retaining the “dispassionate objectivity” (Jackson 2002:262) necessary for analysing *how* the films were made and the *kinds* of relationship that developed as part of that process. If I proceeded to make films myself, my attention would be diverted to the film as artistic product, rather than remaining focused on the processes of production. This realisation prompted a diversion from my original

⁶ Personal communication with Andrew Garner, 26th August 2008

strategy of relying on the filmmaking process to provide a shared context for developing relationships with patients. Instead, these relationships grew slowly as a result of multiple visits to the day centre, and listening to people's stories.

In my research into the assisted dying debate, my utility for participants rested with my (assumed) ability to offer them a platform to air their views. However, this also entailed the hope or even the assumption that my research would endorse their perspective. I was very clear at the start of every interview that I wanted to access multiple perspectives, that I was examining the debate 'in the round,' and that, above all, I held a neutral position on the central issue. In this, I was inspired by Riles for whom "the marker of a true expert is a subtle agnosticism" (2006:59). Whether or not my interviewees accepted that I was agnostic was another matter. People hold very strong convictions about the 'rightness' of their cause, as Section Two of this thesis seeks to show, and because of this, I often felt that they were sceptical of my reassurances of neutrality.

In Garner's research into fox hunting in Britain, for example, he found that he was expected to have an opinion on the issue and that neutrality or "subtle agnosticism" is not a position that activists can either understand or accept⁷. Garner proposes that one way of measuring "objectivity" is to ensure that both sides object equally to the interpretation the researcher puts forward. If one or other side seems happier with how they are represented then this could act at least as a warning that the interpretation needs to be examined more closely⁸. In the interviews I conducted, however, although interviewees nodded as I explained my 'balanced approach' at the outset, as the interview progressed, they would attempt to solicit and scrutinise my personal beliefs, presuming that some bias must be detectable despite my politically correct 'neutral' exterior.

In terms of my relationship with FATE members, this plea of "subtle agnosticism" left me in a difficult situation. The deep insights I was seeking were dependent on building up trust which required first and foremost that the activists perceived me as

⁷ <http://www.theasa.org/networks/apply/ethics/case.htm>

⁸ Personal Communication 26th August 2008

loyal. The easiest way to establish this loyalty, however, would have been to endorse their views and convert to their cause. I was in a classic ‘double bind’ (Bourdieu & Wacquant 1992). I recall attending public meetings at which advocates from both sides were present and not knowing where to sit. FATE delegates had reserved me a chair but sitting with them might make anti-delegates suspicious. In this situation, I chose to sit on my own at the back of the hall, but not without a sense of guilt that I was ignoring my participants with whom I was privately establishing a close bond. I take comfort in Bourdieu’s comment that:

it is infinitely easier to take up a position for or against an idea, a value, a person, an institution or a situation, than to analyse what it truly is, in all its complexity (1998:22-23).

I will digress here with a few insights on the recent debate about the relationship between activism and Anthropology. Jean-Klein and Riles (2005), for example, have discussed the disciplinary boundaries between Anthropology and human rights activism. They perceive a problem with anthropologists trying to make their research relevant to lawyers, bureaucrats, and activists because if it becomes instrumental in this way, they can end up neglecting or forsaking their own ethical position in relation to the politics of the field and to research participants (2005:182,177). They call for Anthropology to know its own disciplinary difference from and uniqueness in relation to other enterprises (2005:175). For Merry, whereas activists work with a sense of outrage, urgency, and ‘desperate need’, ethnographers should analyse the conceptual categories used by the activists and develop a more complex, involuted analysis (2005:254). However, while the role of researcher and activist may be incompatible in terms of their stance towards truth and knowledge, they are complementary in their effects on global social reform (2005:243). In opposition to Jean-Klein & Riles, who warn about the dangers of anthropological knowledge being instrumentalised by activists, Merry thinks it is inevitable that academic research comes to provide the knowledge base for activism and that there is a level of collaboration (although she would direct such collaborations towards critiquing the terms in which human rights are defined and appropriated globally) (2005:255). Here

she echoes Bourdieu's (1998:58) call to arms that social research should try to be useful to the social movements studied, instead of being lost through irrelevance.

According to Caplan (2003:3), the central ethical question ethnographers should ask themselves is "what or who is it all for?" I certainly think that my participants in all of my research sites granted me access at least initially in the hope that I could be of some use to them. It would be difficult to convince people to allow me access without in some way hinting at the relevance my research could have for them. One cannot expect that people will invite you into their lives for a year just because you are a friendly person! Many of my participants hope that the work I produce will become grist for their mill. But by the end of my fieldwork, I felt I had 'proved' myself to my FATE participants not through converting to their cause but through my sensitive handling of interviews with members planning to go to Switzerland for help to die. I listened attentively to their desires and fears without passing judgment or offering advice and I acted as a witness to their suffering, the importance of which FATE are very attuned to. I also became a source of information, notifying them of conferences and new literature and I acted as a sounding board for their views, putting the alternative point of view/argument to them, which they eventually came to appreciate. This was my relevance to them, and the way I built up intimacy, without, I hope, surrendering my own disciplinary and ethical commitments. These are the reciprocities of fieldwork, in my case taking the form of exchanges of information and perspectives.

Joining the Dots

The task of scrutinising my data (interviews and ethnographic fieldnotes) began with reading through every page of data and conducting a thematic analysis. I then proceeded to construct intricate mind-maps to tease out the connections between the different themes and then attach the relevant data to accompany those themes. Based on this preliminary schematic outline and in discussion with my principal supervisor, I then decided on an overall structure for the thesis, after which I submitted detailed chapter breakdowns. When selecting people's stories to narrate in the text I tried to determine which stories would best illuminate the contradictions and ethical tensions

involved in my different fieldwork ‘sites’. I then wrote each chapter in chronological order, incorporating changes to both content and structure as they were suggested to me by my supervisors (and other academic audiences both within and outwith my own academic department).

In terms of writing style, I chose to write certain ethnographic sections in the present tense. This is a narrative construct that I deliberately chose to use primarily in order to provide textual variety within the thesis and to help evoke a more direct sense of ‘being there’. However, I do not want the reader to infer from my use of the present tense in certain sections that I am unaware of the post-modern critique of the “ethnographic present”. Briefly, anthropologists were criticised for their use of the present tense because it had the effect of presenting a timeless description of the people they had studied which effectively denied their historicity and belied the temporal rootedness of the ethnographic data. More recently, however, some anthropologists have revisited debates about the use of the ethnographic present and have argued convincingly that only the present tense can convey the reality and immediacy of the fieldwork encounter (Hastrup 1990:50):

Using the ethnographic present is to speak from the centre of another time-space, which existed only at that fleeting instant when the ethnographer impressed herself upon the world of the others – and changed it (Hastrup 1990:51).

My selective and intermittent use of the present tense is, I hope, justified in terms of my desire to evoke the specific time-space in which I was present in the various social contexts I describe.

The thematic connections I have drawn between my discrete areas of research (how they all fit into one thesis) are mine and mine alone. That is to say, there is no literal connection between *Rosetta Life*, right-to-die activists and/or the *Mental Capacity Act*. They are all discrete sites. I also kept my avenues of research very separate during my fieldwork. Therefore, I do not intend for participants in any one site to feel

implicated in the themes arising from the other sites. All three sections in this way are self-contained. There is an important distinction to be made between perpetuating the ideology of the transcendental observer who sees things her participants cannot (Tyler 1986:126) and accepting responsibility for making the kinds of connections and abstractions my disciplinary training allows me to make, as separate from the lives lived by research participants. My suggested connections and juxtapositions have arisen through my research 'imaginary' and three kinds of conversations I had pre-, during and post fieldwork. I follow Jackson (2007) in identifying these three conversations. The first is with authors and social researchers whom I admire, the second is with my participants, and the third is with academic peers and my supervisors. All have shaped the development and final form of this thesis.

I have surveyed and referenced a large and diverse range of theoretical literature in this thesis in order to ground my research findings and analytical juxtapositions. Unusually, I have referenced a number of philosophical texts, the most frequent being Heidegger's *Being and Time* (1962). My use of Heidegger in particular resulted from conversations with Chris, the *Rosetta Life* artist, and the time I spent working alongside him and the patients in the hospice day centre. Prior to my work with *Rosetta Life* and the growth in my understanding of the charity's *raison d'être*, I had not felt the need to engage with the work of philosophers writing about death and dying (Heidegger, Derrida, Deleuze, Levinas etc). This is evidenced by the lack of any substantial references in my PhD proposal. Heidegger (1962) is the originator of many of the theoretical ideas about the 'specialness' of death, an idea which *Rosetta Life* artists (among others) subscribe to. He became the starting point for my exploration of the philosophical literature. However, the ethnographic insights I offer in this thesis present a counterpoint to (and often undermine) the abstract notions of these philosophers.

Ultimately I am accountable to those who participated in my research. However, I have not written this thesis from the perspective of an advocate and I do not endorse any single perspective, whether that be of a hospice artist-in-residence, or a woman seeking to assert a human right-to-die through the courts. My ethical commitment

has been to work with self-awareness and empathy with regard to all perspectives that people have been honest and open enough to share with me. The fieldworker's experiences can never equal the diversity of experiences possible, and I left the field with the unsettling feeling of incompleteness. I take heart in Strathern's comment that every approach is only ever partial and can never offer an all-encompassing context or a wholly inclusive perspective (1991:40).

Inevitably, the act of writing creates the false impression of coherence and order (Strathern 1991:109) and fixes and simplifies people's lives and views, concealing "gaps and bumps" (1991:xxiv), in order to make them visible to the reader (Strathern 1991:xiii). This critique of writing can be traced back to criticism of Geertz's textual devices designed to convey a sense of the totality and wholeness of the 'culture' he was studying. Unfortunately, I cannot say that I have avoided such pitfalls in my own writing. My argument and my juxtapositions are, in a sense, an artifice, designed to map new themes in how we approach dying in Britain. But for every answer there is another question, for every connection a gap, and every similarity a difference (Strathern 1991:xxiv). My hope is that I can communicate my laboriously constructed 'field' in my writing without feeling any awkwardness from leaving questions unanswered, gaps unfilled, or difference unexplained.

SECTION ONE

CHAPTER THREE

Rosetta Life: Intimacy and Testimony

“Something begins in order to end: an adventure... achieves its significance only through its death.” Jean-Paul Sartre (1938:59)

Rosetta Life, set up in 1997 by Lucinda Jarrett, a former TV producer, is essentially an umbrella organisation for a number of individual artists who lead creative projects in or in conjunction with hospices around the U.K. Jarrett’s mission in setting up the charity was to enable hospice-users to tell their stories in a form chosen by them (Jarrett 2007). Artists under the *Rosetta Life* umbrella are employed to enable hospice users to “find their voice” and provide a “shape to hold their individual stories” (Jarrett 2007: x). Through this type of engagement with people who are at the end of their lives, *Rosetta Life*, and the hospice movement which supports their activities (and, one presumes, the funders behind both), believe that there will be a transformation of the individual in terms of how they view and value their lives and their relationships. In addition to this ‘inward’ transformative intention, there is a secondary goal of ‘outwardly’ transforming public representations of dying. It is this goal that is more contentious within the hospice movement, as well as proving more of a challenge for the individual participating patients. The charity’s belief in the prospect for and power of personal transformation is in clear accord with the hospice movement’s ethos of treating the ‘whole person’ and not just the disease. The movement’s ‘communitarian’ values emphasising, above all, the family as the primary ‘unit of care’, would seem to offer a fitting backdrop to *Rosetta Life*’s reflective engagement with patients and their families. But the discord I perceived within my hospice fieldwork site to the charity’s secondary intention, that is, to represent these transformations in a *public* way, highlights the tensions with which this thesis is concerned, between our intimate, private world (of which hospice care is a part) and our public lives and the public narration/representation of our lives.

In the following two chapters I want to address the tensions between intimate lives and public worlds that we encounter at the end of our lives, by examining what it is *Rosetta Life* seeks to do, in what context, and with what effect. This section of my thesis is based on time I spent volunteering for *Rosetta Life*, working primarily

alongside artist-in-residence Chris at a hospice day centre in South East London. However, I also base my analysis on knowledge gained volunteering, often as cameraperson, on other artists' projects and speaking to those artists and the patients with whom they worked about their experiences.

This first chapter will give some background on the hospice movement in general and then some particulars about my fieldwork site and the purpose of *Rosetta Life*'s residency there. What kind of sociality exists among day centre patients? Do people express an (unprompted) wish to talk about their (possible) dying? I will then move to reflect theoretically on the notion of the 'transformative self' and the idea, very embedded in hospice literature and the backbone of the *Rosetta Life* philosophy, that being diagnosed with a life-limiting illness potentially heightens the clarity of the individual in what Heidegger called our 'being-towards-death'. How much do people need to be prompted to attain this clarity and can it indeed be elicited by an outsider? Using theories about testimony and confession, I will analyse the intimate relationship between the *Rosetta Life* artist as "confessor" and the patient who gives testimony through a retelling of the 'self'. Here, I will give an account of how *Rosetta Life* has set itself up in this 'intimate' environment in order to encourage people to "give voice" to their experiences, with the possibility of transformation and transcendence. Ultimately, I want to discuss how *Rosetta Life*, as well as the hospice movement of which they are a part, portrays the value of storytelling and 'giving voice' to people at the end of their lives and whether this matches the patients' own expectations. My reflections here will be guided by the *Rosetta Life* projects I witnessed and my knowledge of the relationships and responses they elicited.

Locating the 'End' in 'End-of-Life'

Rosetta Life artist-in-residence Chris has worked at the hospice since 2001. Chris is 63 and has had a very varied career. He started his professional life as an Art History lecturer, then moved on to set up a 'radical left-wing' theatre company in the North of England. From there he went to work in the TV industry, making documentaries, drama documentaries, and TV operas. Beyond this, he is also a published writer and librettist. He finally left the world of TV because he says he felt "disillusioned" by

the “lack of quality programming” and by what he felt to be a loss of control over his own artistic voice and vision.

The hospice where Chris holds his residency stands in the middle of Borstall Woods, exactly on the county border between London and Kent. The site was purchased from the Co-operative Wholesale Society in 1991 for £1 in order to build a hospice to serve the needs of the local community. The building was thus purpose built and stands relatively isolated within a clearing in the woods. One wonders whether this seclusion was to give the patients some peace and quiet, or to keep them secluded from the nearby towns. The majority of the patients who use the services of the hospice have lived in the local area all of their lives. When Chris first started working there, many of them had worked at the Royal Arsenal, Woolwich, which is nearby, producing armaments and ammunition for the two world wars. The Arsenal was shut down in 1967. It is fair to say that the patients are predominantly white working class, and proud of their local heritage. However, during my time spent visiting the day centre, there were a handful of patients of different ethnic backgrounds.

Walking towards the hospice down a long winding road, the building looks unimposing on approach and distinctly non-medical. Friendly volunteer receptionists greet visitors on entering the building. At this point, Chris and I would usually head straight downstairs to the day centre where *Rosetta Life*'s computers and equipment are set up. But on route we would also pass some of the in-patients lying in their beds, sometimes with the door open. I would be compelled to turn to look in on them as I walked passed. Sometimes they were on their own, other times surrounded by family members, and I would quickly turn away, feeling as if I had intruded on something very private. Yet the hospice ethos is a very communal one, as I will attempt to describe, and this was what was so arresting and unnerving as an outsider experiencing this very specific institutional culture for the first time.

One day a week Chris arrives and sits with the day patients at the hospice and talks to them about their experiences of living with life-limiting illness. Some days he says

he encounters a vibrant “buzz” of activity among the twenty or so patients which he says “charges him up for the week” and inspires him. Other times he can walk in and there is a flatness to the atmosphere, usually when certain characters have stayed away due to ill health or other commitments. On days like these, he says he needs to inject a large amount of his own energy to prevent it from feeling too much like a nursing home. There is a real danger of this because a large proportion of the patients are over 70 and some have been coming to the day centre for years. In fact, one patient with whom Chris worked on several projects, has survived lung cancer, three heart operations, and chronic diabetes and is now no longer officially a ‘patient’ but works as a volunteer for the hospice instead. Another lady, 87, has been coming to the day centre for nine years, the longest of all the current patients. In this particular setting, the public perception that a hospice is a place where you go to die would be misrepresentative. Indeed, the hospice website reads:

There is often a common misconception that a hospice exists to care for the dying. In fact we would like everyone to understand that the therapies and care which we provide help our patients live to their full potential.

This sentiment encapsulates the hospice movement’s ethos of enabling people to “live until they die”. As described by Lawton in her ethnography of a U.K. hospice (2000), people who start off as day centre patients can end up being admitted as in-patients when their illness progresses or when they are reaching the last few weeks of their lives. However, for many, the progression of their disease is not simply one of steady decline, but rather one with periods of relatively stable but poor health. This type of decline lends itself to extended periods as a day centre patient.

People in the local area who have active, progressive and advanced disease are referred to the day centre by their GP, home care nurse, or hospital consultant. They are then given a place for one day a week. Often this is as much to give primary carers a day of respite as it is to offer hospice services to the patients themselves. The temporal relativity of this term ‘life-limiting’ – limited by how long? - was not immediately apparent to me on commencing my research. My initial meeting with artist-in-residence Chris and a senior nurse in the day centre was aimed at deciding

which patients it would be appropriate for me to approach and how I was to go about describing my project to them. A discussion about terminology ensued, indicative of this general problem of identifying the dying. The senior nurse rejected the word “dying” which I had used liberally throughout my proposal. It was her opinion that many, if not most, of the people coming to the day centre would not identify themselves as “terminal” or “dying.” Her rejection of the terms signalled her concern for the well-being of the patients in her charge who might be upset by my use of them. This corroborates Lawton’s experience of patients responding angrily to the word “terminal” because it gave the impression of having been “written off” (2000:47). Chris diplomatically interjected: “How about replacing “dying” and “terminal” with “life-threatening” or “life-limiting?”” We discussed the relative connotations of both and finally decided on “life-limiting”, so long as I prefaced it with “living with” (as opposed to “dying of”). As the meeting drew to a close, Chris quipped “life-limiting illness – that’s life isn’t it?!” and we all laughed awkwardly. Although we may have settled on the terminology I was permitted to use, I was still confused as to how one delineates ‘end-of-life’, especially if, as is the case for the hospice movement, people in that ‘end’ bracket are your target patient group.

This sensitivity around terminology as well as the difficulty of predicting differently configured ‘ends’ is part and parcel of the epidemiological shift of the 19th Century from infectious to chronic diseases as the primary cause of death. It is also the decisive activity of biopower in the modern era: to try to extend life or “to make live” wherever possible. In the mid-19th Century death rates from infectious diseases such as smallpox, scarlet fever, cholera and typhoid began to fall and historians typically attribute this to improved public health measures in housing, nutrition, and sanitation (Seale 2000). The wealthy countries of the world are currently witnessing an unprecedented degree of ageing beyond the age of 60 (OECD 2005). The age expectancy for people in the U.K is now 76.9 for men and 81.3 for women.⁹ For men born in 2008, their projected life expectancy is now 88.6 years, and 92.9 years for women. But the great success of modern medicine has been to transform acute

⁹ National Statistics Office, <http://www.statistics.gov.uk/cci/nugget.asp?id=168> (Accessed 7th January 2010)

causes of death into chronic illnesses, so that we live longer in a fragile state of health. The experience of people in my hospice was of chronic and degenerative diseases like cancer, Parkinson's, Motor Neurone Disease and Multiple Sclerosis that they were indeed negotiating "living with." The dominant myth about dying does not fit many people. As Lynn (2005:S14) points out, our language has not got to grips with this new reality and people are either categorised as "temporarily immortal" or "dying", with no space for the "zone of indistinction" (Agamben 1999:120) which is chronic illness.

The *World Health Organisation* describes palliative care as:

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹⁰

There is no mention of "dying" or "end-of-life" in this "broad vision" or public health orientated definition (Seymour *et al* 2005:2). For Randall and Downie (2006:213), aiming for "*impeccable* assessment and treatment" for people with complex needs sets unobtainable goals for palliative care, only a medical specialty since 1987, and still struggling to define itself now that medical technologies and medications have wholly blurred the distinction between 'living with' and 'dying of' for people who have serious diseases.

Terminal care is officially considered part of palliative care in the U.K. and usually refers to the management of patients during the last few days, weeks, or months of life.¹¹ But this term has gone out of vogue since the 1980s with the trend towards extending palliative care to all care not directed at cure. But as Seymour *et al* (2005:3) highlight, there is a continuing widespread association of palliative care with terminal care or the terminal phase, and this affects the access and acceptability

¹⁰ www.who.int/cancer/palliative/definition/en (Accessed 23rd May 2008)

¹¹ The National Council for Hospice and Specialist Palliative Care Services 1995 *Specialist palliative care: A statement of definitions* London: NCHSPCS

of palliative care services. The WHO definition was no doubt designed to offset such problems, but as a consequence of the terminological shifts, as with attempts to isolate those patients eligible for hospice day centre services, there is still widespread confusion about what palliative care *can* and *should* provide and for whom (Randall & Downie 2006).

With the substantial increase in life expectancy since Victorian times, and the epidemiological shift to chronic diseases, people crucially have more time in which to *anticipate* their death. As Seale (1998) notes, one of the features of death from cancer, in particular, is that there is a medically predictable trajectory and this has fundamentally influenced the late modern ability to anticipate our own death. At the same time, however, the original markers of the dying phase – the onset of disability and life-threatening illnesses - can instead signal a new phase of life. The WHO definition's focus on "quality of life" is indicative of an overall shift in health care priorities from no longer just alleviating people's symptoms but rather maximising or optimising their life experiences in a state of chronic illness.

The Modern Hospice Movement

As I outlined in the Introduction to the thesis, the modern hospice movement grew out of a discontentment with the general "effacement" of the dying (Aries 1974:85) in British society. There was a sense that they had been abandoned to an isolated and lonely existence in institutions because we had lost the ritual capacity to make sense of death (Elias 1985, Gorer 1965). Cicely Saunders founded the modern hospice movement at St Christopher's in 1967. Hospices did exist before this, although this is often eclipsed from the historical record in the rush to amplify the influence Saunders had.

After starting her career as a nurse at the outbreak of World War II, Saunders went on to train as an almoner (medical social worker) and later a doctor. She converted to Evangelical Christianity aged 28 while working at St Thomas's in London: "she had searched and she had found" (Du Boulay 1984:49). The choice of an Evangelical form of Christianity is significant, given *Rosetta Life's* work with testimonies, in that

one of its central pillars is the individual's personal relationship with God and the importance of the narrative of conversion or of being 'born again.' Saunders was dramatically influenced by David Tasma, a Jewish refugee from Poland, who died of cancer on her ward at St Thomas's in 1947 and with whom she fell in love (Du Boulay 1984:54). Through this relationship, and her subsequent relationship with another Polish patient, Saunders recognised an acute need to offer more holistic care for the dying to better relieve their suffering. Care of the dying in 1940s Britain was a wholly neglected field: "medicine was about cure, if they couldn't cure doctors felt they had failed" (Du Boulay 1984:78). And too often an inability to cure translated into a reluctance to care.

This failing was picked up by Illich some years later (1976:73-76) who criticised doctors for often failing to recognise the point at which there was no cure and for standing at the patient's bedside as "agents of evasion or outright dissimulation" (1976:103). Illich proceeded to issue a scathing attack on the medical profession who, to fulfil public demands, had created a drug for everything and in the process destroyed people's autonomy in caring for their own ills. For Illich, it was not only doctors who were "agents of evasion", but patients themselves who were culpable in their own "enfeebling" for buying into the fallacies of the technologies and the drugs. He called on people to take control of their own diseases by de-medicalising death and engaging in an ethic of 'self-care' (1976:270), that is, assuming responsibility for curing their own bodies, or admitting when there is no cure. This call to competent self-care reflects Saunders's view when she started the modern hospice movement. This was that people should be encouraged to recognise when they are dying and should seek ways of individually coming to terms with their circumstances without necessarily requiring the endorsement of the medical establishment. What the medical profession could not or should not seek to provide, the 'community' and Christianity would take care of.

Saunders named the hospice St. Christopher's after the patron saint of travellers, a name recommended by a dying patient (Du Boulay 1984:80). Just as the eighteen foot tall Saint Christopher would carry people safely across a dangerous river, so the

image is of hospice patients being safely 'shepherded' as they travel to the 'other side' i.e. heaven. The religious basis of the hospice was clear in Saunders's early vision. She hoped that every patient would receive adequate pain relief, but she also hoped that they would 'come to know the Lord' (Du Boulay 1984:95). The religious conception of the 'good death' was rooted in the idea that human weakness and sin could be forgiven as the dying person:

 faced the ultimate truths of Christendom: immortality of the soul, sin, and God's saving grace. Like a Gothic cathedral, dying could make visible the relation between man and God, heaven and earth (Lavi: 2005:10).

Lavi's analysis of the Methodists' approach to death shows that for Methodist believers, 'being-towards-death' was a matter of constant reflection and examination of one's soul and one's faith. Methodists were to spend their life preparing for their deathbed scene where they could finally achieve Christian perfection. This seeking of perfection and focus on the *ars moriendi* (art of dying) served the additional benefit of assuaging the fear which death gave rise to (Lavi 2005:32). This religious 'art' of dying was what Cicely Saunders, doing 'God's work' as she saw it, was trying to teach her hospice patients.

While the desire for religious conversion on the deathbed is no longer evident in the 21st Century hospice movement, its religious foundations still have a bearing on the current palliative care philosophy. For example, the principle established by Saunders that "you matter because you are you", still championed in hospices, could be viewed as a secularisation of the religious idea that a person is uniquely loved as a child of God (Randall & Downie 2006:6). Equally, concepts such as 'meaning', 'fulfilment' and 'authenticity', used as much in palliative care as by *Rosetta Life* artists, can be seen as secularised versions of religious ideas. The proliferation of these terms accompanying the rise of the psi-sciences (Psychiatry, Psychology, Psycho-therapy) in the last part of the 20th Century has offered patients a new mode of conversion. In place of God, this conversion is now to a belief in the discovery of an authentic, pure, and concrete 'self'. As Keane argues, the Protestant insistence on

inwardness and sincerity became part and parcel of the self-conscious project of becoming a modern subject (2002:68). Protestantism de-emphasised the physical body, material goods, and social standing as the source of a person's authority, instead premising the interior 'self' and autonomous human intentions (Keane 2002:74). So although there may have been a substitution of religious terms for psychological ones, the emphasis of Saunders's original evangelist project continues, as demonstrated by the psi-sciences focus on inner-directed conversion to a sincere or authentic 'self'.

Saunders's flagship hospice was undoubtedly a physical embodiment of her devout beliefs, but was also a reaction against impersonal medical bureaucracies. She emphasised that hospices should be microcosms of the community around them, with a smooth transition of care from the home to the hospice community (Du Boulay 1984:136-8). This is reflected in the hospice ethos and palliative care philosophy which both stress the importance of the family in the care provided. Most hospices have volunteer staff from the local community, which is also likely to support regular fundraising initiatives¹². Health professionals working in hospices, according to Saunders's model at least, are supposed to have more time to spend with patients than their hospital counterparts, listening to their stories while effectively 'palliating' their pain. This has been termed the 'Asclepian' model of hospice/palliative care services. Asclepius, the son of Apollo, was the Greek god of healing, and Asclepieions, or healing temples, were common in Ancient Greece. People would go to the temples to be closely attended to, have rituals performed with snakes, and to report their dreams to a priest (Hart 2000). Randall and Downie (2006:7) suggest that hospices, at their best, should embody these Asclepian values of healing and quiet listening. They go on to argue, however, that in recent years, palliative care has become over-professionalised, with staff too busy to listen and with an overly 'Hippocratic' emphasis. Hippocratic medicine is based on the assumption that every disease has a cause which can be discovered through the pursuit of scientific knowledge, and that this knowledge is generalisable. Hippocratic tools in palliative

¹² Hospices are not wholly funded by the *National Health Service*. On average, they receive just 32% of their costs from the government. The rest must be generated from the local community through fundraising events, donations, and legacies.

care might include questionnaires or quality of life scales (QALYs) (Randall and Downie 2006:203). But it is generally the Asclepian aspect of care – creative healing, quiet listening and, above all, the harnessing of the patient’s capacities for self-care – that attracts particular people to the hospice movement, like *Rosetta Life* artist-in-residence Chris.

Bob and his Asclepiads

Chris has been working with Bob for a year now. They struck up a relationship when Chris first launched his “Apothecary” project in the hospice day centre. The aim was to encourage patients to isolate one positive thing that if it were possible, they could bottle or ‘capture’ and distribute to the world. Chris’s intention was to counterpoise something positive and individually determined with the mass of prescriptions and drugs that hospice patients have, literally, to swallow. In an era where there is a ‘pill for every ill’, Chris wanted people to create their own pill or analgesic which would make life better for them in some way. In this project it is possible to identify the impetus towards ‘self-care’ and self-empowerment in an imagined appropriation of medical technologies. But the poster advertising the project had been up in the day centre for some months and people had taken little notice of it. To inject some enthusiasm, Chris started approaching people directly. One woman related a story about a starfish that she remembers seeing on a beach one particularly memorable summer when she was a young girl. She recalled being transfixed by it and because she felt very happy that summer, the vision of the starfish has always stayed with her and she finds it comforting to visualise when her illness is at its worst. Consequently she registered her desire to bottle the vivid memory of the starfish that could generate a sensuous re-imagining of that happy summer, and put her mind at ease. This was exactly the kind of idea that Chris had hoped to “tease out” from talking with patients.

Bob is 55 and has had Motor Neurone Disease (MND) since 2003. He worked at a factory most of his life making the chemicals that bind wood pulp together to make paper. When the factory closed down, he then became a lawnsman for a golfcourse which he says he found quite lonely in contrast to the camaraderie in the factory. He

still lives in the house in which he was born on Shooter's Hill, one of the highest points on the outskirts of London and infamous for attracting highwaymen in earlier centuries. Bob's brother, John, is his primary carer and lives with him in the house where they grew up together. When Chris posed the question "so what would you bottle Bob?" his simple answer was "a discriminating fly!" Bob, prior to the onset of MND, had been one of the country's biggest collectors of Asclepiads, the small succulent cacti that are particularly difficult to grow north of the equator. Asclepiads are named after the Greek God because of the medicinal uses to which some of the plants are put in different parts of the world. The reason Bob wanted a "discriminating fly" was in order to prevent cross-pollination among his Asclepiads.

Chris was intrigued by Bob's passion for these little plants which filled two heavily insulated greenhouses in his garden overlooking London. After further probing, he discovered that because Bob (now paralysed from the neck down) could no longer tend to the plants, he had arranged for them to be adopted by a fellow member of *The Asclepiads Society* who was living in the north of England. Bob was about to be saying goodbye to his beloved plants forever. Chris leaped on the idea of making a film about this farewell and about the passion and the sadness contained therein. From the bottling of a "discriminating fly" a whole story was unravelling for Chris about the life of a collector and classifier being brought to an abrupt end by the onset of his disease. MND has brought chaos to the normal ordering of Bob's life (and his passion for ordering) while at the same time requiring of him another kind of regimental order – to structure his daily routines as necessitated by the severe limitations imposed on him by the steady and rapid deterioration of his body. Chris, the artist, said he had recognised some 'universal truth' in his story, that just as a "discriminating fly" highlights nature's adaptive qualities through Darwinian selection, so Bob has to adapt to the circumstances of his disease and the re-ordering of his world.

In a way, we can recognise in Bob's cataloguing of Asclepiads and his creation of a national Asclepiads seed bank the same ordering of knowledge which defines the Hippocratic 'scientific' model of medicine which the hospice movement was

originally a reaction against: the desire to know the world through universal, observable principles that are able to be quantified. In the same vein, Chris liked to view Bob's hobby as indicative of the 'universal' structures of the mind at work as he catalogued his Asclepiads, always in relation to each other (which could cross-pollinate, which could not). Chris was determined to read some general principles into Bob's taxonomic impulses. However, the care which Bob took over every single Asclepiad – making sure each had adequate heat and water, collecting seeds from their pods to store, taking seasonal photos of each one – was, for me at least, not reducible to 'structures of the mind' or universal principles. His passion was far more Asclepian than Hippocratic in its inspiration! Each tiny succulent plant did not just represent a box in a table for Bob, but had a history of nurture and care attached. In distilling his idiosyncratic passion to universal structures of the mind, Chris was trying to create a meta-narrative for the film. But in doing so, there was a danger that he would over-intellectualise Bob's world by trying to fit his passion into a story about generalisable principles and truths.

Undoubtedly, Chris, through making the film with Bob about the loss of his much-prized Asclepiads, was trying to engage in an Asclepian way with Bob's story ('quiet listening' and attending to his individual perspective). Bob's bottling of the "discriminating fly" was intended, in the grand scheme of Chris's "Apothecary" project, to symbolise what was important to Bob outside of the Hippocratic treatment and management of his disease. However, while Chris's interaction with Bob may have been Asclepian, his belief in universal truths and universal structures of the mind displays the kind of generalising impetus that is Hippocratic in bent, and therefore less person-centred than *Rosetta Life* often likes to portray the work that they do. Chris cannot seem to shake off his own structuralist mindset and his own intellectualisation of Bob's hobby. Chris stated to me on several occasions that in making films with individuals he hopes to reveal some general truths about the human condition, to find some salient element or "gold nugget" of insight (Rawlence in Jarrett 2007:4) that others will be able to recognise in their own lives. Watching the Asclepiad film being made raised two related questions for me. In wanting to communicate to a large audience through film (using the standardised structuring

devices of this medium), were the personal and individually specific elements of Bob's story distorted in order to tailor it to some pre-conceived meta-narrative? Secondly, whose 'voice' is really being heard, is it Bob's or that of Chris/ the artist? Certainly there is a tension for *Rosetta Life* between highlighting the uniqueness of individual's personal testimonies and identifying commonalities in people's experiences which can then be held up in public forums as examples of the human condition. In *The Revival of Death*, Walter also identifies two competing discourses in hospice care: one which emphasises the uniqueness of each individual's story, and the other which tries to create a meta-story around universal processes and stages of adapting to life-limiting illness (Walter 1994:69). It is clear that this competition between the unique and the meta-story is a point of tension both for the hospice movement, as identified by Walter, and for *Rosetta Life*.

Hospice Sociality

The hospice day centre exists as a social hub, where people come to discuss the week's events with friends and volunteers and to see the consultant, chaplain, or complementary therapist. "I need to check your bloods today!" the nurse says loudly to a patient in a wheelchair. I have entered the hospice with the Japanese student who volunteers once a week to teach some rudimentary Japanese and chat to patients. She is very smiley and says hello to everyone, which fits with the general atmosphere here – everyone is all smiles. When I first encountered this, I found it quite disinhibiting. It is so markedly different from any other medical establishment I have ever visited before. On my way past, I ask the senior nurse if there is "anything I need to know?" - a habit we both agreed I should adopt in order to keep informed of any changes in patients' conditions. "Nothing today" she says. On another occasion she informed me – "We lost Tom last night." What a wonderful euphemism, I thought! This is the type of news which, before my fieldwork, I might have thought that people would be discussing. However, it seemed that talking about it too much can be seen as bringing the mood down, as people start wondering "who's next?" In other words, the general conversation does not focus too long on who died the previous week, or if it does, it is in hushed voices. There is no ritual marking the "loss" of that person, no official acknowledgment that that particular individual will

no longer be frequenting the day centre. But this is not to say that patients were not discussing it privately amongst themselves. I take a seat and start chatting with Bob, who is having trouble lifting his head up off his chest today. Essentially, his neck muscles are going, and the physiotherapy he has been given only made things worse. He says he needs a new wheelchair with neck support, but is having trouble acquiring one. He struggles to maintain eye contact with me as we talk, and I desperately want to improvise a neck brace for him somehow. I can hardly imagine how frustrated he must feel. After a while the drinks trolley (or “jolly trolley” as it is known!) clinks by for ‘elevenses’ and people order drinks, whetting their appetite for lunch.

There is a clear division of the day centre into the “women’s corner” and the “men’s corner.” I was told this developed as a natural separation, and that when new patients arrive, they just gravitate towards their ‘gendered’ area. Although there are occasional gestures towards the other corner or jokes about the division, nobody expressed a wish to break the mould. While there are roughly equal numbers of male and female patients, the vast majority of the volunteers are women. This could be part of a “feminine ethic of care” which Walter (1994) identifies as a key attribute of the hospice movement, or it could just be that those are the particular local retirees who have the time to volunteer. Without speculating further as to whether hospice care is ‘gendered’, it is important to note that the volunteers are just as responsible for ‘setting the tone’ of the day centre as are the staff or the patients. Often people volunteer because they have had a relative who has died in the hospice. Others do so because they live locally and want to ‘give something back’ in their retirement. Whatever brings them to the hospice, once there, the volunteers contribute to what artist-in-residence Chris refers to as an atmosphere of “jollification.” This is the attempt by staff, volunteers, and even patients, to “jolly things along”, by which I mean to keep the mood of the day centre cheerful and light-hearted. Diversionary activities like bingo, dominos, and arts & crafts were regular features, supplemented by the occasional musical performance from local groups. This phrase “to jolly along” I also heard used in other hospices by both ‘healthy’ people and by people with life-limiting illnesses to describe their attempts to keep a positive frame of

mind. The psychological question here is whether by “jollyng themselves along” they are merely responding to ‘healthy’ people’s expectations of them by trying to perform their sick role in a culturally acceptable manner. As Lawton (2001) concludes in her hospice ethnography, in their desire to ‘consume’ a palatable image of illness-towards-death, people ‘gloss over’ what for her are the shocking realities of ‘living with’ life-limiting illness. Reading Lawton’s stories of bodily deterioration, one can certainly understand this tendency towards “jollification.” Chris’s role in the day centre was to create a space and offer support for other ‘tones’ to be set and sentiments expressed. Indeed, the challenge facing Chris and *Rosetta Life* is that of encouraging a more reflective, serious, and challenging space within the day care without upsetting the “jollifying” elements.

“Jollification” demonstrates a proclivity, albeit with some dissenting voices, not to linger too long on thoughts or conversations about dying. But patients *do* manage to talk about illness. So while the very real prospect of death might present a limit to sociality in terms of being able to talk openly about it, managing illness does open up avenues for conversation. Topics might include discussions about the drugs they are on, how the drugs have affected them (“sometimes the side-effects are worse than the pain itself” commented one patient), or which drugs they wish they could get but cannot because they are not freely available. They discussed their different experiences of medics: “Their attitude towards you can help you with your attitude towards what you’re suffering from”; diagnosis: “I don’t particularly want to know when I’m going to turn my toes up”; and why they come to the day centre: “stay at home and you can get down in the dumps.”

Rabinow coined the term “bio-sociality” in the mid-1990s to mean the collective identification and organisation of people based on their ‘biology’, which for the purposes of his research was people’s genetic predispositions (1996). He analysed the mobilisation, activities, and efficacy of a French advocacy organisation comprised of patients and their relatives affected by various degenerative diseases. In the hospice day centre, ‘bio-sociality’ consists not so much in advocacy and collective mobilisation or collective ‘voice’, but rather in the fact that the one

commonality among the patients is that they are all 'living with' a life-limiting illness. There is, if you like, a biological basis to their social interaction. They all have to manage the effects and daily routines of different long-term diseases, so this becomes a common topic of conversation. Yet even given this 'sociality' arising from discussions about biological commonalities, as Sontag (1977) points out, different diseases have their own associated statuses, social expectations and metaphors attached. Sontag compares discourses related to Tuberculosis (TB) with those surrounding Cancer. The former was romanticised in the 19th Century as a disease of delicacy, sensitivity and longing, whereas cancer, in the 1970s, was associated with the sloth, affluence, and unregulated growth of industrialised society. This perception of cancer has changed dramatically in the West since the 1970s and there is now a well-established public discourse about the 'moral worthiness' of people 'living with' cancer, in part due to the revivalism of the hospice movement (Seale 1998:107). Now there is disparity between the status of cancer and other diseases like MND, MS or Parkinson's, which have not received the same medical and public attention or the same widely available specialist care which cancer has benefitted from. Also, it is interesting to note that while the common factor among all of the patients was that they have life-limiting illnesses, if people were too ill, they would generally stay away from the day centre. Lawton describes this in her ethnography, concluding that it was because seeing very ill patients would upset the others. I do not know if the same was true of my hospice, but certainly when people became very unwell, or succumbed to a bad choking fit over lunch, I noticed it was greeted with a degree of embarrassment from the patient themselves and disquiet from those around them.

Despite the lack of uniformity in perceptions of different illnesses and different degrees of illness in the hospice, there was a sense in which patients' biological subjectivity, which stigmatises them or marks them out as different in wider society, becomes *the* point of reference in social interaction. Illness can act as a leveller and in this environment, there is a tacit understanding of what it means to be 'living with' a life-limiting illness. Lawton suggests that patients' 'social death' in wider society is compensated for in the hospice setting by encouraging a form of 'pseudo-kinship'

(2000:51). That is to say that bonds between patients and between patients and staff or volunteers exist as a kind of *ad hoc* kinship in terms of the support offered and practical needs met. For me, likening hospice sociality to kinship, an amorphous, polythetic (Barnard and Good 1984: 188-9), and anthropologically-loaded concept, is not effective in this context. Indeed, one of the difficulties in current hospice care identified by Randall & Downie (2006:31) is that healthcare professionals often try to take responsibility for aspects of a patients' well-being or "quality of life" which, in these commentators' judgment, should remain firmly in the domain of family life. They criticise the "paternalistic" trend within palliative care and hospice provision, encouraged by WHO guidelines, to overstep the realms of their professional expertise by trying to influence what is essentially people's private lives. Equally, I would argue that patients in the day centre would not describe their social bonds as "diffuse, enduring solidarity" (Schneider 1968), but rather a "ships-in-the-night" relationship, as one patient described it. So while 'pseudo-kinship' may be problematic, patients in the day-centre were nevertheless bound by shared experiences of an attenuated personhood due to the effects of disease.

The political dimension to Rabinow's concept of 'bio-sociality' however, I found to be more lacking in the hospice day centre. This dimension is often allied in the literature with Rose & Novas's concept of "biological citizenship" (2007). They argue that individuals' biological vitality is being isolated by the state in a multitude of ways in order to engender new modes of citizenship and derive new economic potential or biovalue. Individuals, they argue, also create and sustain these biological affiliations by articulating their identities and feelings, as well as making normative judgments about and claims on the state, in "biologically coloured languages" (Rose & Novas 2005:445):

An active scientific citizenship is increasingly enacted, in which individuals themselves are taking a dynamic role in enhancing their own scientific - especially biomedical - literacy (Rose & Novas 2005:446).

A patient coming to the hospice day centre may be engaged in “processes of biomedical self-making” simply by virtue of the fact that their daily routines are wholly ordered by the illness that they are ‘living with’ (as Chris tried to engage with in his ‘self-prescription’ Apothecary project). However, most patients were actually far too ill, their worlds grown too small, to feasibly assume a “dynamic role” of the active, advocating type described by Rose & Novas. A lot of the patients were simply coping with day-to-day realities, trying to manage their prescriptions, their emotions, and their relationships. For every animated conversation about the disparity of access to drugs – the postcode lottery, as it is known - there was also a post lunch, analgesic-induced reverie of heads lolling on necks, the silence punctuated only by the bingo call.

Bingo is a game in which players mark off numbers printed on a ticket as they are called out in a random order by a nominated “caller”. The player who marks off the winning combination of numbers must shout out “bingo” to win the game! The game seemed popular among day centre patients and was played most afternoons in lieu of any other diverting activities. The hospice website assures people that although the day centre is in part a “social hub”, it is also offered as “a place for quiet and rest”. One patient, Steve, who was very active in user-involvement organisations (he belongs to 15 to be precise!), would often try to initiate political discussions about, for example, the latest controversy involving the local Primary Care Trust (PCT). However, it was my impression that his efforts were often greeted with a collective sigh. Another (female) patient wanted to know everything about her disease, what type of bodily disintegration she could expect, and her (changing) prognosis, but she was a lone voice among the other women she had befriended, who, to her dismay, were happy to, as she said, “live in a state of ignorance”. Many patients seemed to consider themselves “too frail to fight”, or were in too much discomfort to assume a politically or socially dynamic role. So while patients may well be capable of displaying “biomedical literacy” when it comes to making claims on the health service or state-funded agencies, in the hospice setting at least, patients whose horizons were rapidly and radically shrinking, were equally as likely to be disengaging from any ‘active’ citizenship role. This certainly did not mean that they

were resigned to bodily deterioration and impending death, but rather that individuals were careful as to where they expended their increasingly limited time and energy. This factor also undoubtedly contributed to Chris's Apothecary project poster calling for participants remaining unanswered for weeks.

When 'living with' life-limiting illness, increasing frailty can shrink a person's social world as their capacity for action and 'doing' wanes. I often wondered whether people in the day centre were bored because of this inability to act. Very few ever stated explicitly "I am bored", but some would make comments that could have indicated boredom, like "I'm ready to go now, I've got no one left" or "I'm frustrated because I can't do what I used to do and now I can only watch." Boredom arises often when a person is frustrated in doing what they want to be doing or when time is considered "empty," that is, without meaningful content. Svendsen (2005) argues that we experience boredom as a result of our lives failing to live up to romantic ideals which stipulate that all time should be infused with personal meaning and that the 'self' should accumulate through time, changing as it experiences various intensities and transgressions (2005:100&152). Svendsen thinks that our modern censorious attitude to boredom, at least in part, derives from the great emphasis we put on originality, innovation, and efficiency (2005:27). *Rosetta Life's* philosophy is that the loss of meaning which can often accompany 'living with' a life-limited illness, does not necessarily have to result in boredom. With some help, especially from the creative arts, new meaning can be discovered and boredom can be alleviated. This philosophy subscribes to a belief in the creative power of boredom to open up new avenues of meaning. One man in the day centre told me that he felt "privileged" that living with cancer had slowed down his hectic lifestyle and had given him the time to appreciate the small things in life which he had never before had chance to notice. He recalled sitting in the hospital waiting room between bouts of chemotherapy watching people parking their cars out of the window for hours on end. Even though he realised he should have found this boring, he told me he took pleasure in the activity because of its simplicity and because it was something his working life had never allowed him to do.

Arendt (1958) argues that it was freedom from necessity and from the constraints of the household that enabled humans to enter the political realm and engage in what she calls rational discussion. Heidegger and Svendsen argue that it was freedom from necessity that enabled humans to be bored, now an essential feature of the modern condition (Svendsen 2005:126). For the patient who enjoys watching cars being parked, being freed of the necessity of work because of a life-limiting illness gives him the chance not to be political, but rather to be bored. Heidegger thought that the nothingness of boredom could offer opportunities for genuine insight and philosophy, that profound boredom could enable us to grasp our own possibilities for being (Heidegger 1995:149). Svendsen questions this Heideggarian notion that boredom can have wide-reaching ontological implications (2005:132). He asks why the boring life cannot be liveable just for the fact that it is a life, rather than living with the expectation of some profound philosophical revelation. Were the patients sitting in the hospice day centre bored? Inactivity for those who are healthy and active might seem capable of yielding only negative boredom. *Rosetta Life* was invited to take up residence in the hospice at least in part to fit the day centre's "diversionary" mandate i.e. to provide activities which could prevent boredom. Chris certainly would only licence boredom if it gave someone the time to creatively re-imagine his or her life. Boredom that is not profound in the Heideggarian sense, or creative as *Rosetta Life* would like to make it, is generally viewed negatively. This is an assumption that I will explore later in this chapter, when I will draw parallels between negative views of boredom and the negative view of silence often given in the literature, such that silence is seen to represent an absence or a lack.

The Art of Self-Knowledge

Artist-in-residence Chris thinks it is difficult to foster sociality of an active kind when one has waning energy due to illness. If, as Strathern (1996:64) argues, sociality is that "relational matrix" which constitutes the life of the person, then one wonders if energy and stimulation are needed in order to establish and nurture those relations? Chris's role is to offer alternative, 'artistic' modes of stimulation for patients wanting to 'dig a little deeper' and side-step Bingo. He says that putting a camera on people acts as a stimulant to discussion and interesting things can be

revealed. However, whether this ‘digging deeper’ entails a politicisation of patients’ biomedical identity or a questioning of how their biological ‘vitality’ is being used in citizenship projects depends on both the artist leading the project and the inclinations of the patient. Chris has no political axe to grind and as with his “Apothecary” project, any nominal political motivation is usually a means of eliciting something more psychoanalytical. Ultimately, what Chris is interested in is ‘biovalue’ of a different sort to Rose & Novas.

Rosetta Life’s stated mission is to “enable people...to take ownership of their identity, their lives they lead with illness, and the places where they receive care” (Jarrett 2007:xi). As Chris articulated to me, when faced with death (and even if one is “living with” life-limiting illness, one is still faced with the prospect of dying) the “frivolous things fall away and what is salient remains...although no one wants pain, loss, bereavement etc... it can also be a time for self-knowledge.” There is ‘value’ then, in being encouraged to harness that self-knowledge, to “gain wisdom through the horror” as Chris put it, and there is also value in sharing that perspective with other people. In pursuit of finding meaning in a person’s dying, Chris sees his role as that of “shepherd”, showing people what they are capable of and releasing what he views as their intrinsic creativity. The biblical connotations of the word shepherd again echoes the religious foundation of the hospice movement and Saunders’s vision of her role as spiritual guide.

For me, what is intrinsic to Chris’s engagement with patients, and perhaps *Rosetta Life*’s goal more generally, is the assumption of a desire to pursue self-knowledge and self-reflection. There is an emphasis on ‘creative engagement’ (Jarrett 2007) that reflects an understanding of individuality akin to Rapport’s notion of the “transcendent individual” (1997). Essentially, Rapport’s view is that for too long, Anthropology has critically neglected the creative and interpretive impulses of individuals due to a preoccupation with the socio-cultural construction of persons. As with Strathern’s emphasis on ‘sociality’, he *does* give centre stage to personal relations, but for him, personal relations are always known and experienced differently by the different individuals engaged in them (1997:25). This is because

relations and social structure are always subject “to creative interpretation, to individual manipulation and re-rendering” (1997:42). Unlike Strathern’s (1992) idea that relationships produce the individual, for Rapport, individuals are ontologically prior. Hence an individual is capable of transcending his socio-cultural environment by application of his *unique* imagination and creative impulses. This idea is reflected in Keane’s discussion of the Protestant conception of the modern ‘self’. As discussed earlier in this chapter, the basis of this particular conception is that the subject can be abstracted from its material and social entanglements in the name of freedom and authenticity (2002:83). Inherent in such abstraction lies the possibility of transcendence. Keane himself argues that this project of transcendence will always conflict with the inescapably material dimension that exists in human social practices (2002:84). But such a project is certainly reflected in *Rosetta Life*’s belief that, when faced with death, the power of art lies in its ability to “reawaken people to their imaginative capacity” and “transcend” the uncertainties of serious illness¹³. So inherent in *Rosetta Life*’s modus operandi is a specifically Protestant ontology, whereby transcending the material world becomes a matter of transcending the materiality of bodily decay by turning inwards to the ‘self’.

Anthropology also has a modus operandi that reflects a Protestant ontology, too long left unacknowledged by the discipline, according to Cannell (2005). Just as Rapport criticises Anthropology for its reluctance to celebrate the creativity of individuals in ushering in the “unstructured” (1997:38), due to its blinkered focus on social structure, so Cannell (2005) has similarly tried to draw attention to another of Anthropology’s unrecognised orthodoxies: its Christianity. Cannell thinks the discipline’s uncritical approach to its Christian ontology is due to the fact that Christianity is part of the culture anthropologists tend to come from (2005:340). When anthropologist *do* theorise Christianity, it is with a focus on asceticism, that is, the inferiority and sinfulness of the body compared to the soul, as the “authentic” Christian belief system (2005:341). We can recognise similarities here with Keane’s Protestant ontology and the project of transcendence of the ‘authentic’ spirit. Cannell uses her ethnographic study of American Mormonism, “a strikingly different form of

¹³ Chris Rawlence, personal communication during fieldwork

Christianity” (2005:338), to reveal these biases in the discipline. Mormonism does not place body and spirit in opposition but rather celebrates fertility in heaven and views eternal kinship as the distinguishing feature of divine status in the afterlife (2005:343 & 349). This is an entirely different notion of transcendence, one that does not clearly privilege the spirit or belief in an authentic ‘self’ over and above the material, mortal, and fertile body.

What I identify as *Rosetta Life*’s Christian ontology is manifest in their belief in and pursuit of an ‘authentic self’ that is arguably constructed through their reflective practices. As noted earlier, the Evangelical roots of the modern hospice movement are still evident in the essentially secularised psychological philosophy accompanying the new palliative care discourse. When facing death now, one is directed to seek “meaning” or “fulfilment” through confession of a ‘self’ that desires authenticity and authentication, not dissimilar to the notion of Christian absolution. The psi-sciences, according to Rose (1999), in particular the confessional interview of the psychologist, are the new “technologies of power” which propagate a belief in the ‘self’ as an irreducible essence capable of being discovered and corrected. Baxtrom (2008:7) has interrogated whether ‘selfhood’ is ever experienced as unitary or moral, stable or singular, as certain Western approaches to identity formation lead us to believe. Inspired by Khan (2006) and Deleuze (2001), Baxtrom ventures that the ‘self’ should be understood as produced when various pre-subjective possibilities are actualised in different contexts. In this model, difference is considered internal to being in the form of a multiplicity of potential selves that can emerge at given moments in response to the world. Baxtrom here is trying to escape critiques such as that of Rose whereby the ‘self’ is wholly conditioned by disciplinary discourses. I want now to discuss how artist-in-residence Chris, crucially self-identified as a non-Christian, mediates between the roles of “confessor,” and artist, and, following Cannell, identify the religious resonances, or ontology which persist in the practices associated with the merging of these roles.

Testimony & Christian Confession

Rapport's (1997) emphasis on the creative power of individuals can be recognised in *Rosetta Life*'s philosophy and outlook. Approaching death is not just about the practicalities of dealing with the end-of-life, but also about a search for new meaning or an enhancement of meaning. In order for patients to be creatively reawakened or enabled on the path towards this new meaning, a "shepherd" is required in the form of a *Rosetta Life* artist-in-residence. Their role is to creatively engage with hospice-users and allow them individual self-expression in the form of "giving voice" and "telling stories." They are not strictly art therapists, where the art produced is secondary to the uncovering of psychological issues. Instead, *Rosetta Life* artists focus on the art itself. As one artist said to me: "People think I'm a martyr for working in a hospice. I'm actually a mercenary. It's artistically very inspiring." According to Jarrett, *Rosetta Life* artists are also not supposed to act as interpreters of people's stories and worldviews, but rather as collaborators (Jarrett 2007:xiv). This principle does not always translate in practice, and observing Chris's engagement with patients, it was clear that there was a large amount of "interpreting" at work.

In Rabinow's description of his French advocacy organisation, he identified "a heavy panoply of pastoral keepers" who help the patients and relatives affected by degenerative diseases "experience, share, intervene, and "understand" their fate (Rabinow 1996:102)." Hospice patients too are surrounded by various "pastoral keepers" all wanting to hear their stories and guide and support them. Most hospices have a hospice chaplain, alternative therapists, occupational therapists, social workers, counsellors, psychologists, doctors, nurses and of course, the volunteers. In my hospice day centre, as already outlined, the "pastoral keeping" undertaken by the staff and volunteers was directed more towards diversion and "jollification", with hints of paternalism involved. Chris's "pastoral keeping", on the other hand, was directed more towards opening up alternative spaces for patients to "experience...and understand their fate," in Rabinow's words. This bears similarity to Arnason's (2001:300) *Cruse* bereavement counsellors, who downplay their own status as experts in order to enable the bereaved to become experts in their own grief.

The specific mode of interaction adopted by Chris, I understood to be a form of eliciting testimony. Ross uses the word testimony in place of story when referring to narratives of violence in South Africa, because she argues that the word implies a narrative formality that became apparent in the standardisation of victims' narratives (2003:331). While this standardisation of form does become an issue in Chris's films, it is the religious connotations of the term – that is, to publicly profess or bear witness to one's faith – which I think makes testimony a more suitable term than story. Choosing to work with Chris on a *Rosetta Life* project suggests that the patient has a degree of 'faith' in the artistic process, the worthwhileness of pursuing 'self-knowledge' and, most importantly, faith in Chris the artist as executor of their vision. This trust that is placed in Chris, I argue, casts him in the role of "confessor". He guides patients towards bearing witness to (and confessing) their own life stories in an act of giving testimony, helping them to "understand' their fate", as Rabinow writes. In order to delve a little deeper on this point, I want to draw on Foucault's genealogy of Christian confession in the creation of modern notions of the 'self' (1993[1980]).

Foucault identifies three stages in the development of 'technologies of the self'. The first stage is the Stoic technologies applied in Ancient Greece. According to Foucault, the Delphic precept, *gnothi seauton* - "know yourself" - was a philosophical obligation in Ancient Greece (1993:204). The goal of Greek philosophy was essentially the transformation of the individual to enable him to acquire riches, participate in the affairs of the city, and gain public opinion (1993:208). Although there was an examination of conscience at work, it was more about administering one's actions and conforming to fundamental rules of conduct (1993:207). It was not about *discovering* a 'self' by means of the truth hidden inside oneself. The 'self' was instead *constituted* through a superimposition of knowledge and will (1993:210). "Truth" in Ancient Greece was a "force inherent in principles...[which lay] before the individual as a point of attraction" (1993:209). Herein lay the technologies which constituted the gnomonic 'self', according to Foucault.

The second stage in the development of ‘technologies of the self’ came in the first centuries of Christianity in the form of ‘doing’ penance. This was a theatrical public performance whereby one had to make one’s sin somatically visible through the infliction of suffering (for example, by remaining unwashed, deprived of food, covered in ashes, being scarred etc...) (1993:213-4). The ‘truth’, which in Ancient Greece lay before the individual as a goal, now had to be manifested on the ravaged body of the penitent, or martyr, which was then required to be witnessed by others. The dramatic means by which the penitent punished himself eventually lead to reconciliation in a dramatic moment of self-revelation through self-destruction. This whole process was referred to by the ancient Greek term “*exomologesis*”. There was no analysis of the sins required and no necessary correlation between the sins committed and the punishment exacted on the body of the penitent. It was purely the somatic demonstration of sinfulness which was required. *Exomologesis* occurred through the renunciation of the ‘self’ by the penitent as he was witnessed willing his own death (1993:214). One of the key elements of this dramatic demonstration was that witnesses did not necessarily need to *understand* or to analyse the sins the penitent had committed. This type of *performance* of the ‘self’ and the requirement for its renunciation to be witnessed is relevant to what *Rosetta Life* seeks to do in the hospice day centre and will be discussed in depth in the next chapter.

The third stage in the development of ‘technologies of the self’, according to Foucault, arose through the establishment of monastic confession in Christianity. These monastic ‘technologies of the self’ were about reflecting inwards, reading the ‘self’ as a text and bearing witness against oneself in the presence of a priest. “Truth” now lay within the nature and substance of the penitent’s thoughts that, crucially, had to be verbalised to a priest. This was known by the Greek word “*exagoreusis*” (1993:220). This kind of examination of conscience was more concerned with the verbalisation of thoughts than with actions (1993:26). If the Stoic was interested in conformity to acts and rules, and the early Christian penitent in having his acts of somatic self-renunciation witnessed, then the Christian monk was concerned with having his thoughts authenticated through verbalising them to his spiritual “confessor”. Critically, Foucault highlights one clear parallel between the two

Christian experiences. In both *exomologesis* and in *exagoreusis* the person has to sacrifice themselves in order to discover the truth about themselves and vice versa (1993:221). Foucault's final claim is that this later Christian *exagoreusis*, dependent on a "permanent verbalisation and discovery of the most imperceptible movements of our self", now dominates (1993:222). The interpretative 'self' now reigns free. The sense of sacrifice has been lost, and instead a "positive self" open to indefinite interpretation has emerged. And yet, the dynamic for *Rosetta Life*, as I hope to elucidate, revolves around the interplay between the two aspects of the Christian 'self' – the one which is performed and witnessed, and the one which is verbalised and interpreted.

Chris's Exagoreusis

If we liken Chris to a "confessor", then his role is to encourage the patient with life-limiting illness to look inwards to discover the truth about their life and its meaning. This truth then becomes known through the verbal act of giving testimony (confession), primarily to Chris and perhaps, later on, to others in a public setting. Verbalisation of one's thoughts in the presence of someone else, as described by Foucault, is key to understanding this process of uncovering self-knowledge which is part of *Rosetta Life's* goal. Like Anthropology's bias towards asceticism when theorising Christianity (Cannell 2005), Foucault draws attention to the Christian bias towards the verbalisation of 'self' over and above the encounter of 'self' in being or doing. Foucault's insights are reflected in Keane's (2002) account of the Protestant conception of the modern 'self' and its emphasis on sincerity in speech. According to Keane, this emphasis on sincerity is based on a certain understanding of the relationship between language and thought. When being sincere, one is thought to be revealing an interior state or 'self' (2002:74). Keane's view is that Protestantism encourages the giving of these sincere or "truthful propositions", over and above ritual activities (doing) or bodily disciplines (being). If one could be fully and transparently 'sincere', there would be no disjuncture between thoughts and their verbal expression and therefore "nothing significant would remain of the material forms or social origins of words" (Keane 2002:74). Keane thinks that the Protestant viewpoint denies that words always bear some trace of their origins and prior usage

and have some reference to the externality of the speaker (2002:77). It also denies the role/influence of the “confessor”, which Foucault highlighted, and the political authority, and the social conventions that elicited the words.

Rosetta Life participants are encouraged in this belief that giving a verbal testimony of one’s experiences of illness is a way of discovering or even creating the new ‘self’ which those experiences have given rise to. While patients can give verbal testimony to other “pastoral keepers” affiliated to the hospice, for example, the hospice Chaplain, there is something specific about the testimony given to Chris. This is that the testimony is given the form of a work of art and the patient’s discovered ‘self’ is made manifest *in* that work of art. The film is meant as an authentic representation of the individual. This representation is shown to other people but crucially is also reflected back to the individual themselves, so that they can judge themselves anew.

Chris’s role, I would argue, is one of “interpreter” rather than “collaborator”. This gives him a certain power over the ‘self’ that is discovered in the patient. It is not clear whether the “self-knowledge” and harnessing of “intrinsic creativity” which Chris professes can occur as people contemplate death, is self-generated or whether it is discovered within the ‘self’ only by way of a “confessor’s” encouragement of verbalised testimony. Put more simply, how far does an artist’s interpretation create the ‘self’ that is the subject of the artwork and eventually reflected back to that ‘self’? At a public viewing in a museum of a collection of *Rosetta Life* films, Chris spoke publicly about the problems of negotiating the relationship between artist and patient. He said that if a participant felt they recognised themselves in what they saw on the screen, or felt that Chris (or another *Rosetta Life* artist) had managed to capture some “essence” that they recognised, then this verified the sincerity of the artistic representation. Clearly Chris and other artists are willing to publicly recognise the problems of assuming words or art make transparent a patient’s interior state, yet it is also clear from Chris’s comments that he believes the *authority* of the words spoken or the art viewed is generated by the patient themselves, and not from external powers and practices.

One interesting illustration of the power involved in the act of interpreting is Chris's use of voice-over in his films. Chris, with his background in TV, uses narration or voice-over in all of his films. Voice-over, so the observational critique goes, is authoritarian and gives the impression of a "voice of God" (Loizos 1992:54). This creates for the viewer a sense of an omniscient, disembodied figure directing the viewers' attention and so seems to be in control of what is happening. Most interestingly in all this is that Chris always uses his own distinct and authoritative voice to read the voice-over. This takes me to two key issues in my understanding of *Rosetta Life's* goals more generally. If verbalisation is vital to the giving of testimony, then it assumes in the first instance that patients have something they wish to say (keeping in mind that the Apothecary project poster remained unanswered for weeks). And if patients *do* express a desire to give testimony, is this in order to give "authentic" voice to their particular version of selfhood, or is it rather the "confessor's" construction or interpretation of that 'self' which is heard?

Claire's Poems

Chris has known Claire for 6 years now, since she first started coming to the hospice day centre. He told me that of all the patients with whom he has worked over the years, his most intimate relationship has been with Claire. Claire is thirty-six years old and has a very progressive form of Multiple Sclerosis (MS), an autoimmune condition in which the immune system attacks the central nervous system. Her disabilities have progressed severely over the time Chris has known her. She is now in a wheelchair permanently, has very little movement from the neck down, and has very slurred speech. Claire's mother also has MS, although a less progressive type. Claire used to be very active – she played hockey for her county and did international tours with the team. She has the energy of a thirty-six year old, but her body is essentially dying on her. She lives with her partner, Paul, whom she met before she developed the disease, and they live together in South East London.

I first met Claire at her home when Chris took me there to introduce us. We sat in the garden and Chris asked her how she was doing that day. She said she was annoyed because she felt a lot of her carers (she needs constant home care) were lazy, but

because they were of African origin, she was worried that if she complained, it might be construed as racism. On the back of the voicing of this concern, Chris asked Claire if she wanted to write a poem to express how she was feeling. She agreed and as she responded to his questions, he began creating verses out of what she said. After a few lines were down on paper, he read them back to her, in that distinctive ‘received pronunciation’ voice of his. When the poem was finished, he read it out loud to her in full, placing his own emphasis and added feeling. Claire seemed very satisfied hearing her own words read back to her and said that it expressed ‘exactly how she felt.’ As Chris explained to me later, that was how he now worked with Claire, meeting up every few months and writing a poem together. This is where his skills as a librettist come in. He says the key to assembling this type of poem is subtly sculpting the individual’s words to fit the correct meter. It is also about picking out what is salient in what people are saying, searching for those “nuggets of gold”, as Chris calls them, and “nudging them into a shape” that preserves the “deceptive simplicity” of Claire’s words. I was personally impressed, watching him work in this way, and witnessing Claire’s positive reaction. It was particularly poignant given the problems Claire now has in speaking. Previously, Chris would film Claire reading out the poems, but she can no longer do this. Chris has become the mouthpiece for her thoughts and feelings: her voice is now his voice.

On another occasion, when Claire had come to the hospice for respite (upstairs this time) while her partner was mountain biking in France, Chris and I visited her and I watched them write another poem together. Claire said she was not happy, that she felt abandoned by her partner, and felt generally bored, lonely, and “frustrated”. She said this word over and over again. This time the poem was about the endless waiting for people to turn up to visit her:

I hate not knowing when
They’re going to come
All they’ve got to do
Is phone...
I hate not knowing when
It makes me so dependent
And I hate that
It makes me angry
Not at them

But at
My whole situation.

Claire, like many of the patients Chris works with, is waiting for something but it is not entirely clear for what. Ostensibly it appears she is awaiting the return of her partner from holiday, or a friend to come and visit. More fundamentally, however, she is waiting for a change in her condition - some improvement - when inevitably the change will only be further incapacity and a foreshortened life. Waiting, in both the short and the long-term, is about anticipating change in a long process of adapting to life-limiting illness. Articulating her feelings to Chris and hearing her words read back in his voice was a way that she said released some of that frustration. Chris did not want to “placate her” by “jollyng her along”, a reaction many (myself included) have to someone’s continual expressions of unhappiness at their life situation. Chris’s reaction instead is to say “yes, things are shit for you, and they are not going to get any better, so how can we vent those feelings and communicate them to people?”

Chris also incorporated Claire’s testimony into a musical he wrote with *Rosetta Life*’s Lucinda Jarrett and the composer Orlando Gough, called “The Mariners.” The musical intertwined the stories of four women, including Claire, from different London hospices, all ‘living with’ life-limiting illness. Two of the women have now died. The charity’s description of the musical is as follows:

Beginning with diagnosis, the story takes the audience on the roller coaster ride of life-threatening illness - the fears and the pain, but also the laughter, exhilaration, and understanding.¹⁴

There is a DVD of the performance, inter-cut with testimony from the four women. Claire says things like: “I never had to think before about a simple thing like drinking” and “I hate the word can’t – it’s just not a part of my vocabulary.” Claire has very fond memories of making the “The Mariners” and while I was at her house she asked her husband to show me the DVD. He said she watches it all the time, and when I looked over at her during the viewing, she was crying. Chris recalls a time

¹⁴ www.RosettaLife.org

when he found Claire beside herself crying on her bed. When he reached out to comfort her, she said to him that she couldn't stop her "silent tears...like a quiet Niagara." Chris thought this phrase beautifully captured something 'quite profound', and it became a key refrain in the musical. Again, he is using Claire's words, but it is his application of them which creates the art. As with the film about Bob and his Asclepiads, Chris provides the form/ structure for the art, while the content remains individually specific.

Chris has recently arranged for all the poems he has written with Claire to be published in a book, which is available to the public to buy and which has garnered national press coverage. This now acts as written testimony of her experiences of 'living with' increasing paralysis. Claire has always referred to Chris as her 'toy-boy.' She clearly feels close to her "confessor". Chris told me he represents the "possibilities of another life" for her, while her story gives him "artistic inspiration" and the chance to tell universal truths. His relationship with Claire is more collaborative than many of his other relationships, where he undoubtedly does much more interpreting. Perhaps this is because, as he says, it is the most intimate relationship he has developed with a patient, and collaboration takes intimacy. Chris says in general he doesn't get close to patients, or let their stories personally affect him. Even in Claire's case, he is trying to withdraw now because he "wonders where it can go from here". If Claire loses the ability to communicate altogether, there will be no possibility of writing poems together, and Chris will no longer be able to act as her voice.

"Giving voice" or "taking it on the chin"?

It is clear to me that Claire wanted to 'give voice' to her sadness and frustrations and that *Rosetta Life* has been successful in enabling this. By giving artistic form to her feelings, Chris has tried to bridge what Perrin calls "the insurmountable difference, the insurpassable distance" between the one who is dying and the other who lives on (2004:133). The musical and the poems have allowed Claire to communicate her feelings in a way that she was unable to do in her everyday life. *Rosetta Life*, in its engagement with Claire and other hospice patients, demonstrates a refusal to accept

that we can never find the words to respond to someone who is dying. But just as there are patients, like Claire, who want help to verbalise their feelings and help finding an ‘authentic’ vehicle for communicating their fears and frustrations, there are also patients who simply do not want to ‘give voice’, and this is not just because their illness silences them. Some perhaps do not want an artist intruding into their lives, while others may want to devote their waning energy to their family. Alternatively, they may feel cynical about whether Chris can initiate a transformation. The overwhelming majority of the patients in the day centre are traditionally working class and may feel they have little in common with Chris’s middle class artistic sensibilities. As another artist-in-residence working in a another hospice in London told me, what she does is often viewed as “artsy fartsy” because it is outside of people’s experience and knowledge and so raises suspicions. However, this particular artist encountered resistance more from the staff and volunteers than from patients. The issue of class and its influence on how the arts and artistic endeavours are perceived is important given the wide range of patients *Rosetta Life* works with. If working-class patients are more inclined to “take things on the chin”¹⁵ then why does *Rosetta Life* assume that people want to ‘give voice’ when perhaps they are content just to “get on with things”? Randall and Downie (2006) have voiced concern as to how far healthcare professions should be made responsible (as stipulated in the WHO guidelines) for patients’ emotional, psychological, and spiritual lives. Their argument is that palliative care specialists are not responsible for enabling people to attain a meaningful death (2006:161) and indeed it would be paternalistic to think that was possible:

To those outside palliative care it seems astonishing, and incredibly paternalistic, that professionals whose qualifications are in nursing or social work should feel confident enough to make the meaning of and fulfilment in the patient’s life an aim of their health care (2006:33).

While this certainly does not apply to Chris - his very purpose in being artist-in-residence at the hospice is that he has the skills to engage with the ‘meaning’ that people are seeking – the fact that other “pastoral keepers” may be involving

¹⁵ A *Rosetta Life* Artist-in-Residence used this phrase about patients at her hospice day centre.

themselves where Randall and Downie (2006) think perhaps they should maintain a respectful distance, is all part of the context as to why patients may be cynical as to Chris's motives and method.

What is also problematic is the political backdrop to people's giving of testimony. Two anthropologists looking at narratives of violence among victims of Apartheid in South Africa have questioned the discourse of catharsis and empowerment in the Truth and Reconciliation Commission (TRC). According to Ross, the first issue was that the TRC assumed that what had preceded its work was "voicelessness and silence about the Apartheid past" (2003:327), whereas actually many stories had already been told, but in a diverse range of genres and registers. With the setting up of the Commission, certain narrative conventions were alighted on as the most socially viable in terms of promoting the healing of the individual and social body (2003:327). The Commission's role in eliciting testimonies was one of "sculpting a linguistic form to carry the experiential" (2003:337), but this did not always match the intimate register and personalised styles chosen by people to speak of their experiences. This standardisation of storytelling by the Commission is confirmed by Colvin who describes the format as:

short, quickly recited stories of traumatic suffering, reduced to the most important, shocking and morally obvious details of harm, circulated less as specific histories...but more as "signs of violence" or a "representative sample" (Colvin 2004:2).

According to Colvin, this format was intended to heighten the emotional power of people's stories and open up the possibility of healing or 'catharsis' (2004:3). However, like Ross, he highlights that such conventional formats often supplanted "creative and more locally resonant narrative impulses" and so failed to offer "closure" or "healing" for many people (2004:8). Colvin thinks that too often the positive liberal discourse of storytelling as a means toward political empowerment ignores the disillusionment and cynicism which some people feel about the so-called redemption which can occur (2004:12). Jean-Klein & Riles (2005:178) have also incorporated Anthropology in this critique of liberal discourses, arguing that

anthropologists often envisage the giving of testimony in the ethnographic interview, for example, as therapeutic or healing for the participant. They question whether anthropologists in this mindset could equally recognise participants who “would mark “silence” as a socially productive posture and who would refuse the anthropologist’s invitation to speak” (Jean-Klein & Riles 2005:179).

Some of the same problems around ‘giving voice’ and narrative formats are faced by *Rosetta Life* artists in their quest to help patients find meaning and self-knowledge in their ‘being-towards-death.’ Some patients may want to be purposefully/productively silent and resist the psycho-analytic impulse to “talk it through.” Others might maintain a non-purposeful silence, in that they simply have nothing they wish to say or share. Reflecting on my earlier question as to whether day centre patients are bored, perhaps it is presumptive to view boredom or silence as a negative state, indicative of a lack of something – a lack of a Romantic ideal of a ‘self’ infused with personal meaning that needs to be continually reflected on, added to, or improved upon. Perhaps viewing boredom as a ‘lack’ simply reveals our own capitalistic preoccupations with productivity and efficiency, as hinted at by Svendsen (2005). In her ethnography of mourning practices in Inner Mani, Greece, Seremetakis reveals how a silent death, that is, a death in the community not given vocal lamentation, is viewed as an asocial or bad death because it indicates a lack of social relation with the dead (1995:101). The same argument may account for why silence and boredom are viewed negatively and resisted by hospice care providers: they fear that it could indicate that the dying have been abandoned or forsaken. Equally, the bio-sociality model assumes that even when experiencing extreme illness, people will still find ways of communicating and sharing that experience. This is Arendt’s view when she emphasises talking as a way of de-individualising experience:

Men in the plural, that is, men in so far as they live and move and act in this world, can experience meaningfulness only because they can talk with and make sense to each other and to themselves (1958:4).

This is perhaps another reason why hospice carers feel that people should be encouraged to talk and to seek meaning over allowing silence or boredom to reign.

Another reason patients might not want to talk is that they may be cynical about the transcendence that becoming involved in a *Rosetta Life* project will bring. I witnessed Chris asking one patient if she wanted to be involved in a film project, and her response was resoundingly “No, I have no interest in that.” On the other hand, there are patients, like Claire, who clearly have a lot of sadness and frustration they want to express. Giving testimony to Chris has had a positive effect on how Claire has adapted to a life limited by disease. Yet as with the TRC, the redemptive formats of the art produced by *Rosetta Life* involve a certain standardisation of the stories told. As with Bob and his Asclepiads, there is often a ‘Hippocratisation’ of people’s stories, as the nuances and complexities of their testimonies are reduced and reified in order to become generalisable. For example, Chris’s authoritative voice(-over) dominates the majority of his films, drawing conclusions on behalf of the audience. His films usually take the form of presenting a problem which is then ‘resolved’ or the individual ‘redeemed’, if only by the film ending on a positive note. Although this is a long way from day centre “jollification”, it is also a long way from some of the testimonies given by Lawton’s hospice patients’ where they describe the horror and despair of bodily disintegration (Lawton 2000). Chris’s filmed testimonies are not shallow portrayals of a hollow redemption (his films are both sophisticated and thought-provoking) but equally they never present a total break with narrative conventions about catharsis and healing. Art, according to Schweizer, has a role transforming the unshareable truth of suffering into bearable fictions (1997:3). Patients’ personal testimonies are ultimately filtered through Chris’s perspective, and the same goes for any artist-in-residence working for *Rosetta Life*. If patients’ testimony could be self-elicited and directed, then one could speculate that there would be no need for an artist in the first place, in that it is art which gives form to the formless and makes feelings visible:

If reality could come into direct contact with our senses and our consciousness, could we enter into immediate communion with ourselves and others, art would be useless, or rather we should all be artists (Bergson 1911:150).

The Quest for Authenticity

To end this chapter, I want finally to look at the issue of storytelling as a way of producing an “authentic self”. Both Colvin (2004:10) and Ross (2003:333) have commented on the TRC’s “quest for authenticity” and how storytelling was seen as a way of facilitating this quest. When encountering the testimony of people ‘living with’ life-limiting illness, this authenticity comes in the face of impending death. Rosetta Life encourages them to explore their ‘self’ just as that ‘self’ is coming to an end. Authenticity is also a key theme in the existential literature. In *Being and Time*, Heidegger postulates that “authentic Being-towards-death” overcomes the “evasive concealment...which dominates everydayness” (1962:297) and the “constant tranquilization about death” (1962:298). For Heidegger, death is the ‘not yet’ which always lies ahead of *Dasein* (being), one’s “ownmost potentiality” before which one must feel a healthy “anxiety” (but not fear). It is this existential “anxiety” in the face of death which gives a person authenticity in their ‘being-towards-death’. And it is only when death is experienced authentically, according to Heidegger, as a limit to which one should remain open, that we can be truly free. If we use the language of Heidegger, we might say that *Rosetta Life*’s aim is to enable people to express themselves ‘authentically’ in their ‘being-towards-death’, through opening up possibilities for giving testimony. As Chris put it, there is wisdom to be gained in the horror of disease, and ‘self-knowledge’ to be reached when one is faced with the possibility of death. Anticipating death or an end to ‘self’ can give life its ultimate meaning and bring a desired authenticity to existence.

However, Heidegger’s existential philosophy or ‘philosophy of death’ as Adorno calls it (1973:137-8) has also attracted criticism from other philosophers. Deleuze argues that Heidegger mistakes our ‘being-towards-death’ as imbuing our life with its ultimate source of meaning: the never-reached horizon of experience in light of which the “authenticity” of our experiences and decisions can be measured. Deleuze thinks that at most death should be considered a “bad encounter” to be resisted and even overcome (1988:12,100). Life should present a challenge to death. It should not be lived in anticipation of death. Inspired by Spinoza’s ideas, Deleuze attempts to produce a philosophy of life that is not a meditation on death, *a la* Heidegger, where

death is somehow redeemed by the meaning it confers. Rather, he states that death is extrinsic to the 'self', and is therefore an impersonal event, that cannot be deemed to be a source of personal uniqueness (1990:145). Death can truly be considered "nothing", not in the Heideggerian sense of "nothingness" as the horizon of being, but rather "nothing" because it does not inspire or produce meaning. Instead, our goal should be to live "so intensely...that death, always external, is of little significance" (Deleuze 1988:41).

These philosophical perspectives may seem a long way from *Rosetta Life's* real life aims. However, the philosophical idea that death can be redeemed because it provides life's structure and meaning is a guiding principle for the charity. As we have heard from Chris throughout this chapter, he believes that to be 'living with' a life-limiting illness can heighten one's desire for self-knowledge and bring moments of transformation of the 'self'. Our 'being-towards-death' is seen to have intrinsic, transcendent value. If Deleuze or Spinoza, on the other hand, were to comment on *Rosetta Life's* working model, they might argue that encouraging reflection on an authenticity of selfhood in the face of life-limiting illness actually detracts from the intensity and power of life as lived in the moment. Death, after all, being "nothing".

When he writes of living "authentically" by way of *practically* affirming our mortality, does Heidegger make a place for other people to enhance our authentic being? When contemplating whether experiencing the death of Others could offer any existential foretaste or foresight for a person's own death, he contends:

The dying of Others is not something which we experience in a genuine sense; at most we are always just 'there alongside' (1962:282).

Heidegger is supported here by Derrida in *The Gift of Death*, where he states that "death is very much that which nobody else can undergo or confront in my place" (1995:41). For both writers, 'being-towards-death' as one's innermost possibility, as well as one's singular responsibility, emanates from the 'self' as it simultaneously constitutes the 'self'. It is about differentiating oneself from the "constant tranquillization" of "the they's" denial of death (1962:298), and thereby encountering

one's individuality and singularity. For both, death is an internal relation of self-to-self (Baugh 2000:77) and so a person's 'being-towards-death' cannot be accessed by others. But an alternative view is that our experience of others dying is the main way that we experience our own death, hence why we experience it in anticipation, through the loss of others. Levinas, for example, thinks that the Other interrupts Heidegger's theory of death as a relationship internal to being (1987). Levinas's concern is that because Dasein understands itself as a possibility of itself (Heidegger 1962:33) it is its own meaning-bestower and things can become instrumentalised according to their possibilities for Dasein. Levinas sees the natural conclusion of this argument as National Socialism. For Levinas, ethics always precedes ontology, and the ordinary and the everyday, which for Heidegger are 'inauthentic', is where the ethical encounter with the Other takes place:

Why does one buy a watch? ...not because I am hurtling towards death, or because my existence is a 'being-towards-death'. I buy a watch because I need to make sure I am at the station on time or to be at a meeting with colleagues or friends. I need a watch because there are other people, and time is not my own (Purcell on Levinas 2006:83).

Levinas's accusation that Heidegger's Dasein is only concerned for itself is troubling. It is relationships with others and dealing with the pragmatics of illness which most affects the daily lives of the patients in the day centre. Although the vicissitudes of illness mean that patients, in theory, have time on their hands to contemplate their 'being-towards-death', in reality they are often preoccupied with "getting on with things" and "taking it on the chin". Perhaps this is why Levinas (2003:55) cites transcendence as the ability to "get out of being" and "to break the chains of the I to the self" rather than Heidegger's notion that it leads to some supreme authenticity of selfhood.

For *Rosetta Life*, witnessing other people's deaths is just as important as the 'self-to-self' contemplation of one's own death. As Colvin (2004) and Ross (2003) both point out, 'giving voice' requires 'being heard', testimonies require to be 'witnessed' and a shift in self-perception often requires a shift in other people's perception of

you. Contra Heidegger, these writers argue that the production of an “authentic self” *can* be enhanced by the recognition of the death of Others, and herein lies the more political dimension to *Rosetta Life*’s mission. Veena Das argues that pain is not something inexpressible that destroys communication (as famously argued by Scarry (1985)), but rather is a claim (made in a cultural register) asking for acknowledgement and recognition, which of course may be given or denied. To this end, an expression of pain “is not a referential statement that is simply pointing to an inner object” but is rather, following Wittgenstein, about the (imaginary) experience of another’s pain inside your own body (1997:70). Equally, eliciting testimony, as *Rosetta Life* does, is about seeking recognition and acknowledgment of patient’s experiences and frustrations, as Claire does with her poetry via Chris her “confessor”. The charity’s mission is to try and find a formula of expression that cuts through the “insurpassable distance” (Perrin 2004:133) between the one who is dying/suffering and those who are not. Das’s interpretation would suggest that soliciting this recognition is not an appeal to the intellect, but rather an appeal to the imagination (1997:80). *Rosetta Life* may make intellectual films, but they are ultimately intended to appeal to the collective imagination or spirit. Dying does not just present an opportunity for authenticity and a reflection on the ‘self’, as Heidegger assumed, but it also presents the chance to gain final recognition from others. The appeal to recognition by others in our ‘being-towards-death’ will be the focus of Chapter Four.

Conclusion

At the start of this Chapter, I outlined *Rosetta Life*’s goals in the context of the modern hospice movement. As people live longer with chronic illnesses- a shift from ‘dying of’ to ‘living with’ – they also have a longer period during which to anticipate their own death. The rest of the chapter was devoted to the ways in which patients at the day centre and participants in *Rosetta Life* projects do and do not (or can and cannot) speak about dying. In the period of ‘living with’ life-limiting illness, new socialities can emerge, attendant on people’s biographies-in-illness or biographies-in-dying. In the hospice day centre, there was also non-sociality (as opposed to a ‘lack’ of sociality) as manifested by boredom or silence. These spaces were often filled

with day centre “jollification” or games of Bingo. *Rosetta Life* too wants to fill these spaces. For the charity, death is not a limit to communication, but rather makes communication even more vital and profound. Creative engagement in the arts, they believe, can offer transcendence or personal transformation for the patient. This idea of transcendence and of the *Rosetta Life* artist as healer or shepherd undoubtedly has echoes of the Christian treatment of the dying.

Artist-in-residence Chris makes films with patients by eliciting personal testimony from them. He tries to offer Asclepian attentive listening and healing focusing on the uniqueness of the individual. But as his relationship with Bob and his Asclepiads shows, he is indelibly drawn to structures of the human mind just as he is to filmic structures and narrative conventions. This reveals a tension between identifying the specifics of an individual’s life and circumstances and wanting to make more general claims about universal processes and stages (Walter 1994). The singularity of human experience is often dissipated through the use of prescribed cathartic formats and attempts to speak for the many. *Rosetta Life* hopes to discover an “authentic” or sincere ‘self’ that can be represented accurately on film. But in the final part of this chapter I asked how far “knowing oneself” or one’s place in the world through *acting* in the world has been replaced by thinking oneself and verbalising oneself into a ‘sincere’ existence. It is in the next chapter that I want to turn to the ways in which *Rosetta Life* also aim to facilitate an *acting* in the world, when they go about making people’s testimonies public.

CHAPTER FOUR

Rosetta Life: Public Witnessing and Recognition

In man, the struggle against the erosion of time, fixes itself in a privileged manner upon the image (Morin 1985:32).

The charity *Rosetta Life* was named after the Rosetta Stone, the ancient Egyptian artefact which was the key to deciphering hieroglyphic writing. “Rosetta Stone” is now idiomatic for something that is key to a process of decryption or translation. *Rosetta Life* then, in its very choice of name, conveys its desire to use individuals’ testimonies as templates to highlight or decode more general themes about what it means to be living with life-limiting illness. While the charity does underscore its appreciation of the fact that many patients simply want to use their art to restore their self-esteem “on a personal level” (Jarrett 2007:xi), there is undoubtedly a strong belief that the art produced can become a form of public testimony:

Personal creativity also has a public and political role in enabling people to choose whether or not to get more involved in the places where they receive care. The arts can make an effective public statement (Jarrett 2007:x).

It is the quest for public recognition of individual experience that extends the scope of *Rosetta Life*’s enterprise beyond the intimate realm into public life. Imprinted on the artwork created by the charity is the relationship between the patient and the artist, the relationship between the patient and their multiple selves, and the relationship between the patient and their wider social world. What is *extrinsic* to the artwork, on the other hand, is the context in which the art is shown and the reception it is given by an audience. That audience could consist of fellow patients in the hospice day centre, the Mayor’s advisors at London’s City Hall, or unknown visitors to the *Rosetta Life* website. Neither the artist, nor the patient, can control the context in which their art is viewed (there will always be mediating factors), or the reception it is given. Once the art is witnessed by people other than those involved in its creation, it can assume a life perhaps unintended by its creators, and its meaning can change. It becomes involved in a public, political discourse on dying. However, it is

only by reaching out to the wider hospice community and beyond, to the general public, that *Rosetta Life* hopes its “Rosetta Stone” templates will assist in “changing the representation of the dying” (Jarrett 2007:xi). Through their projects, the uncertainties and contingencies of personal experience are transformed into an accessible narrative, and the individual becomes metonymic for collective views and experience.

The move here is one from eliciting testimony to eliciting recognition, or bearing witness to the testimony presented. As Derrida states, testimony can never be guaranteed in advance because it requires to be witnessed (2005:68). Making their testimony public is one way that patients may envisage they can ‘transcend’ their own intimate lives and connect with collective concerns. Das (1997) claims that in speaking out about suffering we are asking for acknowledgement of our pain from our community. Only by receiving this acknowledgement are individuals capable of self-realisation and, if one takes a psychoanalytic approach, self-esteem (Honneth 1995). If striving for authenticity, as discussed in the previous chapter, calls on me to discover my “ownmost potentiality” (Heidegger 1962) that is inwardly generated (perhaps with the help of a *Rosetta Life* “confessor” figure), then in seeking recognition I acknowledge that my identity depends on inter-subjective, dialogical, or mutually-constitutive relations with others. For those patients who want to speak out and communicate their experiences, there is a desire to move beyond their own thinking and reflecting ‘self’ and venture into the world of others also facing their own deaths. Heidegger states that to live the good life is to live “authentically” by accepting our own mortality. But he was also a firm believer in the importance of linking ontology with ethics (1977:235): that there is a place for making claims about how a person *ought* to approach his or her mortality. *Rosetta Life* too is attempting to challenge and influence the healthcare community and public attitudes more generally, offering ways in which mortality *ought* to be approached, and not just by those who have daily reminders of it. The charity wants to challenge the public’s expectations of the kind of roles which befit people with life-limiting illness. It is using the arts to deliver a message. The question is: how far do other audiences, outside of *Rosetta Life*, accept the charity’s sentiment that living with a life-limiting

illness can bring a heightened sense of meaning and self-knowledge? The most commonly reiterated sentiment at *Rosetta Life* events is that “the dying can teach the living how to live.” In this chapter, I want to analyse what form this teaching can take and how receptive different audiences are to the use of normative Rosetta Stone templates.

If Chapter Three was about how people do or do not talk about dying and give testimony about their experiences, this chapter is about who is listening. Claire, whom I introduced in the previous chapter, was one of the first *Rosetta Life* participants whom I encountered. Observing her reactions when watching the films of herself, especially given her drastic physical deterioration since they were produced, I could see that she was very moved. When she came into the hospice for respite whilst her partner was on holiday, she brought the DVDs with her and would try to find any opportunity to show them to the nurses. The films and poems seemed to communicate something about her predicament that she felt unable to convey herself. She wanted to secure an audience for her testimony, and, I would suggest, recognition (as opposed to pity) from that audience for her many frustrations.

But how were the films received by the audience she so persistently sought out? Neither the poems nor “The Mariners” musical are overtly downbeat or emotive. In the poems, Claire’s wicked sense of humour shines through, while in the musical, the score itself is uplifting, even if the words (“crying my Niagara” for example) express sadness. When Claire asked one nurse “have you seen my films?”, the nurse replied that she had already seen them and that they were “very moving; really very good.” Another nurse who passed by said she hadn’t found time to watch them yet, but would try to later, and was sure she would enjoy them. But how do we decipher whether the audience is sincerely engaging with Claire’s testimony? And what happens if the content of the films is more downbeat? If *Rosetta Life* is trying to challenge audience expectations of sick and dying roles, then do they also take account of the expectations the film’s participant has about the audience’s reactions? Claire’s frustrations and fears did not appear to have been assuaged by the nurses’ responses to her films. Recognition, if she finds it, will never bring a cure for her

MS, and this is what she desperately wants. This is a limit to the *Rosetta Life* enterprise that Claire appears to have difficulty accepting. When she showed the films to me, or when I witnessed her showing them to others, it seemed as if the viewing acted as a launch pad for more venting of emotions. This begs the question of what does recognition look like and how can we tell whether it has really changed a person's self-esteem, or their authentication of 'self', in their 'being-towards-death'?

This chapter begins with a discussion of some new initiatives by professionals in palliative care and the care home sector. These initiatives contextualise *Rosetta Life*'s aim to find an audience outside of palliative care for patients' testimonies, and indicate that, while unique in its set-up, the charity's is not a lone voice. I then move on to examine reactions to *Rosetta Life* projects in various different 'publics': the hospice day centre, a theatre workshop, a well-attended funeral, and a profile-raising debate at the *Greater London Assembly* (GLA) in central London. In all these different 'publics', I ask what patients themselves hoped to gain from going public with their testimony. And how was their testimony, delivered in the medium of film, drama, or debate, received? I critically analyse theories of recognition and witnessing and some of the impediments *Rosetta Life* and their participants face in securing either. In Chapter Three I discussed the Heideggerian quest for "authenticity" of 'self'. But in turning outwards from the 'self', one seeks not authenticity, but authentication from an Other. This chapter is about new ways of fostering a shared context for a discourse about dying.

New Initiatives

In recent years, there has been a decisive move to try to increase patient choice and person-centred care within the *National Health Service* (NHS) in the U.K. The model is a consumer driven one in so far as British citizens, who pay for the NHS through their national insurance contributions, are deemed entitled, as consumers, to make demands on those services with which they come into contact. This move towards person-centred care has had a direct impact on the development of what is called "narrative based medicine". This is considered a "holistic", hermeneutical approach

that aims to listen to people's biographies-in-illness and then repackage them in the form of a 'medical history', admittedly a Hippocratically structured and standardized format. Greenhalgh & Hurwitz (1999) argue that the lost tradition of narrative should be revived in the teaching and practice of medicine:

The relentless substitution during the course of medical training of skills deemed "scientific" - those that are eminently measurable but unavoidably reductionist - for those that are fundamentally linguistic, empathic, and interpretive should be seen as anything but a successful feature of the modern curriculum (Greenhalgh & Hurwitz 1999).

They argue that in curative medicine, the process of hearing narratives may help the doctor uncover diagnostic and therapeutic options. In palliative care, which aims at healing rather than cure (Randal & Downie 2006:6), it could be used to even greater effect. *Rosetta Life's* Jarrett sees links between personal storytelling (or giving testimony) and narrative based medicine:

The development of narrative based medicine is a good example of how doctors and patients can collaborate in the development of simple strategies to build bridges between finding voice and user involvement (Jarrett 2007:xiii).

Rosetta Life's rhetoric continually aligns these two aspects - "finding voice" and "user involvement" – because its aim is to empower patients to see themselves as "active participants in their narrative" (Jarrett 2007:xiii). While it is questionable whether narrative based medicine has had any mainstream impact on the evidence-based paradigm within medicine, there are some narrative-based initiatives, including *Rosetta Life's* work, being developed on the periphery. Many would agree that palliative care practitioners, with their focus on healing, would be ideally positioned to develop some of these methods. After all, Cicely Saunders's concept of "total pain" was developed from listening to patients' illness narratives and essentially allowed for a more subjective, holistic understanding of suffering, rather than one exclusively defined in terms of physical pain (Clark *et al* 2005:2). Two particular, and very different, initiatives highlight this trend towards using and developing narrative-based care.

Professor Malcolm Johnson, a gerontologist, has spent the last decade working in care homes trying to train care home workers to listen to the testimonies of the residents, many of whom are in their nineties. In devising his training package, Johnson coined the term “biographical pain”, by which he was referring to the distress experienced by people with endless time to think about their life mistakes and regrets, but no capacity to make amends (Johnson 2007). Through Johnson’s experience of working with hundreds of elderly care home residents, he believes that this “biographical pain” prevents many from dying good deaths. The training he advocates is focused on developing empathetic listening to people’s life stories, without falling prey to Hippocratic pressures to ‘patientise’ or ‘pathologise’ people and their experiences. Johnson believes that in simply saying to elderly care home residents “I want to hear your story” and then “positively reframing” it, care workers can facilitate the easing of “biographical pain” and improve the chance of a good death. This initiative may appear like therapy in a new guise, but the care workers are not trained therapists. They are being trained to give people recognition for lives lived and stories told.

Another initiative, developed in 2007 by the Birmingham Palliative Care Network and funded by the U.K. Arts Council, aims to use storytelling as a methodology to “empower communities and individuals to articulate their needs, talk about their experiences, to improve End of Life Care” (Smith 2007). The rationale behind the project is that, in the absence of a religious framework, communities lack a meta-narrative for giving death meaning and a new community framework needs to be established if meaning is to be regained. The project enlisted the skills of a “professional storyteller” to “hold a creative space” (reminiscent of *Rosetta Life*’s “holding” of people’s stories – see Chapter Three) and guide participants receiving palliative care to tell their stories. A “wrap-around’ collective story was then produced from the individual stories and fed back to the community via local community newsletters, the distribution of audio CDs and postcards, and via a

website¹⁶. According to the project leader, the storytelling was not supposed to be cathartic or therapeutic for the individuals involved, but was “to be used as a community resource to support the public in decision-making around their own dying” (Smith 2007). The ultimate aim of this initiative was to “empower” some of Birmingham’s most disadvantaged and ethnically diverse communities to articulate their end-of-life needs.

Both these initiatives appear to echo some of *Rosetta Life*’s working principles and aims: empathetic listening to heal biographical pain; storytelling to fill the vacuum left by the absence of a meta-narrative about death and dying. They use similar language (“giving voice” for example) to describe their efforts and all protest that their engagement is not therapy but rather attentive listening of the Asclepian kind. Both projects highlight that *Rosetta Life* is not the only organisation devoted to harnessing the power of testimony at the end-of-life. However, these projects also raise a number of questions. Can people be healed purely by virtue of being listened to? Are all patients concerned with unburdening themselves in their ‘being-towards-death’ or do some simply want to ‘get on with things’ and engage in day-to-day practicalities? And how does putting an individual’s story on a website or in a community newsletter re-establish a community narrative about what one can anticipate at the end-of-life?

Since the seminal works of Gorer (1965) and Aries (1974), which identified a taboo on death in Euro-American societies, academic discussions have centred around ways of bringing death and dying back into public discussions and public consciousness. For example, a new Centre for Death and Society was established at Bath University in 2005 as a response to the growing society-wide impetus to bring death out of “the ghetto”, where Baudrillard (1993) located it. As the Director of the Bath Centre, Glennys Howarth, says:

¹⁶ Personal Communication with Pauline Smith, End of Life Care Lead, NHS West Midlands (see <http://www.wellbeingindying.org.uk/stories.htm>, accessed 10th January 2010).

Public and academic interest in death has developed rapidly over the past decade, and people are increasingly thinking about death in new ways (Wignall 2005).

The new narrative-based initiatives I have cited are part of this wider “revival” (Walter 1994). But the question remains: to whom are these projects appealing? And who is responsible for initiating a change in public attitudes? Tom Gordon, the Chaplain at the Marie Curie hospice in Edinburgh, expressed his opinion that hospices cannot be responsible, or even regard themselves as being responsible, for pioneering new attitudes towards the dying. It is his view that their role is to deliver excellent care for individuals with life-limiting illness, and although this may have the incidental effect of reducing the fear for family members, should they need to engage hospice services themselves at some future point, it does not directly involve the local community or “get death talked about” outside of the hospice¹⁷. According to Gordon, hospices aim to cater for the needs of individuals, not to make death more visible in wider society. Clark *et al* reflect a different opinion, claiming that hospices are part of a social movement which “may well have contributed to a new openness about death and bereavement in evidence in the late twentieth century” (2005:3). *Rosetta Life* is one very small part of the death and dying puzzle (they only have 20 hospice residencies, and hospices only cater for 4% of those who die each year). However, some of the issues *Rosetta Life* artists encounter in their work are indicative of broader tensions and confusions when providing for individuals and when trying to “get death talked about”.

Suffering

In my first meeting with Lucinda Jarrett, artistic director of *Rosetta Life*, we discussed the research proposal I had submitted to her in which I requested a voluntary placement with the charity. In my proposal, I wrote: “I am interested in studying how you use art to make public private suffering.” Jarrett immediately contested my use of the term “suffering.” She told me that *Rosetta Life* was focused on “empowering” the dying person, helping them to think positively about their

¹⁷ Tom Gordon, Personal Communication, April 2008

experiences and “awaken” them to the new facets of the ‘self’ that can be discovered by way of those experiences. They were certainly not about “making public private suffering.” Throughout my ethnographic engagement with *Rosetta Life*, the term “suffering” was noticeably absent. This is perhaps what Johnson, in his training of care home workers, would call a “positive reframing” exercise. It is my understanding that in resisting the term “suffering”, Jarrett and her co-artists are not denying that hospice patients can and do suffer, but rather that *Rosetta Life*, as an organisation, does not want to cast people as passive victims in their illness narratives. Through their creative work, the artists want to construct an alternative narrative to one of suffering, one that focuses on the positive contribution the dying can make to society and on their creativity and vitality, rather than, say, trying to elicit sympathy or pity. But equally, the reluctance to use the term “suffering” could be deemed by some to be a part of the ‘palliating’ (from the Latin *pallium*, meaning ‘to cloak’) of people’s experiences, and so to run contrary to their professed ideal of ‘giving voice’. Again, perhaps it is more a question of what is being communicated by that voice.

Das (1995), in her work on recent “critical events” in India, highlights the conflict between ‘victims’ narratives of suffering and the discourses on suffering developed by various institutions (both state and community). For Das, the “critical events” which created these victims also momentarily made them visible and provided a potential space for them to ‘give voice’ to their experiences (1995:17). However, because the institutional and state forces at work were concerned primarily with shoring up their own legitimacy, they created a discourse on suffering which managed to deny the authenticity of the individual victims voices (1995:22). Das’s victims of India’s Bhopal disaster may appear a far cry from patients using a U.K. hospice’s services. However, it is interesting that Das’s contention is not with whether the people she describes are suffering, but rather with the lack of acknowledgement from state and community institutions for that suffering. In *Rosetta Life*’s case, and one could say more generally in hospice discourse, if suffering is voiced by patients, it is translated into a narrative of “empowerment”, of active participation, and even of transformation itself. In this case, when suffering is

acknowledged by institutions, it is relabelled and then fed back to the patient in a positive reframing exercise, described by Johnson (2007). This is what *Rosetta Life* hopes will happen when participants become involved in a project and then watch the finished film with an audience, whether that be their family, the hospice day centre, or an unknown audience at a public event. However, given that suffering is expressed by people in a multitude of ways, how far can *Rosetta Life* legitimately reframe patients' words and experiences and be certain of retaining their 'authenticity'? Lawton (2000), in her ethnography of "unbounded, leaky bodies" in a U.K. hospice, asked if there are absences and silences within the hospice revival of death which tend to cloak the more unpalatable experiences of dying? *Rosetta Life* is involved in complicated processes of translation and representation, in part because of their didactic aim to change how dying is perceived in the U.K. But is there ever a danger of mistranslation, whereby reframing efforts can inadvertently turn into an act of cloaking?

Aversion

Artist-in-residence Chris holds what he calls "celebration events" at the hospice in South East London a few times a year. I was present for two of these during my fieldwork. Chris told me that he has to think carefully about which films he shows at these events in order that they do not give rise to emotions that cannot be contained or managed responsibly. He pulls down a projector screen in the middle of the day centre, and as patients wander back from lunch he calls their attention to the films he is about to show. If patients do not want to watch, they have to actively remove themselves from the main area of the day centre. The nurses and volunteers also sit down to watch. On one occasion, Chris chooses to show a film about a hospice resident who recently died, but had been 'living with' Motor Neurone Disease (MND) for a number of years and was a regular in the day centre. Before becoming paralysed by his disease, the patient was a professional cello player. Chris had arranged for a cellist to come to the hospice to play for him – to act as his hands – and had made a film about the patient's reactions to watching him play. Needless to say, the film was emotive, even more so when playing to an audience who had known the patient featured in the film for a number of years. As the film plays, the

nurses seem to be keeping one eye on the film, and the other on patients' reactions to it. Chris decides to switch the film off half way through, saying it is too long to show the final section. Indeed, a couple of patients have nodded off (possibly a morphine-induced slumber). Chris had told me earlier that when showing challenging films, knowing how far to push an audience and when respectfully to hold back was something that could only be gauged from experience and intuition. He told me that he felt he could read people and knew intuitively how far constructively to challenge people, to try to elicit some recognition, and when to disengage. Switching his film off half way through could have been just such an intuitive act of disengagement.

The next films he shows are part of the *Rosetta Requiem*. This is where patients work with famous musicians to turn their testimonies into songs. One of the films he shows is called "We Laughed", another is called "Life". The names of both songs are indicative of their upbeat tone, despite their 'heavy' content. Presentation, it would seem, is important. When the viewing comes to an end, a number of patients approach Chris to get CD copies of the songs, which he duly distributes. He then asks them what they thought of the films. There is a silence. One man speaks up and says he thought they were sad. Chris prompts him as to why he thinks that. Silence again. Chris explains the background to "We Laughed"- a song about a mother diagnosed with cancer celebrating her relationship with her teenage daughter. The song actually became a Top 20 U.K. hit. He suggests that perhaps we, the audience, can find comfort in the expressions of other people's sadness. Another man in a wheelchair stirs: "it made me think about what might be lost." I am impressed by his honesty and assume his comment will open up the discussion. I had spent the earlier part of the day helping him buy some jewellery on the internet for his girlfriend. But nobody else sees fit to respond, so his words just hang in the air. Chris decides to wrap up the event quite quickly, sensing the awkwardness creeping in as he struggles to elicit a reaction from other patients. After a short lull, a volunteer starts setting up for Bingo. Bingo tickets displaying random numbers are distributed. "Eyes down!", says the number caller. The number 11 comes up on the automatic random number generator. "Legs Eleven!" she calls out (the slang term for the number 11, thought to look like a pair of legs). Everyone wolf whistles.

“Aversion” means a strong feeling of dislike of somebody or something¹⁸. When I first met the head nurse at the day centre to discuss my project, she told me that what they (the staff and volunteers) were primarily interested in was “aversion”. At the time, I assumed that she had meant “averting” in the sense of preventing anything harmful occurring to the patients in her care. I wonder now whether the nurse’s use of this term could be considered a Freudian slip, in the sense of an institutional “aversion” to or dislike/fear of death. Throughout that first meeting with the nurse, I also wondered what the staff thought of *Rosetta Life*’s work and the service Chris was providing for patients at the day centre. The slightly apprehensive reaction I detected from them to the celebration event I have just described is, in my view, indicative of an institutional preoccupation with both protecting patients (averting potential harm) and not eliciting from them emotion that cannot be contained or controlled. Chris and other *Rosetta Life* artists also worry about the potential harms of eliciting emotion in an irresponsible way. Chris told me that it is part of *Rosetta Life*’s mandate to engage “safely” with patients’ emotions, for example, through watching emotive films. The difference here may lie with the fact that Chris generally works with patients on an individual basis, relying on the personal relationship he has built up over weeks of one-to-one contact, to judge how far he can responsibly stimulate that individual’s emotions. Chris has a relationship with his participants outside of the institutional setting, spending time in their homes, or at filming locations. The day centre staff, on the other hand, are responsible for all the day centre patients at all times. At *Rosetta Life* celebration events the staff are understandably concerned that if one patient discloses their feelings or emotions, others may feel themselves being *coerced* to do so, or may feel their emotional state destabilised by hearing and witnessing other patients’ confessions. Staff feel they have a duty of care to those who may resist this role of witness, a responsibility for the well-being of the collective. The on-screen testimony has the potential to elicit further spontaneous testimony from those patients willing to act as witnesses. These celebration events are not supposed to involve passive spectatorship, but rather active

¹⁸ Random House Dictionary

and engaged witnessing. However, it is their potential for stimulating unregulated emotion to which the staff at the day centre seemed to have an ‘aversion’.

Regulating Emotions

Utility demands that these outbursts [of feeling] should be foreseen and averted (Bergson 1911:158).

The other meaning of the term “aversion” is found in “aversion therapy” which is “designed to modify antisocial habits by creating a strong association with a disagreeable stimulus.”¹⁹ According to early sociological accounts, it is assumed that it is the institution’s role to modify and regulate what come to be collectively classified as “anti-social habits”. This might include the display of individual emotion which may threaten the stability or utility of the group. Consequently we are conditioned as to what are socially appropriate expressions of emotion. In Wikan’s account of the Balinese response to death and sadness, for example, donning a “bright” face is considered a social duty with public health implications (1990:xvii). In Wikan’s assessment, the expression of sadness and distress not only reduces one’s own life force (*bayu*) but also threatens to diminish that of others. The practice of laughing at funerals in Bali (people do *also* cry (1990:143)) is actually a means of regulating emotion - the destructive “feeling-thoughts” of the sufferer - and hence sustaining their *bayu* and that of kin and the recently deceased (1990:146). So reads the socio-centric account of collectively controlled and prescribed emotions.

Many of the interactions I witnessed in the hospice day centre demonstrated a definite reluctance to stimulate any form of emotional confession, at least in the open plan area (I was not party to private discussions in the consultation/treatment rooms). A volunteer told me one lunchtime about a particular piece of music she was trying to track down to play at her funeral. Although she had not heard it since she was a child, in her memory it was the most “emotionally moving” song she had ever heard. I suggested that if she eventually sourced a recording of the song, she should play it in the day centre for the patients. She replied incredulously: “Oh no, we could never

¹⁹ The American Heritage Dictionary, Fourth Edition

do that, it might upset someone!” This reluctance to engage with patients’ emotions presents a vacuum which *Rosetta Life*, through its artistic projects, seeks to fill. But despite emotional, cathartic engagement being its objective, *Rosetta Life* still has to operate within the institutional boundaries of the hospice, and in many senses, these compete with its aim. Protection concerns often override desires to open up spaces for ‘authentic’ reflection. While the higher authorities in this particular hospice and the hospice movement more generally may support the shift in emphasis that *Rosetta Life* tries to promote, the staff and volunteers who have to ‘manage’ patients on a daily basis may feel slightly differently towards their aims. Their main concern, after all, is to maintain the general functioning and harmony of hospice services in a careful balancing of needs.

“Jollification”, as discussed in Chapter Three, I consider to be another means by which the hospice staff and volunteers manage patients’ emotions. As in Wikan’s account of Balinese well-being requiring a “bright face”, so “jollying” patients along in the hospice encourages them to keep upbeat and dispel potentially depressing thoughts:

“Manage your heart better”...is an injunction that safeguards community life and communal relations. But there is no doubt in the minds of Balinese that the individual is also best served this way (Wikan 1990:171).

“Jollification” would also be encompassed by Sennett’s definition of “civility” as that type of activity that shields people from having others unburdening themselves to you (1974:264). “Civility”, for Sennett, is society’s means of regulating a compulsion to become intimate, while still allowing people to enjoy each other’s company. Like Svendsen’s (2005) critique of the Romantic disavowal of boredom as time that lacks personal meaning, Sennett believes this compulsion to become ‘intimate’, also influenced by Romantic ideals of self-realisation, has destroyed our belief in the value of an impersonal and diverse public world (1974:6). Hence our world has become “uncivilised” as we have lost our respectful distance from one another. “Jollification”, on the other hand, could be understood as a way of maintaining a respectful distance. Undoubtedly, individual patients want to ‘fit in’

with the prevailing atmosphere. No one wants to be singled-out or ostracised from the group by showing explicit resistance to being “jollied along”. According to Bergson (1911), comedy or laughter acts as a social corrective to “absentminded” and inflexible individuals in society. Society is suspicious of separatist tendencies and the social gesture by which it aims to restore sociability is laughter or poking fun (1911:18). Bergson also notes that laughter is incompatible with emotion (although one assumes that for the purposes of his argument he does not include happiness, the emotion most commonly associated with laughter) (1911:139). When we experience sympathy, pity or fear, we find it impossible to laugh, writes Bergson, and it is the job of laughter to exterminate those (negative and socially-destructive) feelings²⁰. “Jollification”, for Bergson at least, would be a way of preventing excessive focus on particular individuals’ emotions and bringing “separatist” minds back into the realm of sociability.

The nurses were keen to maintain a buoyant atmosphere among the group. They would regularly and in loud voices poke fun at individuals’ idiosyncrasies, especially those of well-known “characters” in the group, who would always respond humorously. This banter would put an immediate end to any serious discussions, and as Chris acknowledged to me, it acted as an impediment to any weighty engagement with individual stories he may have been hoping to initiate.

Humour was also initiated by the patients, however. One male patient saw a nurse taking a blanket over to a female patient on the other side of the day centre and commented: “I thought she had died!” (-implying the blanket was being used as a shroud). Nobody heard the comment except the nurse and me, and the nurse clearly did not know how to respond. This to me demonstrated a more subversive use of humour that, while still making light of possible tragedy in order to diminish any sad emotions, also made a direct reference to the “elephant in the room” – death. The nurse’s response was partly conspiratorial –supporting the use of humour for “jollification” - but also showed discomfort – the humorous reference drawing

²⁰ One wonders then how a film such as Roberto Benigni’s *Life is Beautiful* could use laughter to underscore the horror of a Nazi Concentration camp in World War II.

attention to that which jollification is intended to divert attention from. Langley-Evans and Payne, in their ethnography of a hospice day-centre, also mention the use of “light-hearted death talk” and humour that they describe as a “psychological defence mechanism” (1996:1096). They argue that this form of sociality imposes limits on patients’ awareness of dying, protecting them against the fear of death. Hockey, in her ethnography about dying in a residential care home, puts it more eloquently:

Residents’ oblique, sometimes humorous, statements represent a powerful challenge, either to care staff or to the institution as a whole. In response to jokes made by residents about impending death, staff struggle weakly for another joke which can effectively counter, and diffuse the power of this embarrassing honesty (1990:124).

Subversive jokes, like the one about the blanket/shroud, give some agency to patients without causing them to be ostracised for excessive displays of emotion. Such jokes were also designed to promote conspiratorial feelings of intimacy between the teller and listener. Bergson’s argument about humour only focuses on its use as a social corrective or leveller and ignores the fact that humour can also create feelings of intimacy among strangers. However, while patients, staff, and volunteers in the hospice may in one sense be intimate strangers, in another the “jolly along” is directed purely at keeping patients socially buoyant (happiness being a welcome secondary effect!).

Managing patients’ emotions through jollification is a way to prevent individuals from becoming overly reflective and withdrawing from the group. Social responses are disciplined through jollification. In a similar way, Hirschkind (2001) has discussed the ways in which notions of Islamic piety are imbued in believers through the disciplining of a range of social behaviours. He specifically examines how piety is inculcated through a type of self-scrutiny and “ethical self-discipline” promoted by listening to tape-recorded sermons. He writes of people’s sensory responses to the sermons, as they are encouraged to listen with their heart and not just with their ears (2001:639). Listeners are encouraged to repent and to develop their “moral reflexes” through an “emotional-kinesthetic experience of a body permeated by Islamic faith” (2001:628). Here, emotional discipline helped to embody a normative model of

Islamic moral personhood (2001:640). In the hospice, I suggest that emotional discipline is practised in order to keep spirits high and prevent excessive focus on individuals and individualised death, and to maintain a buoyant personhood in the face of individual decline and deterioration. This is another reason why jollification works against *Rosetta Life*'s aim to focus on what is unique about the "transcendent individual."

It is my contention that hospice users are guided to the correct responses in social interactions by way of jollification and the avoidance of certain issues, like how close to death they might actually be. However, it is clear that the disciplining of the Islamic 'self' is a continual and embodied process whereas hospice jollification is only experienced once a week when patients come to the day centre. This allows for the possibility of outside ruptures in the day centre's patterns of avoidance (although this is not to say that patients do not experience jollification in other social settings and, indeed, it is likely that they do). The embodiment of Islamic ideals identified by Hirschkind depends heavily on self-scrutiny and it is difficult to tell to what degree day centre patients have interiorised the types of avoidance patterns I outline. One could speculate that the day centre is a microcosm of the society-wide reluctance to talk openly about death, the "taboo on death" thesis I discuss in the Introduction, and that patients have internalised that reluctance which is further perpetuated by the "jolly along" of the nurses and volunteers. Speculations aside, it is clear that *Rosetta Life* is trying to inculcate its own type of self-scrutiny or disciplining, but this time based on a confession of the 'self' model, with creative and emotional liberation as its goals.

Emotive Spectatorship

For Bergson, emotions like sympathy, pity or fear "exterminate" the possibility of laughter (1911:139) and draw our attention away from comedic 'character-types' (those at whom the nurses most often gently poke fun) to what is individual and unique. Moretti (1983) and Sontag (2003) have another perspective on the role of emotions, but this time in relation to how they affect the witness. For Moretti, when we cry or have involuntary emotional responses to provocative images, we are

actually insulating ourselves from what we are seeing in a “ritual of reciprocal collective absolution” (1983:173). On a similar note, Sontag asks whether it is not better to have an unsentimental response to witnessing the pain of others if “our sympathy proclaims our innocence as well as our importance” (2003:91). By this rationale, expressions of sadness when watching Chris’s films actually absolve people of the need to reflectively engage with what they are seeing and hearing, which reduces their capacity to act as effective witnesses to the testimony. Sontag’s argument about the relationship between photography and witnessing is essentially directed towards Debord’s critique of the “society of the spectacle” (1977). She criticises people’s desire for absolution when passively viewing images of atrocities in the non-Western world, and challenges people to see beyond tears and compassion to acknowledge their complicity. Sontag’s thesis, therefore, supports a move from believing in the value of emotional states to believing in the utility of emotion-centred action. This reiterates the tension highlighted in the last Chapter between looking inward in a quest for authenticity of the ‘self’ and turning outward to perform that ‘self’ in solidarity with others.

According to Aaron, emotive spectatorship encourages people to assume a moral perspective rather than engage ethically (2007:117). Ethical responses are based on recognition, realisation and reflection, whereas morality is about prescription, proclamation and punishment (Aaron 2007:109). Is Chris’s job to promote ethical reflection and recognition, or to offer a new normative script for the dying? Should his films seek to emote or not? In the Introduction I mentioned the very public death in 2009 of the reality TV star Jade Goody and I asked how *Rosetta Life* films differed from the TV documentaries depicting her last days. Clearly the sensationalism of these documentaries is not something to which *Rosetta Life* would aspire. Yet these documentaries garnered massive audiences and in obituaries to Goody she was praised for “prompting many more women and men to contemplate the certainty of their own death” (Brooks 2009). Is this not also *Rosetta Life*’s aim: to “change the representation of the dying”? *Rosetta Life* films, of course, have more artistic merit than a “Living TV” exposé. But do they not also seek to distance the viewer from the person on screen in order to elicit responsibility rather than cheap emotional

sensationalism? This move towards responsibility is founded on the ability to recognise that person and to recognise one's own needs and desires in that other person. As Butler states when she argues for acknowledgment of our global interdependency: we need to step outside of first person narratives and recognise our ethical responsibility for the other (2004:44).

By using the term of 'responsibility' I do not wish to imply that day centre patients are responsible for their fellow patients' pain. Rather, I want to suggest that because of the bio-sociality in the day centre, there exists a sense of being responsible for ensuring each other's 'good death' experience. For example, one patient thought it was her duty to try to overcome her fellow patient's long-standing denial about the severity of her disease. This involved phone calls to her at home and multiple attempts to discuss her illness openly with her. Through recognising the severity of her friend's illness despite the latter's lack of self-recognition, this patient wanted to encourage her friend towards an awareness that she was dying and therefore towards a 'good death' experience²¹. But in order to feel a sense of responsibility for one's fellow hospice users, it is necessary to feel that one is *in* the world, and *part of* the world. This is a pre-requisite for engaging in the type of emotion-centred action advocated by Sontag. However, the problem for many people 'living with' life-limiting illness is that they no longer feel part of the world of action. Their lack of energy and physical ability to do things, coupled with their emotional withdrawal (or "dulled resignation, apathy, lethargy and exhaustion" (Lawton 2000:80)), makes the fostering of a sense of responsibility more of a challenge in that it requires an *active* engagement. Pain, for example, is known to have an individuating and isolating effect (Jackson 1994) and often makes a person withdraw into himself. It seems likely that the 83 year old woman who told me "I'm just waiting for him [God] to take me now" had already withdrawn from the world and could not be expected to feel a sense of responsibility for her day centre companions.

²¹ In Kubler-Ross' classic book "On Death & Dying", acceptance of dying is the fifth and final stage of the journey towards the 'good death,' following denial, anger, bargaining and depression.

The theories of emotive spectatorship advanced by Moretti and Sontag, therefore, may not entirely hold when applied to day centre patients watching films of fellow patients. Partly, as I have just described, because it may not be a fair expectation to have of very poorly people. Patients also may not be able to avoid becoming emotional when watching a film of a fellow patient who may have been a friend. Equally, their death is likely to remind them of their own imminent death. Displaying emotion cannot ‘let them off the hook’, because their own illness acts as a reminder of their shared circumstances. In some instances, the subject seeking recognition through filmed testimony – the viewed - sits alongside the viewer as witness. Interestingly, this may have the effect of stifling the type of involuntary emotional response that Moretti and Sontag warn against (the “easy tears”) for fear of upsetting the film’s protagonist, who may very well be sitting right next to them. This could, in theory at least, move viewers beyond narrow feelings of sorrow and produce a more ethically engaged response. What will they say to that person when the film finishes? Will they see them in a different light? A response that achieves “recognition, realisation and reflection” (Aaron 2007:109) is what *Rosetta Life* ultimately hopes to elicit. Recognition is the key concept here, more useful than responsibility, with its moralising overtones. I want now briefly to explore some theories of recognition.

Recognition

Taylor (1992) traces the concept of recognition back to Rousseau in the 18th Century. Rousseau believed in the uniqueness of each individual, the importance of a person’s internal moral voice, and the need to strive towards an ideal of an authentic ‘self’, similar to that discussed in Chapter Three (Taylor 1992:27). But whereas Foucault traced this inward looking, ‘soul-searching’ trend to the rise of Christian confession, Taylor traces it back to Rousseauan politics. Whatever the origin, the rise of the authentic ‘self’ as a life project marks the beginning of identity politics, where one’s inwardly derived, personal, original identity strives for authenticity in an unequal world. It is only through recognition of this unique identity by others (fellow citizens), that true equality, according to Rousseau, is attained. Taylor notes that although Rousseau never uses the word “recognition”, this is what he is advocating when he calls for reciprocity, equality, and unity of purpose towards a ‘general will’

and freedom for all. Unfortunately, this freedom can come at the price of turning the 'general will' into a homogenising tyranny, as Taylor sees it, and this remains the conflict within modern liberalism: that between respecting differences between people while pursuing universalist, equalising aims. Taylor wants to escape this universalism/ particularism divide, particularly prominent in contemporary debates about multiculturalism, and return to the concept of recognition. Because one's identity is confirmed through "dialogical relations" with others, recognising another's equal but different identity actually confirms one's own. In other words, recognition by others actually constitutes the 'self'. His point is reminiscent of Arendt's "subjective in-between", which becomes the basis for dialogue between people and can join public and private interests (1958). Taylor finally argues for a "procedural" rather than "substantive" commitment to equality through recognition, a distinction first used by the ethicist Ronald Dworkin (1985). A "procedural" commitment, suggests Taylor, would require a presumption of equal worth without making "substantive" judgments about the *value* of people's differences.

Honneth's account of recognition is also an enquiry into the inter-subjective conditions for individual self-realisation (1995). Honneth views recognition as a way to attain self-esteem, that is, to view oneself as valuable in the eyes of the other. Following Hegel, he opposes Hobbes's mechanistic view of human nature, that humans are only motivated by rational self-interest, and instead presents an inter-subjective account (1995:9). Honneth identifies three ways we can recognise the other and also create the 'self': familial love, legal recognition, and solidarity. Legal recognition will be the subject of the third section of this thesis. Respecting another's legal rights may be part of the "procedural" notion of recognition. But in terms of *Rosetta Life*'s aims, Honneth's concept of "solidarity" is more useful. "Solidarity" is not about 'sympathy' but about shared concern:

Social relations of symmetrical esteem between individualised subjects represents a prerequisite for solidarity (Honneth 1995:129).

"Solidarity" is not just passive tolerance, but about felt concern for what is individual and particular about the other person (1995:128). The premising of "solidarity" over

sympathy here reflects Sontag's (2003) arguments about the need to withhold hollow sympathy in order to fully realise one's complicity in a shared world.

I identify *Rosetta Life*'s aim as one of pursuing "solidarity" through recognition in one's 'being-towards-death'. The "celebration events" demonstrate an attempt to reveal the dialogical or inter-subjective character of personal identity. Although they claim not to have a therapeutic aim, eliciting a positive response to filmed testimonies from the public (whichever public that is) can increase the filmed participants' self-esteem and, by Taylor and Honneth's rationale, the esteem of those who offer that recognition – the audience. The problem of *Rosetta Life*'s assumption of an authentic and concrete 'self', highlighted in Chapter Three, persists in these accounts of recognition because it begs the question of which potential 'self' of a multiplicity of potential selves (Khan 2006) is being offered recognition. There may be conflicts between how a patient sees himself and how Chris has depicted him in the film, for example. Equally, Chris cannot control how a particular audience receives the film and recognition may be unexpectedly withheld, as in the case of the previous "celebration event" which produced a very awkward response. Before I move on to discuss the difference between recognition and witnessing, I want to describe one more celebration event in the day centre that managed to elicit what could be considered "solidarity" from the patients.

Another Celebration Event

When Chris and I came into the hospice one day, a man called Derek started playing the harmonica. He played very well yet it transpired that he had never played in public before. Chris felt that there was something poignant to be captured in this wistful music floating across the day centre, so he decided to film him. The final film showed Derek playing his harmonica, with shots of other patients listening or generally going about their business. When the film was shown a month later in the day centre, the same patients sat down to watch themselves watching Derek playing his harmonica. Debord (1995) might have interpreted this as an example of modernity's need to turn something into a 'spectacle' in order to experience it as real or as interesting. But viewing themselves and the day centre in this way offered a

new perspective. The usually shy and increasingly ill Derek was thrilled to be the centre of attention and proud of his playing. It was the most animated I had seen him throughout the period of my fieldwork. The film had no words, but the music and accompanying images of life in the day centre intimated something that could not be spoken. When the three-minute film ended, people complemented Derek on his playing and he responded with pride. Watching the film together, and watching themselves and Derek on screen seemed to give a sense of the “solidarity” identified by Honneth (1995). The wistful and rather surreal qualities of the film could have provoked sadness and silence (as at the previous celebration event), but instead people could respond to Derek in person and the film revealed a new side to his identity. Derek certainly felt he had gained recognition for something he had been doing all his life, but which he had never shared in public and certainly he had never seen himself playing on film before Chris had made a ‘spectacle’ of it. Derek died a few months later and in this filmed performance he has become immortalised in some small way. This is his final unspoken testimony and when watched since his death, assumes a different significance.

However, I had been struck by the difference between the awkwardness apparent at the previous celebration event described, and the recognition granted Derek at this later one. This difference might have something to do with an appreciation of craftsmanship. Sennett (2008:9) writes that craftsmanship is the desire to do a job well for its own sake. The discipline and commitment required wins the craftsman respect and, argues Sennett (following Marx), it is through making things, bodily practices, and technical understanding that social relations develop. Craft differs from art because whereas the artist is turned in on himself and produces art in order to distinguish his own creativity, craft is a more collective pursuit that turns the craftsman outward to his community (2008:65). But with both art and craft the work is envisaged to transcend the maker (2008:294). In terms of day-centre patients’ appreciation of Derek’s harmonica playing, it seemed that there was a strong appreciation for his mastery of his ‘craft.’ It was this craft that people recognised, and which transcended his own personal identity and turned him outward to his community. As Honneth states (also following Marx), in producing something, one

not only realises oneself as an individual possessed of particular abilities, but it enables one to be recognised as a cooperative partner within the context of community life (1995:146).

As mentioned earlier, the testimony *Rosetta Life* is involved in eliciting only becomes effective when it secures receptive witnesses. This reflects Derrida's argument about testimony, that it can never be guaranteed in advance because it requires to be witnessed (2005:68). This bearing witness, for Derrida, is not a matter of proving, but rather of promising - of using one's "singular and irreplaceable" experience to attest to and to engage with that which is presented to you (2005:77). In other words, the veracity of a testimony need not be proved, but rather it is through the act of bearing witness to a person's testimony that confers on it power and efficacy. This is done with dramatic effect in the mourning rituals in Inner Mani, Greece, where women actively perform their role as witness through improvised poetic discourse and mournful screaming (Seremetakis 1991). The deceased's life history or posthumous testimony which is being confirmed here is achieved through a multimedia performance, and in a concrete sense it ensures the safe passage of the dead person from "inside to outside," a separation of the soul from the body (Seremetakis 1991:67-69). In Inner Mani, a death which is not witnessed is a "bad death" and is associated with nakedness, poverty and abandonment (1991:76).

Witnessing and Testimony

In Chapter Three, I explained how a patient's relationship with the *Rosetta Life* artist-confessor was based on a model of bearing witness to oneself and one's own life events in advance of one's death. This filmed testimony is then projected before you onto a screen. However, we can also witness others' testimony about events in their lives, if not the actual event itself. It is not necessarily about gaining privileged knowledge through first-hand experience (Frisch 2004:36). But are witnessing and recognition the same? The various theories of recognition I have outlined imply that the person who recognises understands, or is even able to analyse, the other's testimony which is presented to them for authentication. Witnessing, on the other hand, I take to mean a less identity-driven authentication of the Other. A witness

need not necessarily *understand* the inner workings of the ‘self’ (their motivations, beliefs, preoccupations etc) presented to them, but will acknowledge the symbol attached: “one does not have to possess or own the truth in order to effectively bear witness to it” (Felman 1992:15). To clarify this distinction, I refer back to Foucault’s genealogy of the modern ‘self’ (1993) that I discussed in Chapter Three. In the first centuries of Christianity, sinners would undergo a theatrical public performance of repentance whereby their sinfulness would be displayed on their punished body and in actions symbolic of repentance (self-maceration, starvation, shaved head etc). No analysis of the content of the sin was required and there was no need for a verbalised repentance. The only requirement was that the performance of repentance be witnessed. In this sense, whereas “recognition” is based on a psychoanalytic model (with an impetus towards verbalisation of one’s testimony), “witnessing” can be understood to derive from a religious one (early forms of which were non-verbal).

Witnessing and testimony have a clear legal etymology. In Latin there are two words for witness – *testis* from which testimony derives and which signals the third party at a legal trial who can judge between facts presented; and *superstes* meaning the person who has lived through something (Agamben 1999:17). So whereas *testis* can be understood as bearing witness to something after the event, *superstes* is the act of witnessing in the moment. As Frisch (2004:39) identifies, there is a temporal and ontological gap between these two moments. Much recent theory on witnessing and testimony has centred on a specific historical event – the genocide of the Jews under Hitler. The concept of the witness has been particularly problematic in this context. Laub argued that “there was no witness to the Holocaust” because all outside witnesses were destroyed and all inside witnesses became convinced (by the Nazis) that their experiences were no longer communicable, even to themselves (1992:81-2). Agamben, on the other hand, is determined to find the *superstes* in order that Auschwitz is not pushed into the realm of the “unsayable” which would have the effect of glorifying it (1999:32). Agamben identifies the figure of the *muselmann*, “half living beings” who were dying of starvation and who moved in slow motion, as the closest we can come to a “complete witnesses”. After all, survivors of the camps represent the “exception”, exceptional *because* they survived. But the *muselmann*

cannot speak and needs the *testis* – the testimony of survivors – in order to be heard. So the survivors bear witness to the *muselmann* who is both human and inhuman, a “zone of indistinction”, an indefinite being who represents the final remnant of humanity – that which it is never possible to wholly destroy (Agamben 1999:120-1,133-4). Survivors bear witness to the desubjectification which occurred in the camps, and when they speak for the *muselmann* they speak for the humanity that remains in him – that which cannot be destroyed (1999:158).

For Laub, because there were no witnesses to perceive and assimilate the totality of what was happening at the time, testimony only becomes possible retrospectively. His theory essentially supports Honneth’s psychoanalytic reading of recognition (he is a psychologist after all!) by calling for testimony from Holocaust survivors to be “authentically listened to”... “in a dialogical context” (1992:91) so that the listener becomes the co-owner of the traumatic event (1992:68). Indeed, although there is a temporal gap between the moment of witnessing and the moment of bearing witness (Frisch 2004:39), the two acts *testis* and *superstes*, whether performed by the same or different people, as in the case of survivors testimony of the *muselmann*, are co-constitutive in the sense that one gives voice to the other. One can bear witness to one’s own life (when one gives verbalised testimony about one’s life on film), or one can bear witness to another’s life or death (through watching that film), but the testimony of what one has witnessed must always be directed *to* someone and must be received by them (Frisch 2004:46). For Wynn (2002:128), nurses are analogous to the survivors of the camps because they can bear witness to those, like the *muselmann*, who exist on the limits of life e.g. neonates, comatose patients, and the profoundly demented. In holding a fragile baby until it dies, nurses offer “performative testimony” of his living and dying by “standing alongside” (Benner 1996:148). Rather than focusing on testimony as speaking as Agamben and Felman & Laub have done in the impetus to make the “unsayable” sayable, Wynn proposes that the simple act of holding a baby can be a form of testimony as well.

The type of witnessing which *Rosetta Life* tries to encourage is predominantly based on a person’s verbalised testimony about their own life or testimony about what one

has witnessed of other people's lives. But there are also moments of performative testimony, which is unspoken, for example, when patients silently listen to Derek's harmonica playing. Chris also told me that he finds patients often crave touch – a kiss on the cheek, a hand on the shoulder - to show that there is someone “standing alongside.” Another form of testimony is the eulogy. For Victoriano (2004:220), the eulogy is an act of translation, speaking for the dead person when we are left without words. The memorial service is thus a testamentary scene. If a family member or a *Rosetta Life* artist undertakes that translation for a funeral, they bear a huge responsibility for marking the absence of the individual's voice. But what of people who want their own voice to persist in their eulogy? Victoriano (2004) gives the example of a suicide note, which for him exempts the mourners from the responsibility of representation, because the deceased's words fill the gap making death seem permeable. Another example of testimony from ‘beyond the grave’ is when *Rosetta Life* artists help patients to create their own living memorial on film which will be shown at the person's funeral.

In all the films I have described so far, Chris was the catalyst for the projects and he decided where the films were shown. In the project I now describe, the patient himself instigated the project, elected where the film would be shown *and* who the audience would be. He was taking charge of the *kind* of witnessing he wanted to elicit.

Living Memorials

I met Nick through a *Rosetta Life* artist-in-residence working in a hospice on the south coast of England. Nick has developed cancer for the second time in his life. He has spent his whole life living on a small island off the Dorset coast, and feels his identity is very much bound to that place. He asked the artist-in-residence, Catherine, if she would make a film about his life. He wanted this to be played at his funeral. Catherine's previous project had been a “visual poem” for a woman who wanted to leave a permanent record behind for her young children who would grow up without her. Again, the film was played at her funeral. Like this woman, Nick also wanted to leave a material record through which his friends and family could access memories

of him. The film would therefore act as both an aid to memory and as testimony indicating exactly *how* he wanted to be remembered. He worked with Catherine over several months, filming interviews with key people in his life and visiting sites of major significance for him. In the opening voice-over to the film (the “voice of God”, as we recall from Chapter Three), Nick requests that the viewer “understand who he is.” In this sense it is very prescriptive. Later, we see him visit his church (he has a strong Christian faith), which is where his funeral will take place, and where the film will ultimately be shown. Mourners sitting in Nick’s funeral service will have him beaming down at them from a screen, as if he were in the church with them, delivering his message. In this scene he looks directly into the camera and says that he wants his ashes to be scattered off the island where he lives because this will be symbolic of him leaving the earth. The music rises to a crescendo and the image cuts to a white bird flying in the sky. I sat next to Nick in the hospice while we watched an early edit of the film. As he watched this scene for the first time he burst into floods of tears. Through watching his memorial film in which he was talking to an imagined audience of loved ones and referring to himself in the past tense, Nick was truly experiencing his death in anticipation.

When he had regained his composure, Nick and Catherine discussed how he envisaged the screening. Catherine offered to arrange things on the day, setting up the projector, hiring speakers and so forth. Nick asked her if she could place an empty chair next to the screen, in which he wanted the assembled crowd to imagine he was sitting, watching them watching him on film. Catherine expressed some technical concerns about connecting the speakers to the projector at which point Nick told her not to worry as he would be there to help out. There was a short pause, after which we all burst out laughing. Nick had spent so long imagining himself as a spiritual presence in the room, he could not disassociate this from being there in person. He was planning his funeral so meticulously, he could not imagine being absent as its host. He wanted to be his own chief mourner to grieve the loss of his own life, to be the “third man” (Green 1984) at his own funeral, assessing people’s responses to his death. So much so, in fact, that once the film was completed, he decided to arrange his own “celebration event” and premiere the film in advance of

his death (which he perceived as imminent). He asked his partner, Dave, to sit at the front of the church with him during the event. Dave refused and chose instead to stand at the back. Overcome with emotion, Dave left the screening half way through, missing the scene in which Nick asks him “what would you change about me?” and he responds “Nothing...except to make you well.”

In staging his own “celebration event” in advance of his funeral, Nick was seeking direct recognition while he was still alive. He was seeking acknowledgment for all of his achievements, for his relationship with Dave, and for his place in and contribution to his local community. He was requesting recognition of all of his unique abilities and accomplishments. The inter-subjective aspect of all this was that through affirming Nick, the island community would also be affirming itself. Jackson’s view is that storytelling enables individuals to reclaim agency and to feel that “events that overwhelm one from without may be brought within one’s grasp” (2002:36). Storytelling:

moves us, transports us, carries us away, or helps us escape the oppressiveness of our real lives...stories change our experience of the way things are (Jackson 2002:30).

The event that threatens to overwhelm Nick is the death that he is experiencing in anticipation. It is the “oppressiveness” of thoughts of his death that he is trying to escape by making an emblematic film about his life. In the film, Nick is the hero of his own story and he is free to create a myth around his persona. His partner Dave’s rejection of his ascribed role at the “celebration event” for me symbolised his hurt at Nick’s desire to experience his death in anticipation, without considering whether others wanted to do the same. How was Dave to place himself in Nick’s carefully crafted self-mythology? Nick was experiencing Dave’s grief in anticipation of his death, to the extent that it was putting a strain on their relationship in the present. Although the film was intended for the benefit of his relatives and friends, the narrative arc of the film focused intensely on Nick as an individual and his journey towards selfhood. As Butler points out, there is always a tension between the “truth

of the person” and the seamlessness of the story we want to generate about ourselves (Butler 2003:44). In order to be a coherent auto-biographer, “forces of circumstance tend to be reduced to mere obstacles heroically surmounted” (Jackson 2002:230). By subjecting his life’s becoming - with all its contingencies and discontinuities - to a myth-making enterprise of autobiography, Nick had forsaken some of the complexities of his personhood, including his relationships. In seeking recognition from his loved ones, Dave felt that Nick had not sufficiently recognised *his* wishes and feelings, and his part in their continuing and evolving relationship and shared biography.

As a post-script to Nick’s story, six months after his mock-funeral “celebration event”, he died. Catherine, who had worked closely with Nick to produce the film, regretted that she had not scheduled any final discussions with him about the actual funeral service. When she spoke with Dave, he told her that they had decided not to show the film at the funeral because most of the attendees would have seen it already. Catherine told me she felt uneasy about this given that Nick had specifically made the film for his funeral and had wanted it to be shown as his last testimony. Perhaps the reluctance to show it was something to do with the fact that the long build-up to Nick’s death, including the previous showing of the film, had stimulated “anticipatory grief” on the part of his partner and his family. Lindemann (1944:18) identified that the relatives of servicemen serving in wars sometimes experience “anticipatory grief” to such an extent that if the serviceman returns alive, the relationship breaks down because it has already been mourned and the relative “emancipated”. It is impossible to say whether Dave or Nick’s family had some ulterior motive for not showing the film, but it is clear that for whatever reason, the film was not used for its original purpose of gaining posthumous recognition. Instead, its main function had been to elicit recognition *in Nick’s lifetime*, in his ‘being-towards-death’, and not posthumously.

Rosetta Life films can act as ‘living memorials’, constructed while the person is still alive and edited to fit their requirements. Such memorialising practices link into people’s desire to be immortalised on film in order to make certain they will not be

forgotten and to make permanent their legacy. Memory, according to Sontag, is the only relation we can have with the dead (2003:103). One of the key ways people aspire to becoming immortal is through having children. Their children then become their legacy. In “Ghosts of Memory”, Carsten (2007) draws our attention to the place of kinship in memory making. In undertaking processes of self-making, we are forced to acknowledge the role of ancestors in our past. Relatives in a sense are reincarnated as we evoke our memories of them (2007:11). But Carsten is explicit in emphasising that memories are continually created and reconstituted in what Arendt calls the “subjective in-between”. Nick may have wanted to define the terms in which he will be remembered, but his wish did not take account of how memories of him will be reconstituted by his relatives in their lives without him, when he is gone. Just like our multiple and contingent selves, memories cannot be “pre-scripted or foreclosed” (Carsten 2007:26) as we might wish. I want to look now at a different type of event organised by *Rosetta Life*. This event, while revealing different aspects of *Rosetta Life*’s mission, offers further insights into the relationship between memory, kinship and also performance.

Immortalised Performance

“Celebration events” at the hospice were witnessed mainly by staff and fellow patients. However, relatives are also a target audience. For relatives, who are most likely to be the primary carers, the act of witnessing involves a different set of processes and effects. After all, their relationship encompasses the intimate zones of everyday life. They also have the everyday knowledge of the person’s identity and of how illness has changed them. Of course, some of the patients I met in the day centre did not have any close relatives, so for them, the hospice features more prominently as a source of intimate relations. Where kin do exist, it is always dangerous to assume a normative model of familiarity and comfort, animated by an expressive and emancipative kind of love (Berlant 1998:281). Often there are strong ambivalences within these intimate zones of everyday life. Following Sennett’s (1974) argument about the tyranny of intimacy in public life, I now want to explore the dynamics of a *Rosetta Life* project which aimed at giving dramatic shape to patients’ life stories in a public space, outwith the hospice setting.

In the summer of 2007, I documented, with a video camera, a week of *Rosetta Life* workshops, jointly funded by the *National Theatre* and led by Lucinda Jarrett, the charity's founding director. The workshops involved working with four young professional actors and a director who were instructed to listen to hospice patients telling stories about their lives and then to recreate those stories as improvised pieces of theatre. The week culminated in a performance of a selection of the stories to an audience comprising all the patients who had participated. The aim was to facilitate the sharing of patients' stories in a creative encounter and to encourage both the witnessing of other's stories at the same time as revealing something about one's own life history and attenuated personhood due to illness. The majority of the workshops took place in the *National Theatre*'s rehearsal studios and without any hospice staff present.

The project certainly raised issues about representation. On the first day, we visited a hospice (*not* my fieldwork site) and heard one woman's story of how her illness had affected her relationship with her children and grandchildren. After talking with Martha for about 15 minutes, the actors improvised a short scene in which they depicted a day out in the country with Martha and her family and the conversations they imagined had taken place. While Martha said she had enjoyed watching the performance, she also indicated that she was not sure she recognised herself in it. Later, as we were driving home, Lucinda received a phone call from the hospice saying that Martha had been upset by the way in which she had been represented in the performance. Lucinda immediately telephoned Martha at home to find out the reason for her distress. It transpired that she was unhappy both with the actress's depiction of her, as well as by the fact that the workshop had been filmed (by me). For Lucinda, Martha's reaction revealed the central issue of how self-perception and self-image are fundamentally shifted when one is 'living with' a life-limiting illness. For me, it raised issues about both the intentions behind the project and the disjuncture between public and private representations. In an attempt to create a dramatic scene of generalisable significance from only the bare bones of Martha's individual story, Martha felt the project had compromised her personal identity and

therefore she rejected the process as in any way ‘cathartic’. She rejected the actors claim to be able to speak for her. Sensitivity to an individual’s circumstances, including their ‘body-in-illness’, had lost out in the push to ‘make public’ and share stories collectively. The additional presence of the camera only served to heighten her impression that she did not have control over how her story/image was being represented.

Jackson (2002:23) is interested in how narrative enables people to negotiate an existential balance between themselves and “spheres of otherness.” He believes that telling stories acts as a coping strategy in that they enable individuals to take centre stage in the re-telling of their life, making life seem less contingent and insignificant (2005: xv). Even more than this, Jackson states that stories change people’s experience of the way things are:

all experience undergoes [transformations] as it is replayed, recited, reworked and re-construed in the play of inter-subjective life (2002:23).

In the *National Theatre* workshops, peoples’ experiences of life-limiting illness were elicited by Lucinda (playing the role of “confessor” in this instance) in the form of testimony, and then reworked by actors and performed back to the patients. It involved a verbalisation of one’s life and then a representation of that life by virtual strangers. This model did not rely on a relation of intimacy between the patient and the “confessor” or the actors/director. The parameters of the project dictated that the immediate encounter between the people in the room was the limit of the knowable reality. As Sennett writes, the rules dictating such an encounter in the theatre create a sense of “public geography” which does not require an excessively intimate relationship between the performers and the performed (1974:39). Sennett’s (and Arendt’s) critique of modern politics is that impersonal public engagement in society has been displaced by a craving for intimacy. The public register has been infiltrated by the expectation of intimate expression and revelation much to the detriment of public life, ‘civility’, and the diversity of experience that should be able to find public acknowledgement. Although the improvised scenes in this project may have depicted intimate moments, the fact that it was a performance of an abstraction - a

dramatic simplification of an already re-imagined experience – had the effect of preventing conventional emotional responses by distancing the participants from the action. Moretti and Sontag might argue that this distance allows for a more reflective recognition of the other's experiences. Sennett also would have celebrated the opening up of a “public geography” whereby matters of death and memory could be discussed among strangers without recourse to an emotional register.

One story successfully dramatised was Charlie's. Aged 67, Charlie ‘lives with’ lung cancer. He does not have any close family and gets most of his support from his local hospice. In discussion with the group, Charlie said that his greatest bereavement was the loss of his health and his virility:

When someone dies, at least it's closure, whereas with what I've got, it just goes on and there's no closure, and there's nothing I can do about it.

Charlie said that when he saw young people on the street he found himself begrudging them the “invincibility” of their youth. In addition, his cancer drugs had destroyed his sexual appetite that he felt had always been a defining aspect of his personality. To recreate a sense of this loss of virility, experienced by many with life-limiting illnesses, the actors performed a sequence of vignettes about a passionate love affair ending when the male character develops cancer. The character was not meant to *be* Charlie, but was rather a metonym or a vehicle for his views and emotions about his illness and impending death. Charlie, unlike Martha, was accepting of this interpretative licence and relished the opportunity to watch his story being re-worked. When I met him months later he told me it had been one of the best days of his life watching a group of talented people perform “my life”. Charlie did not seek control of his story, but allowed it to be transformed by others in a public space. From the way in which he spoke about the event later, I suggest that Charlie valued the experience not so much for the opportunity it gave him to reflect inwards on the ‘self’ as for the opportunity it offered him to become involved in something greater than the ‘self’. That it gave him a sense of “solidarity” in a communal project, to use Honneth's (1995) word. This is akin to what Claire gained from her involvement in the Mariners musical. Watching the audience's faces during the final

performance, I could see that all the patients were absorbed by what they were witnessing without succumbing to the involuntary emotion denounced by Moretti (1983).

One other dramatisation from these workshops that I want to analyse is that which was adapted from a family's memories of their recently deceased husband/father. A mother and three children attended the theatre workshop as part of a bereavement group from the hospice where their husband/father had died. Prompted by Lucinda, the family related stories of their father, the type of activities they did together, particular instances of fatherly love, for example, and the actors took those stories and reworked them into a series of vignettes which tried to give form to their inchoate memories. The mother's stated aim in involving the children in the workshop was to bring the family together - unite them through a joint project - and to "rework and reconstruct" (Jackson 2002:23) happier times with their father in place of the memories of his illness and death. Interestingly, when first encouraged to relate their favourite memory of their father, the children instantly began to cry. But when the focus shifted to watching the actors rework those memories, the children turned outward from themselves and became absorbed in watching their life made public.

The actors depicted various domestic scenes: the father finding a rabbit sick with Myxomatosis and bringing it home as a pet; the father appearing as a ghost to give his son encouragement before a football match. According to the family, the actor playing the father uncannily evoked his presence. Carsten draws attention to the problems which can arise in achieving proper adulthood when the "chains of connection to one's own past have been broken" (2007:8). *Rosetta Life's* attempt to facilitate and find an audience for the dramatic expression of these children's memories of their deceased father was a way to re-establish these "chains of connection." Observing the children's responses to this conjuring act, it was clear that they were remembering their dad as a living presence full of vitality rather than as the dying body they had encountered in the hospice. There was a focus on recognising the life lived rather than the life lost. The family said that they pray to

their father together every night before bed in order to keep him as a living presence in their lives. The actors performance was about making the dead live again. As Carsten points out, “memory work” can be regenerative (2007:16).

Involving this family in a project of this kind so close on the heels of their father’s death could easily have backfired. Lucinda and the actors were certainly most apprehensive about this particular workshop. It could have unleashed the kind of uncontrolled emotions that the nurses in the day centre strive hard to regulate. But by the end of the performance it was clear that it had been the most successful of the storytelling workshops. Perhaps this is because children can access the imaginative aspect of drama more easily. The collective re-imagining of their memories of their father brought into a public space the everyday and intimate aspects of their relationships. The story about the rabbit with Myxomatosis elicited much laughter from the audience. The family could look around them and see a whole room full of people delighting in their father’s presence as conjured before them. Bergson would view this laughter as simply a way of suppressing any unwanted outpouring of grief. But when juxtaposed to the more serious scene of the father appearing as a ghost, I suggest it was more a case of finding effective ways to call forth a witnessing of their happy lives with their father. This is perhaps where Bergson’s oversight with regard to the relationship between laughter and the emotion of happiness becomes very apparent.

For this family, the death of their husband/father could be considered a “critical event” (Das 1995). Carsten uses Das’s characterisation of “critical events” as those events so disruptive to everyday life for the people concerned that they bring into being new modes of action (2007:4). For this family, these new modes of action may well be new modes of relatedness, as familial bonds were renewed via the shared memories evoked. For other patients with whom *Rosetta Life* works, action might take a more political form, fed by a desire to change the way the dying are viewed in society. Such patients want their personal “critical event” – the event of being diagnosed with a life-limiting illness – to ricochet more publicly and to have a wider

meaning. In order to illustrate this particular mode of action, I refer to a *Rosetta Life* debate and “celebration event” at London’s City Hall.

City Hall: Facing the Public

Gorer (1965) famously wrote that post war Britain lacked the ritual support and adequate guidance necessary for people to be able to mourn. Thus death has become like pornography: playing an ever growing part in the private fantasies offered by mass media (violent films, video games, comics etc...) yet cut off from an understanding of it as a natural process and grief its associated emotion, in the same way that pornography detaches love from sex. The *National Theatre* project I have just described could be considered a refashioning of this ritualised approach to death in that it offered a performative outlet for grief and public support to the bereaved. Equally, the project also offered a platform for people like Charlie, who are ‘living with’ a life-limiting illness, to grieve for their own unique biography in anticipation of their death. *Rosetta Life*’s aim to change the representation of the dying (Jarrett 2007:xi) is also a challenge to Gorer’s (see also Aries, Elias 1986 & Illich 1976) denial of death thesis. Through presenting testimonies of patients’ ‘being-towards-death’, they are hoping to elicit recognition, or encourage an audience to bear witness to their “singular and irreplaceable” experience (Derrida 1995), not just among family members and fellow hospice patients, but also among the general (unknown) public. In doing so, they hope to open up public debate about what people need and should be able to expect from others at the end-of-life.

I was present (as cameraperson) at a debate *Rosetta Life* organised at London’s City Hall and sponsored by the *Greater London Authority* (GLA). The motion of the debate was “The only good end-of-life care is care at home.” The issues raised were: the type of care people want, whether people felt supported by the hospice, how far people wanted to be enabled to be active and independent, and how people felt they were perceived by the public. Peter has been ‘living with’ cancer for some years. He used to be a journalist and has always been very politically active, most recently in the *Free Burma* campaign, employing only Burmese carers and going on demonstrations and writing articles. Peter is *Rosetta Life*’s key advocate for user-

involvement and participation in service provision. “User involvement” is an all-encompassing term to describe patients’ increasing demands to have more control over how hospices are managed. *Rosetta Life* wants to turn the ‘sitting on committees’ side of user-involvement into a “creative, collective voice that might deliver change” (Jarrett 2007:136). What this change might be is not to be prescribed by *Rosetta Life* who declare themselves non-political, but rather by the patients themselves. Peter, despite recently having been diagnosed with secondary cancer in his throat, remains a determined and vocal advocate for patient-centred care and is a ubiquitous presence at *Rosetta Life* events. A Jewish evacuee from Nazi Germany, he has been politically motivated throughout his life, and for him, remaining embedded in this mode of action is a sign of both his commitment to his political causes and his desire to maintain continuity with his pre-ill ‘self’. He holds tight onto life by keeping himself at the centre of his social and political world, despite his diminishing levels of energy and his deteriorating body.

In the GLA debate, Peter was arguing in support of direct payments or “individual budgets”, which allow patients to pay directly for the services they choose to procure. Individual budgets are at the core of the government's aim of personalising adult social care services²². Peter endorses this idea because when he seeks support from his local hospice, he finds his personal wishes are compromised because the hospice “does not allow people to be who they actually are”:

By having my own care at home, I can choose to go out when I want to, say what I want to eat, say how I want to behave and how I want to live. I think there is a widespread call for increasing user control and empowerment.

Later, at his flat in a sheltered housing complex, I asked him to elaborate. As is Peter’s usual style, he answered my question by asking me a question in return – “do you think dying people should be allowed to have sex?” Slightly taken aback, I told him I had never thought about it. He said that in his view, if patients wanted to have sex in the hospice, with their partners or otherwise, they should be allowed to do so

²² This was the culmination of a policy process that began in 2005, with the adult social care green paper, *Independence, Well-Being, and Choice*, and developed through the 2006 health and social care white paper, *Our Health, Our Care, Our Say*.

because this was an expression of “who they were” and people should not be confined by institutional rules and procedures. “And the food they serve at the hospice is so bland!” Peter questioned why they did not have a more diverse menu: “I like to eat Asian food, why can’t they serve some of that?” He wanted to see hospice patients “live until they die”, but on their own terms and controlling their own menu!

Interestingly, the issue of choice of food had also been a topic of debate at my hospice in South East London. I draw attention to it because its recurrence as a commonly held gripe about day centres reveals much about the limits of patients’ political concerns. In South East London, the hospice management were keen to discover what patients thought about the day centre, so they approached Chris to make a short film asking people their views. As I followed Chris and his camera around, patients spoke in superlative terms about how much they enjoyed the day centre, but their one complaint (or at least the one thing they felt able to criticise) was the food. Eventually, a list was circulated in the day centre for people to write down their most preferred dishes, and the patients seemed pleased with this concession. Of course, like Peter, one could view choice over meals as indicative of how far the hospice management will endorse patients’ specific and individual tastes – an institutional respect for people’s personal identity and preferences. Equally, one could also view it as a panacea, obscuring more contentious issues around hospice care, not so easily articulated or resolved. Then again, perhaps the complaints about the food were an honest articulation by patients of their sole grievance with day care. If this is the case, then it certainly raises questions about *Rosetta Life*’s stated aim of “enabling patients to give voice”, if their only voiced concern is about the quality of the food and the diversity of the menu.

Peter’s motion at the GLA debate was opposed by a female hospice-user. She considered her hospice to be a sanctuary where she could have “a day out” and be with others without having to “put a face on” and keep up the pretence that everything was okay, as she did with her family. For her, the social aspects of the hospice were its strength, and she felt it to be a place where she was allowed to be ill.

After this lady had presented her case, Chris proceeded to show some of his films. The audience, consisting of patients, their carers, hospice managers and GLA representatives, all contributed to a lively discussion, using their own experiences to give their views on self-directed care, responding to both the debate and the individual testimonies they had watched on screen. Some championed the hospice day centre, some advocated for hospice at home, but most agreed that there was a need for both. *Rosetta Life*'s Chief Executive wrapped up the debate with a comment about the need to tailor end-of-life care to the needs of each and every individual. Here she is in step with current government policy, as laid out in the NHS End-of-Life Care Strategy (2008), which has given support and funding for more person-centred end-of-life care, with care plans tailored to the individual's demands.

In organising such events, *Rosetta Life* wants to foster bonds of association and mutual commitment among those requiring hospice care and those responsible for managing it and promoting it. The charity's strategy at this particular event was to make patients' personal experiences political by giving them a public platform from which to speak. Peter, who has a long-term involvement in and passion for politics, uses *Rosetta Life* events to stay involved in public life. Peter would regularly invite me to local council meetings, user-group meetings, *Free Burma* demonstrations, to name but a few. When I visited him at his home, the phone would ring non-stop and BBC Parliament was always on the TV. He desperately wanted to remain politically active despite the pain and the lethargy caused by his cancer. Involving himself in the hospice user groups and *Rosetta Life*'s work was his way of maintaining continuity with his public persona and a public world. Whereas for the woman opposing his motion at the debate, the hospice provided a place where she "didn't have to put a face on", for Peter, it was the hospice and events such as the one at the GLA which gave him the opportunity to wear the public mask that he felt his illness was depriving him of. Peter was not interested in exploring an "authentic" interior 'self' by producing a film with a *Rosetta Life* "confessor". Instead, he was interested in authenticating his public 'self' by using his voice, seriously weakened by his throat cancer, to talk to people about the issues affecting him and others like him 'living with' life-limiting illness. *Rosetta Life* is providing a platform for Peter to maintain

his public ‘self’ and for him to contribute to “changing the representation of the dying” (Jarrett 2007:xi). In a mutual convergence of needs, *Rosetta Life* is helping to fulfil Peter’s wish to not disappear from public life, and Peter is helping the charity fulfil its aim of making an effective public statement about the dying.

Conclusion

Arendt (1958) champions the politically active life (*vita activa*) of the Ancient Greek city-state or *polis* as the place where humans could overcome the specifics of their private, biological lives (which she calls ‘labour’) and could instead strive publicly for permanence and immortality. Arendt writes critically of the way in which the *vita activa* has been steadily undermined. For her, the public realm is where our intimate lives are “deprivatised and deindividualised” and where we become “assured of the reality of the world and men” (1958:50). Only in the public realm can things “appear out of the darkness of sheltered existence” (1958:51). As we have seen in this chapter, *Rosetta Life* attempts to “deprivatise” people’s experiences by making films for “celebration events”, improvising plays in front of an audience, and arranging public debates about the future of hospice care. I propose that all these attempts fit with the original aims of the *vita activa* in the Greek *polis* – to obtain immortality. Through *Rosetta Life* projects a person becomes immortalised on film or has their testimony archived for future generations. But they are not trying to “deindividualise” patients’ intimate lives. As we saw in Chapter Three, the method they use to elicit testimony from patients actually accentuates the process of individualisation by perpetuating a belief in the importance of authenticity in people’s ‘being-towards-death’. This presents the problem of deprivatising without deindividualising. Or, put another way, *Rosetta Life* has set itself the challenge of making a person’s life public, while retaining the private and intimate value of that life.

One way that these dissonant aims can be harmonised is through a process of witnessing and recognition. According to Taylor and Honneth, procedural recognition allows for difference while uniting people under the ‘general will’ working towards the common good (thereby deprivatising needs and desires through

encouraging “solidarity”). Bearing witness to people’s testimonial accounts of their lives involves an acknowledgment that the individual is not alone, that there is someone to say “I am your witness” (Laub 1992:91). This does not mean that you *understand* what you witness or that you can verify it as true, but that you have acknowledged the presence of the Other. In striving to be witnessed in their ‘being-towards-death’, patients are asking for authentication of their “singular and irreplaceable” (Derrida 1995) experience. Arendt stresses that actually it is human “action” or the *vita activa* that crucially reminds people of their plurality and diversity. It is only when we step out of the house to go to the hospice day centre, or participate in a debate, or watch actors conjure up our lives in front of us that we “appear out of the darkness of sheltered existence” (Arendt 1958:51) and realise not only our commonalities but also the plurality of human perspectives:

The public realm, as the common world, gathers us together and yet prevents our falling over each other (1958:52).

In a similar vein, Sennett (1974:339) argues that the ‘tyranny of intimacy’ in everyday life has made people less comfortable with diversity of experience because one cannot be ‘intimate’ with all forms of experience. Sennett laments the loss of civility, which fosters togetherness and a shared sense of purpose without the compulsion to ‘reveal one’s soul.’ The current emphasis on patients’ ‘self-realisation’ and ‘self-fulfilment’ in palliative care is a direction that Sennett would oppose because it feeds into our ‘cult of personality’, encourages reflection rather than action, and ultimately takes us out of the world:

To know oneself has become an end, instead of a means through which one knows the world (Sennett 1974:4).

Rosetta Life is caught between trying to help patients find ‘authenticity’ in their singular and irreplaceable ‘being-towards-death’ and in trying to authenticate that individual’s story via a public witnessing and recognition. Authentication, unlike a Heideggerian pursuit of “authenticity” in the face of death, requires an ‘other’. *Rosetta Life* artists have to work hard to secure that authentication, by challenging

‘jollifying’ trends, aversion tendencies, a reluctance to speak and a generalised fear of exposing the “public secret” (Taussig 1999) of our mortality. Finding a receptive audience is essential if the films and other creative projects are actually to serve as testimony. *Rosetta Life*’s art may well portray an “intimate vision of society”, disapprove of by Sennett (1974), but it is also directed towards ‘deprivatising’ people’s dying experiences by carving out a place for them in the public realm. Its artists refuse to allow silent deaths. They refuse to accept that there are no words to respond to the one who is dying. Although risky this is the way *Rosetta Life* contributes to a new public discourse on dying.

SECTION TWO

As I showed in Section One, *Rosetta Life* firmly believes in the transformative potential of being diagnosed with a life-limiting illness. In Chapter Three, artist-in-residence Chris acts as a “confessor” or “shepherd”, who elicits from patients their stories about the ‘good life’, in the process encouraging them to strive for “authenticity” in their ‘being-towards-death’. This self-disclosure feeds patients’ expectations about what they can hope for in their dying: a new ‘self’, an authenticated ‘self’, or a well ‘self’, as we saw with Clare. Other people are not interested in answering Chris’s call to confession. They are happy to be bored, to “take it on the chin”, or to have their attention diverted by games of Bingo. Spinoza’s argument that death is just a “bad encounter” that does not structure existence seems to fit with these accounts. In Chapter Four, I describe how *Rosetta Life* organises a variety of public events: “celebration events” in the hospice day centre or films to be screened at people’s funerals, a theatre event where actors improvise people’s stories and a public debate at London’s City Hall. Again, the artists encourage a type of transcendence, this time through immortalisation and authentication through a form of public witnessing. Although some projects successfully elicit a “standing alongside” (Benner 1996) or the creation of “public geographies” (Sennett 1977), others fall flat because the stories depicted are too private, too emotional, or too suggestive to others of “what might be lost.”

Rosetta Life’s mission to “give voice” to people’s experiences implies a Protestant ontology in terms of the primacy they give to speaking one’s thoughts and the assumption that those thoughts are sincere. The artist’s role as catalyst to, or interpreter of experience links them with other psi-science professionals working in healthcare. These professionals are connected by the underlying assumption that patients need to have their experiences mediated. According to Foucault’s theory of governmentality, this process turns people into governable subjects. Section Two of this thesis is about resistance to this professionalising trend. It examines the right-to-die debate: its history, politics, and the activism that brings it to life. Whereas people in my hospice generally spoke positively about the healthcare professionals they had

encountered, people involved in the right-to-die movement want to usurp the control they envisage doctors wielding over their lives. The right-to-die movement is ostensibly trying to resist professionalisation by championing individual autonomy and the right to decide for oneself what one wants. The “authenticity” that they seek is to be true to their own sense of personal dignity and their life’s aesthetic. The transcendence they desire is over the pain and suffering they dread in the dying process. They claim to be able to see through society’s “jollifying” and want to face squarely up to the disintegration and loneliness of dying. People awaiting a ‘green light’ from Switzerland are anticipating their death as a release from a burdensome life. Those who involve themselves in campaigning are anticipating a better future when there will be a legal right to a hastened death. Section Two revisits some of the themes of Section One: orientation to a future dying ‘self’, how suffering is conceptualised and represented, the politics of dying, the role of professionals in mediating experiences and how the aesthetics of one’s life become crystallised in “the art of dying”. This is the theme that begins Chapter Five.

CHAPTER FIVE

Right-to-Die in Context

Self-Deliverance

In December 2007, I found myself in a conference room in a cheerless hotel in central London. Around me sat a handful of people of varying ages, although the vast majority were over sixty. We had broken off into smaller groups and were undertaking a practical exercise. This involved a tank of helium, some metal clamps, some rubber ‘polytubing’, and a large plastic bag. “These clips are so stiff. I suppose it’s my arthritis,” comments one lady who sits on the floor trying to assemble the apparatus. “I wouldn’t be able to attach these without help.” The lady then proceeds to put the large transparent plastic bag over her head. “I just want to see what it feels like.” At the end of the plastic bag there is a tie, which she begins to tighten. Three or four of us look on. She suddenly seems to panic and quickly removes the bag from her head. “I felt smothered. I’m not sure I like that.” In this particular simulated exercise, the aim is to attach the helium tank to the plastic bag/hood using the polytubing. The “stiff” clamps are required to make the connections airtight. For the purposes of our exercise, our tank is empty and none of us are willing to keep the bag on our heads for more than a few seconds. However, this simulation is preparing us for an imagined future time when we will choose to apply this method for real. At this (imagined) time, we will place the plastic hood over our head, pull the tie closed around our neck, open the tank valve, lean back in our chair and let the odourless, tasteless gas pass through the polytubing and into the hood. We will breathe in the gas as it fills the plastic hood, displacing the oxygen, eventually displacing the oxygen in our body, and causing us to asphyxiate within 5-15 minutes.

This workshop is about “self-deliverance”, where people are taught the techniques of how to take their own life. The term “suicide” is generally understood to mean the voluntary destroying of a person’s own life by their own means. But “self-deliverance” is preferred in right-to-die circles because it narrows the meaning to include only the action taken by an irreversibly ill, ‘rational’ person to end their lives. It is with these terms – “irreversibly ill” and “rational” – where much of the

controversy around assisted dying lies. For this workshop, for example, there is no screening or vetting process to ascertain whether attendees are either irreversibly ill or rational. The woman sitting next to me at the workshop tells me quite openly that she has been on anti-depressants for several years. This clearly did not deter her from signing up for the workshop in a bid to acquire knowledge about self-deliverance techniques which have some ‘validity’ in terms of success rates and painlessness. As far as we know. Although there are various, worldwide self-proclaimed experts, no one can ever come back from the dead and confirm “yes, that was painless” or “yes, that was a dignified death.” And because in most industrialised nations these workshops operate covertly (they are not illegal, but equally organisers usually want to avoid raising the suspicions of the authorities by keeping them very low key²³) there is an issue about how far success rates can be monitored. Yet despite an inability to “try and test” these techniques, the people here deem them worthy of learning. All the attendees were studious and inquisitive. They had come for knowledge and the information dispensed was given clearly, although with explicit cautions. For some, the knowledge they seek here is an insurance policy in case of future poor health and a determined will to foreshorten their lives. For others, the knowledge appears to be more urgently required, perhaps for immediate application.

The helium method is only one of a number of methods by which you can self-deliver. At another point in the workshop I find myself with what is known as a “ratchet tie-down” around my neck. It looks like an airplane seatbelt. With each “ratchet” of the buckle, the (approximately five centimetres wide) belt tightens around my neck and, if I were to continue ratcheting, it would eventually constrict the flow of blood to my brain, and, as with the helium, I would soon asphyxiate. A ratchet tie-down, explains the organiser, can be bought at B&Q (a hardware chain store) for £7. This method is known as the “compression” method. It is advantageous, continues the organiser, because it requires only limited equipment and only half an hour to prepare. One does not even need a ratchet tie-down to auto-asphyxiate. A pair of nylon tights and a pencil can also be used to the same effect.

²³ Dr. Philip Nitschke’s workshops in Australia are an exception and are deliberately orchestrated in order to cause controversy and trigger debate about the legality of self-deliverance.

This is something you can do if you are in a hospital bed, for example, and you need to be discrete and quick about your self-deliverance, explains the workshop leader.

I wonder about the will power that would be required to end your own life with a pair of tights. We simulate this method as well. I look around me at the people in the room all slowly and deliberately tightening nylons around their necks, adjusting to the sensation of restricted airflow. I feel an urge to laugh because of the surreal aspect to the scene, so I quickly check myself for my inappropriateness. But, in fact, the atmosphere in the room is not as tense or serious as one might expect. There are moments of humour and the odd giggle, perhaps in response to feelings of awkwardness. For me, there is a degree of intimacy to the workshop. The scene is intimate not because people divulge personal details (there is still an air of civility) but because, to my mind, there is a shared sense of imagining that future moment of finitude. It is what Heidegger called a “moment of vision” when one goes beyond “inauthentic” time to encounter the finiteness of time. These simultaneously experienced, yet individually specific, “moments of vision” foster an atmosphere of intimacy among the strangers in the room. With each new technique simulated, people seem to be imagining themselves performing the act in their final moments, trying each method on for size, checking if it fit their requirements and circumstances, even their personality. Throughout, the organiser placed great emphasis on the idea that choice of method is person-specific. This does not just mean that in choosing a method one must take account of the ability to procure the equipment (the helium tank, the ratchet tie-down), or the degree of privacy in one’s choice of location, but also the person’s *aesthetic* preferences – how they imagined their final moments, or how they imagined themselves being discovered. This was something I had heard from other experts in the field of self-deliverance. A person’s choice of method, we are led to believe, can say something about who a person is or rather, who they were.

This sold-out series of workshops on self-deliverance, which took place in conference centres around the U.K., is evidence that for a small group of people, knowledge is equated with power when it comes to life’s greatest certainty. The

“new epidemiology” in the way we die (Battin 1994:9), brought about by the dual effects of improvements in public health (eliminating many infectious diseases) and the development of life-prolonging drugs and medical technologies, means that in industrialised nations, most people die of deteriorative diseases with many treatment decisions being taken by doctors. As I discussed in the Introduction to this thesis, this “new epidemiology” has resulted in a dying process shaped by medical interventions, social institutions, and bureaucratic practices (Kaufman 2005:2). Aries calls modern death “wild” because it has become so feared, banished from the public realm and subject to the “savagery” of these new medical technologies (1983:614). It is the right-to-die movement that professes to offer an alternative to this professionalisation and medicalisation of the dying process. They want to make death “tame” again, not through familiarity, as Aries argues it was in the Middle Ages, but rather by the exercise of self-control over the dying process, and a refusal to leave it to medical decision-making. Learning the techniques of self-deliverance is one way that people who are suspicious of the new medical interventions and fear the bodily deterioration accompanying illness and aging feel that they can prepare themselves for their death and bring it under their individual control.

Of course, there is a significant difference between self-deliverance and assisted dying, which is what the right-to-die movement campaigns for. The former, in theory, can be a wholly autonomous act (although even if other people are not involved in the procurement of the equipment or present at the person’s side during their “last act”, other people will always be affected by that act, whether that be family members, neighbours, or a stranger who discovers the body). Assisted dying, on the other hand, specifically enlists the “assistance” of another person. The right-to-die movement would prefer that this assistance came from a doctor who has access to the most preferred deliverance techniques of all – morphine and barbiturates. Acting for oneself or for another engage different moral dilemmas, and in focusing on this distinction at the beginning of this chapter, I hope to lead the reader into a discussion of some of the persistent themes in the assisted dying debate. These themes encompass conceptions of suffering and of control over the dying process. What meaning can be attributed to pain and suffering if they are

“demoralised” and “de-Christianised”? Can suffering be objectively assessed or is it only ever to be determined by the individual “sufferer”? I intend this to be a historically embedded account, which will enable me to highlight what distinguishes current trends from older ones. The euthanasia controversy is not new – it has been debated and contested since the earliest days of the medical profession. I want to discuss the development of ethics around this issue and what people involved in the debate think constitutes good or bad ethics and by deduction the good life and the good death. All these trends and themes will then be discussed with reference to the most recent (2006) attempt to initiate legislation in the U.K. Houses of Parliament: The Assisted Dying for the Terminally Ill Bill. My research took place a year after the defeat of this parliamentary Bill, and consequently my interviews with key political actors prompted reflections on and rationalisations of that defeat. Finally, I want to examine this issue of control, which is the major fear or theme for people exerting pressure to change the law.

This section of the thesis is broadly devoted to the rejection of the professionalisation of death by the right-to-die movement. Yet as I attempt to show, the main paradox of activists’ demands is that they would like to see the means of death delivered by a medical professional. This Chapter looks in detail at this paradox and some of the other ‘blurred boundaries’ of this highly charged debate. Only by understanding the historical context to the assisted dying debate – the history of suicide, for example, is informative here - and the different attempts to rationalise suffering and a desire for control, can we understand the motivations and convictions of campaigners on both sides which I go on to discuss in the rest of this section. Ultimately, the political debate and the recourse to principled beliefs are about claims to authenticity of both a particular type of ‘self’ and of the type of death that we envisage for ourselves.

Freedom From, Freedom To...

Surveying the people at the self-deliverance workshop through my plastic hood, I wondered about the ability of these final moments to say something about who we are or who we have been. It presents an opportunity to reflect on one’s life and on what one considers to have been a “good life”. By “good life” I refer to those

subjective determinations which give our life its own “goodness”. Although each person’s conceptualisation is likely to be a variation on a theme, right-to-die activists often share a belief in the “goodness” of the freedoms to which they aspire. They believe strongly that, as autonomous individuals, they should be allowed to strive for an existence (or non-existence) based on their own ethical ideals that represent who they have been and how they have lived their lives. They aspire to what Isaiah Berlin termed “negative liberty”, that is, the desire to be left alone so that they can act “unobstructed by others” (2006[1958]:369) in accordance with their own beliefs. This concept of freedom *from* the dictates of others is predicated on the value of non-interference: the preservation of the private realm in which personal relationships are held as something sacred. J.S. Mill (2006[1859]) was the most vociferous champion of such a conception of freedom which emphasises the individualistic nature of man, whose essence will be lost if he is forced to conform to some uniform will. People desiring to determine their own “final exit” (Humphry 2002) aspire to an ethics of freedom in which they can act upon themselves as responsible people able to judge their own acts and choices and the repercussions of those acts for others.

In outlining his view of “negative liberty”, Berlin also highlights that no man’s activity is so completely private as never to obstruct the lives of others (2006[1958]:370). In this way, we must admit that we cannot remain absolutely free and we must give up some of our liberty, although crucially “without offending against the essence of [our] human nature” (2006[1958]:371). Just what this “essence” is, however, Berlin admits is subject to infinite debate. We want to be true to ourselves, but with so many different selves constituting society, it is difficult to know where the line between our freedom and those of others should be drawn. Berlin’s counterpoint to the “negative liberty” of non-interference is “positive liberty” by which authorities would “make people free” and force them to act ethically towards one another. In other words, the class, state, or nation would be imbued with the responsibility to coerce citizens in the name of justice, rationality, or public health to become wiser, healthier, and more virtuous (Rose 1999:66). This is the idea of liberation by appeal to reason. However, this reason is to be determined by some higher authority that is permitted to override an individual’s own wishes or

reason. Although this second concept of freedom is individualistic in the sense that it appeals to the betterment of the individual, authorities reserve the right to override the individual if their judgment or goal clashes with theirs.

Laidlaw (2002) has argued that Anthropology has often applied a similar normative conception of freedom. It is his view that anthropologists have not paid enough ethnographic attention to how people's conduct is shaped by what *they* imagine as ethical and free living, as opposed to what the *anthropologist* thinks is the right kind of ethics or freedom (2002:315). Anthropologists have applied the concept of "agency" in place of freedom, but Laidlaw thinks it is a poor substitute (2002:315). This is because, in seeking out agency, one looks to the effectiveness of an individual's actions in challenging or transforming societal structures, whereas freedom is also about how the individual goes about constructing those actions and choices in their daily lives. As Foucault so astutely highlighted, an ethical life encapsulates more than the following or challenging of socially sanctioned rules (in Laidlaw 2002:321). An ethics of freedom for Foucault involves the continual application of 'techniques of the self' so that one can make oneself into a certain type of person in order to attain a certain state of happiness (2000 [1981]:177). This fits with his notion that humans are perpetually reinventing themselves through the exercise of choice and action (Laidlaw 2002:323). If, therefore, we only recognise freedom when it conforms to our view of what is rational or what is the right kind of transformative action, then we are in danger of conflating ethics with a more singular and rigid morality.

Again, here we find a qualitative difference between self-deliverance and assisted dying. Self-deliverance as a "technique of the self" can be regarded as an ethical practice of freedom. Yet when the act involves the assistance of another person, or when it involves a third party advocating for another person's freedom to die at a time of their choosing, the practice and negotiation of ethics begins to harden into a prescribed course of action. An intimate decision about the 'self' and how one envisages one's life and death then turns into a technique to be employed by the polity at large. "Techniques of the self" are transformed into "techniques of the

Other”; negative liberty into positive liberty. This is where the controversy surrounding the right-to-die debate begins.

In defining ethics as the “conscious practice of freedom” through acting on the ‘self’ and choosing which kind of ‘self’ one wishes to be (2000:284), Foucault explicitly distanced himself from two utopian ideas of freedom. The first idea is that freedom is only possible in the total absence of constraint (equivalent to Berlin’s “negative liberty”, or Mill’s general concept of liberty). For Foucault, the very practices which constitute the ‘self’ are “proposed, suggested, imposed upon [us] by culture, society, [our] social group” (Laidlaw 2002:323). However, we are no less free because of this, it is only that our freedom is historically produced. This acceptance of an ethics of freedom which is not expected to overcome the interference of the government or the state relates to Rose’s (1991) analysis of governmentality. For Rose, government regulation and non-interference in people’s personal lives are not as incompatible as one might assume. The notion of governmentality, similar to the “advanced liberal” notion of freedom, allows for the fusing of the state as “enabler”, responsible for producing good citizens who can govern themselves, with individuals’ own aspirations for a civilised life. Citizens can be governed in accordance with freedom. The regimental attention individuals pay to diet, exercise, and environment, for example, is a sign that individuals are “both beings of liberty and members of society” (Rose 1999:68).

This idea that we can be enabled to be free through regulation helps us recognise how changing the law on assisted dying can be conceptualised by the right-to-die movement as an ethic of freedom. If we cannot live in a utopian world without some level of constraint and interference, we must accept that our freedom to die has to come with some regulation. The other side to this is that we can practice our freedom *in spite of* regulation through learning the techniques of self-deliverance. This is an “underground” practice that is not subject to any governmentality or regulation. This leads into the second utopian ideal of freedom that Foucault was keen to distance himself from: that to act freely is to act in conformity with reason. Foucault continually questioned the concept of an objective, timeless rationality which

freedom must conform to. Like Berlin's (2006[1958]:380) concept of "positive liberty", freedom as an abstract ideal does not extend to or incorporate what is irrational, stupid, or wrong. But as Berlin argues (2006[1958]:381), our desire-ridden, passionate, empirical selves do not always conform to the 'reasonable' assumptions of the rationalists/political theorists. Indeed, this endless exchange between perceived rationality and our empirical, passionate selves is one of the core dynamics of the assisted dying debate. And Foucault's analysis of the historically produced and variable nature of "rationality" is nowhere more relevant than in the treatment of suicide in the U.K. throughout the ages.

Suicide: From Demotic Incitement to Non-Compos Mentis

During the self-deliverance workshop, there was a strong emphasis on participants' aesthetic preferences, and herein lay the intimacy of imagining their future finitude. The organiser encouraged the group to think about such preferences in terms of both their final moments and the impact of their choice of method upon the person who would discover them. Would that person have to disguise the fact that you had taken your own life, he asked? Will there be social stigma for your family, your friends? It was clear from one woman, Sara, whom I interviewed later on in my fieldwork, that her choice to go to the Swiss organisation *Dignitas* for help to die conflicted with her religious identity. Sara told me how she feared that she would go to hell because God would judge her as sinful. Her assisted suicide would be judgment and death in a single act:

I find God very judgmental and censorious just now. I pray to Mary instead. I'm sorry for my sins. I'm sorry for my pride or complacency, but I don't think I've lived a bad life. But can I say I have lived a good enough life?

For Sara, her belief in her own goodness/Godliness did not fit with a death by suicide. Although she felt that going to *Dignitas* for assistance with her suicide would incur less wrath than a self-deliverance because, being an established organisation, it would legitimate her decision/action, she still felt that her manner of death would belie her internal goodness on Judgment Day.

In early modern England, choice of method for suicide was also indicative of a person's social status (MacDonald & Murphy 1993:185). The conventions of honourable suicide dictated that shooting was the preferable aesthetic for a "gentleman". This was because it was associated with courage and being resolute, a deed of calm rather than impulse. Hanging, on the other hand, was entirely proscribed, as it had been for the Romans²⁴. The Romans generally viewed suicide with neither fear nor revulsion, but rather as a validation of the way a person had lived their lives and the principles they had lived by (Alvarez 1987:82).

If shooting oneself proved your aristocratic stock, then the way in which the state chose to bury you could demonstrate how your chosen death was viewed by society. In medieval Zurich, which strikingly is where *Dignitas* is now based, society demonstrated its general condemnation of suicide by symbolically inverting the method the individual had chosen to end their lives. For example, those who jumped to their deaths were buried beneath a mountain; those who drowned were buried in sand (MacDonald & Murphy 1993:19). Britain's treatment of the bodies of those who committed suicide was equally symbolic. Suicide was subject to severe condemnations and punishments by the church from the 5th and 6th Centuries. Self-killers were buried on public highways, specifically at cross-roads and often with a stake through their heart. Or they were buried in the north side of graveyards, alongside executed felons, unbaptised infants and excommunicates, other eternally liminal souls (MacDonald & Murphy 1993:210). In Christianity, it was St Augustine who first extended the sixth commandment "Thou shalt not kill" to include self-killing. Alvarez (1987:69) calls this an "afterthought", inspired by the suicide mania that was prevalent among the early Christians keen to escape this world of sin and temptation and escape into eternal glory in the afterlife (1987:86). Yet even before the Christian prohibition there was an abhorrence of suicide and many of the desecration rites mentioned above can be traced to pre-Christian folklore.

²⁴ There is no clear explanation as to why this is, although Van Hooff (1990:65) confirms that in Ancient Rome, hanging was considered vulgar and cowardly and incited public horror. If a man took his life by a rope, his name would no longer be mentioned in his family's funerary rituals. Virgil calls it "the rope of ghastly death."

The origins of the negative moral and emotional connotations of suicide can be more generally linked to conceptions of pollution. Douglas viewed pollution beliefs as analogies for expressing a general view about the social order (2006:4). From a functionalist perspective, suicides can essentially destabilise the social order. Human survival is understood to depend on a prohibition against death generally. Hobbes believed that there was never a good reason to abandon one's life and that corporeal self-preservation was one of the fundamental aspects of human nature (1971:116-7). Hobbesian subjects wanted to defer death and prolong their lives as much as possible. In Durkheim's famous text "Suicide" (2002[1897]) he argued that self-killing was indicative of *anomie*, a state in which there is a weak correspondence between society's norms and those of the individual. Excessive *anomie* was dangerous and polluting and needed to be kept in check.

A corresponding aspect to the categorisation of suicide as polluting was the inability of the self-killer's soul to enter the afterlife in both Pagan and Christian thought. Van Gennep (1960:160-1) describes how self-killers were forced to wander between the world of the dead and the world of the living. This encapsulated the quintessentially 'bad death' - when the spirit of the self-killer polluted the world of the living by remaining as a ghostly, egregious presence. Hence the need for the stake through the heart - to prevent the self-killer rising as a ghost, and the crossroads to disorientate him (Alvarez 1987:64,67). This belief was transformed by intensive Christianisation into the idea that suicide was incited by Satan. Religious leaders tried to capitalise on this diabolical interpretation by suggesting that suicidal desperation could be cured by the comfort, redemption, and salvation offered by Christianity (MacDonald & Murphy 1993:38,43). In fact, the severity of the theological proscription on suicide increased throughout the Middle Ages, matched in turn by the legal proscription. This took the form of the forfeiture of the self-killer's estate to the crown, which had the effect of punishing the family of the deceased. These punitive measures reached their height between 1500-1660, as a result of both the Tudor attempts to centralise legal regulation (forfeitures from suicides being administered through a central court) and the Protestant Reformation (the sectarian battleground over the interpretation of suicide) (1993:5).

MacDonald & Murphy (1993) are also alert to the oppositions and subversions which permeated this punitive order. These oppositions eventually found force in Enlightenment principles and rising secularism. In 1641, the central court was dismantled because the punishment of the self-killer's family began to offend the public's sense of justice. At the same time suicides became more commonly classified as *non-compos mentis* (a legal term meaning "not of sound mind") (1993:116). This marked the beginning of the shift from a moral to a medical explanation of suicide: that is, that suicide was incited by mental instability rather than by the devil or sin. It also marked the shift from suicide being punishable by agents of the sovereign or the church to being an illness treatable by mental health professionals aimed at maintaining a healthy, productive population. Yet the remnants of the punitive history persist today. Indeed, it was not until as late as 1823 and 1870 that the religious and state penalties were respectively abolished (MacDonald & Murphy 1993:346). This was because, despite the changes in the meaning attributed to suicide, both church and state continued in their desire to deter the act because of its dangerous, polluting, and subversive qualities. This was why by 1850, the courts started to recognise attempted suicide as a crime and people found failing in the attempt could be punished. This common-law felony was not repealed until 1961 with the Suicide Act (and 1993 in Ireland), and it was at this time that "aiding, abetting, counselling or procuring the suicide of another" became a crime for the first time. The official medicalisation of suicidal behaviour was marked a few months after the passing of this law with a Ministry of Health circular to all doctors advising that people attempting suicide should receive psychiatric attention (Neeleman 1996:253).

This brief history of religious and state treatment of suicide demonstrates something of why it has been deemed a problem for British society and therefore subject to strict regulation but also how its meaning and interpretation have changed over time. In essence, despite a softening of public attitudes in the last two centuries, the belief that religious and state institutions needed to continue suicide deterrence measures, if not punitive measures, persisted. There was a strong feeling that suicide was morally

wrong, because it offended either God and his gift of life, or justice, as Plato and Aristotle argued, because it demonstrated a lack of responsibility for one's community – a shirking of one's duty. Throughout history, suicide has been deemed subversive in that it is seen to represent a threat to authority. For one, it removes a state's monopoly on violence as a form of punishment for individual deviance. Sarat (2001:67) argues that sovereignty has always established itself by taking life. Capital punishment is the most obvious example of this. Sarat argues, with reference to capital punishment in the U.S., that although, as a technique, it may be required to "leave no trace" on the body (unlike in previous eras when methods were chosen precisely for their ability to leave gruesome effects (Foucault 1977)), it still exists to remind the population that the law holds the prerogative on the "technologies of death" (2001:64).

Suicide is also deemed contrary to a presumed instinct towards self-preservation, viewed by Hobbes as a 'natural right' obligation. It is a "defacement" of this natural right. Taussig (1999) has written that defacement destroys what he calls "public secrets": things that are generally known but cannot be articulated. Knowing what not to know is the most powerful form of social knowledge, he argues (1999:2). Is suicide a defacement of the "public secret" of death? To go willingly towards one's death, to embrace it, defies the Hobbesian view (1640[1839]:83) of humans as instinctually self-preserving creatures. It throws into conflict our self-preserving instinct and our belief in the principle of self-ownership (most famously promoted by John Locke). It also defies or "defaces" governmental strategies aimed at promoting the health and longevity of the population. For Foucault, suicide was the ultimate reclaiming of freedom from disciplinary powers. He advocated that if one truly had concern for the moral and aesthetic quality of one's life, then suicide *in health* might be an appropriate exercise of one's ultimate freedom. He therefore advocated not for release from a 'bad' death but rather enhancement of one's entire life through consideration of how one might end it (1996). Foucault's analysis of suicide reveals the "public secret" which is the freedom to discharge one's life. It also reflects the idea evident in the self-deliverance workshop I attended, and in the contemplation of

methods of suicide since the Middle Ages: that thinking about how to end one's life is also a reflection on the good life, one's values, and one's legacy.

The Stigma of Suicide

MacDonald & Murphy (1993:17) highlight that for people with terminal illness, serious incapacities, or even those who were just 'tired of life', the public moral judgment extended to their suicide had always been less severe. Taking one's own life for these reasons was to a degree socially sanctioned in that it was interpretable as a rational choice for a person wanting to speed up an inevitable decline. This could not be considered a shirking of one's duty, as Plato and Aristotle had viewed suicide. Indeed, if the *non-compos mentis* verdict had the effect of decriminalising and medicalising suicide in England after 1641 (by labelling self-killers as "mad" or "mentally ill"), then the arguments which support "self-deliverance" revoke the "mad" verdict and reinterpret the self-killer as a rationally motivated individual with a 'right' to control over his/her own body. The term "self-deliverance", first used in the 1980s, replaced the term "suicide" to differentiate what some people felt to be a rational or justifiable act. Resistance to the term suicide is still strong in the right-to-die movement because of its association with the *non-compos mentis* verdict. The choice of the word "deliverance" is striking for two reasons. Firstly, because it is reminiscent of the expression to "deliver a child" (give birth). This association draws a parallel between bringing life into the world and taking one's own life to leave the world. Second, "deliverance" is also a Biblical term that means to be rescued, released or liberated from evil and oppression by God ("Deliver us from evil" in the Lord's Prayer). The term "self-deliverance", one assumes, would mean the ability to rescue or liberate oneself (rather than relying on God) from the 'evil' of disease and suffering. The religious connotations are intriguing, given the history of opposition of the Christian faith to both suicide and assisted dying. One can speculate that the term may have been adopted as a deliberate subversion of a Christian concept, or perhaps even used to appeal to Christians who were feeling unsure about the morality of taking their own life.

Yet despite attempts to rationalise suicide, there continues to be stigma associated with it, and this is also extended to people trying to escape painful illness. My research participants continue to wrestle with the legal and religious restrictions on suicide in the U.K. A number of the people I met who want to travel to *Dignitas* in Switzerland are committed Christians and each in their own way are wrestling with fears of God's judgment. For Sara, who wonders if she has lived a "good enough" life, her pastor's consolation that God will see her suffering and forgive her, does not relieve her inner conflict. Instead she wonders if she is in "hell on earth" because of the constant spinal pain she lives with as the result of a riding accident. Although those around her all seem sympathetic, her inner conflict continues and she expresses this as a religious conflict.

For Morna, who also wants to die at *Dignitas*, religious fears play a part, but this time they are those of her family. Morna's grown up children have intervened on five occasions (so far) to prevent her from travelling to *Dignitas*. As Morna explained to me, in addition to trying to talk her out of her decision by telling her how loved she is and how they will look after her as she becomes increasingly debilitated (she has Multiple Sclerosis), they have also raised the question of God's judgment:

My son says to me, "where does God come into all this mum?" And I say, "that's what I want, I want to go and be with God." And my son says: "If you think you're going to be with Dad, you might not end up where he is but end up in the other place." And I tell him, "well, I'll take my chance, I'll take my chance."

Morna tries to resist her son's doubts about the morality of her action. She told me that her children also warn her of the possible impact her assisted suicide will have on them, and how they are implicated in her decision:

They say to me, "what will we tell people when they ask? Is this going to be our skeleton in the cupboard?" And I say to them "tell them I died abroad. People only know what you tell them."

Clearly this is a reference to the persistent stigma associated with suicide and in Morna's mind, "appearances" played a major role in her children's refusal to endorse

her decision. Goffman's definition of "stigma" is when someone possesses an attribute that marks them out as different from others in the category of persons available to people (1963:12). Stigma is supported by an ideology that gives an account of why an attribute (or in this case an action) is deemed dangerous, bad, or weak (1963:14). But Goffman's point about stigma is that people manage possible stigma by de-emphasising certain aspects and accentuating others in social encounters (1963:31). Morna defends her actions and the possible stigma arising for her family by advocating that her family de-emphasise the "dangerous, bad, or weak" aspects of her death, which, to use Goffman's term, would be open to being "discredited" (but not "discreditable") (1963:27).

The term stigma originated with the Ancient Greeks to refer to the signs that were cut or burnt onto the body of slaves or criminals to expose their degraded moral status (Goffman 1963:11). It might be useful to recall here Foucault's (1993) distinction between the Ancient Greek concepts of *exomologesis* and *exagoreusis*, as discussed in Chapter Three. *Exomologesis* referred to the early Christian penitent's somatic exhibition of sinfulness and guilt which required to be witnessed in public (the shaved head, the scarred and starved body etc...). *Exagoreusis*, on the other hand, referred to the later Christian tradition of confession, where one's conscience was exposed through the verbalisation of thoughts as opposed to bodily scarification. Although Goffman states that stigma as public disgrace no longer requires bodily signification, people like Sara and Morna still feel as if their actions (travelling to *Dignitas*) or their pain ("I'm in hell on earth") are interpreted as signifying inner sinfulness and moral disgrace. Although stigma is imposed from without, by another's judgment of a person's "sinful" action or body, it is felt within as a metaphorical scar on the person's conscience. In this way, my religious participants felt that suicide, even when inspired by severe illness and bodily deterioration, was subject to stigma and moral judgment. So although the law punishing suicide was abolished in Britain in 1961, the social and cultural remnants of a long history of punitive measures including desecration of the body at burial and forfeiture of a person's estate, leads some people to feel the censorious judgment of God or society upon them when they seek an assisted death.

Sheila's Conflict

Morna's comment to her son that she will "take her chance" facing God's judgment in order that she satisfy her wish for an assisted suicide shows both her sense of desperation but also her resolve to take responsibility for her decision. So, while my religious participants were wrestling with religious teachings, scripture, and theodicy, they were also addressing questions about freedom, choice and responsibility. This I call their existential dilemmas (although my participants did not refer to them as such). What happens when our wishes conflict with the external moral system to which we have subscribed? What happens when our circumstances become such that this system can no longer make sense of our suffering? I want now to tell the story of Sheila, whom I met a few weeks before her assisted suicide in Switzerland. Her story highlights a number of issues about the anguish that is often felt from the moral uncertainties related to a loss of meaning in suffering. Sheila's illness and her desire to put an end to her suffering was, she described, a test of her Christian faith. She found that her religious beliefs were often at odds with what I identify as her generally existentialist views on freedom of choice and accountability. Sheila's agonising over what she perceived as limited choices can illuminate more general themes about how we conceptualise suffering in British society.

I spent two (non-consecutive) days with Sheila before her trip to Switzerland, because at that point, I was intending to travel with her²⁵. She seemed like a very private person, possibly as a result of feeling she had been mistreated by people in the past and so was very careful in whom she placed her trust. She told me that she was estranged from her family after a childhood memorable only for its scenes of violence and victimisation. Sheila was twice divorced and had no children. Her desperate desire to be independent of her troubled family had caused her to cultivate entrepreneurial skills which led her to set up her own (very successful) business working with London's wealthy elite. Sheila spoke proudly of her strong work ethic, her business acumen, and her ability to overcome the hardships of her childhood. Her

²⁵ In the end, I did not accompany Sheila, due to practical, as opposed to ethical reasons. See Methods section for a longer discussion of this.

story was one of 'rags to riches' in the most classic sense. Then, eight years ago, she developed a rare skin disorder for which there are no 'safe' alleviating drugs and no cure.

Sheila would wake up in the mornings and her sheets would be soaked with blood after a night of interminable scratching. "The constant irritation would drive anyone mad" she said. The open sores all over her body would then become infected and several times she ended up in hospital covered from the neck down with bandages to prevent further scratching. Her immunity to the highest strength of steroids coupled with her entrepreneurial attitude led her to seek out various alternative remedies and new drug trials. Unfortunately, these either had no long-term results or caused serious, permanent side-effects which were further damaging to her health. The scars on her arms and legs spoke of the virulence of her disease. When her illness became long-term, Sheila felt she was abandoned by her upper-middle class social world. The development of her skin disease seemed to bring up a whole host of psychological issues from her past, which she believed she had overcome, and she was plunged back into feeling 'dirty' and 'contagious.' "Nobody is interested and nobody understands what I have to live through," she told me. Having lived with the disease for eight years, she made the decision to go to Switzerland. Only this option seemed to give her any cause for optimism.

A strong believer in the Old Testament, Sheila viewed God as an omnipresent father-figure and she prayed to him to respond to her situation. She told me she did not like the teachings of the New Testament because Jesus offers forgiveness without giving people the "guidance and boundaries" they need to be good in *this* life (as opposed to seeking forgiveness in the next). She read and reread the Book of Job, the Old Testament story that most explicitly deals with suffering and theodicy. The message from Job is that one must be stoical in the face of what God inflicts on us in a test of our faith. Sheila hoped that God was testing her faith but that he would eventually come to her aid:

No one can have prayed for an answer as much as I have. He [God] could have sent me an answer. Now this [an assisted death] is the only option I feel I have left.

Sheila even saw her itchy, infected sores reflected in the story of Job when Satan went forth from God and “smote Job with sore boils from the sole of his foot unto his crown” (Job 2:7). As for Job, Sheila’s sores were also a test of her faith. However, she did not believe that her sores were the bodily representation of her sins. She felt she had led a virtuous life, overcoming the sins of those around her. There was no chance for *exomologesis* here because her drastic attempts to cover her scars, in addition to her abandonment by her social group, meant that it was difficult for her to find witnesses to her suffering. She told me she was in constant dialogue with God, even talking out loud to him. She told me she alternated between anger at him not supporting her decision to thanking him for the strength he had given her over the years. Although Sheila worried that God would not forgive her for deliberately ending her life, like Sara, she also felt that “hell can be here on earth as well”. Although at times she felt that her decision was made more difficult *because* of her religion, ultimately, if God did not agree with her decision then he would have shown her “another way...opened another door for me.”

Sheila rationalised her decision to end her life by calculating her options on a balance sheet, which could only be assessed by God. It was no coincidence that a large part of her professional life had been devoted to organising people’s financial accounts. Yet, while she sought God’s approval for her decision, and spent hours agonising over whether it was ‘right’ or ‘wrong’, she eventually determined that she herself was responsible for finding a solution. In an existential sense, she embraced her ‘radical’ freedom and after much wrangling with God, her father-figure, she abandoned waiting for his decision or his action and chose death for herself, hoping that in the final instance she would not be punished for having done so. Sheila’s unmistakable belief in the ‘virtues’ of self-responsibility and personal accountability was perhaps born of her difficult experiences with her family and her belief that they had undermined her throughout her life and prevented her from achieving her ambitions. That she had become a successful business woman despite the odds made

her feel accountable only to herself. This gave her immense determination in securing her own death and feeling responsible for that decision. So while she was not encumbered by “bad faith” in that she was prepared to accept her radical freedom of choice, she was also “condemned to be free” (Sartre 1996) because in making the hardest of all her choices, she had to sacrifice a part of her faith (for which she felt condemned). She told me: “without Him [God] I would have to be more selfish. I would have to believe in me.” Ultimately, it was her belief in herself as the originator of her choices (God, after all, had “opened no doors” for her), and her willingness to take responsibility for those choices, that enabled her to take her own life.

De-Christianisation of Suffering

Sheila’s conflicting feelings of wanting to determine her own fate while at the same time seeking God’s approval as a father-figure exemplifies the feelings of most of the Christian believers I spoke with who were considering an assisted death. When I asked Sheila if she believed she would be eternally damned for her action, she said she no longer believed in a physical place called hell (“hell is here on earth”, she told me). Tierney (1993:156) comments that in late modernity, even though people may be willing to profess their faith in a Christian God, the idea of heavenly immortality has receded from the forefront of people’s imagination, and therefore this belief no longer convincingly guides human actions – it is no longer a “life strategy”, to use Bauman’s term (1992). Although the need for God remains strong because of our anxiety about our mortality, Tierney persists, the idea of a realm of immortality, access to which is determined by God, can no longer offer us the comfort we desire. Instead, we find ourselves turning to convenience and technology *in this life* as a way of denying the body’s limits (1993:156). This idea is supported by research conducted in the U.S. which found that people who prayed regularly were three times more likely to receive intensive life-prolonging care (Phelps *et al* 2009). It was the convenience of a technologically assisted death that gave Sheila the comfort she sought, not the thought of a place in heaven if only she waited for a ‘natural’ death.

One may ask why I have chosen to focus on Christian narratives of suffering and the conflict between one’s own decision-making powers and divine authority. Religious

interpretations of suffering, one might argue, are not the standard interpretation in modern secular Britain and therefore can only be illustrative of a minority viewpoint. As Bruce (2002:60) tells us, church membership and attendance, numbers of full-time clergy and the popularity of religious rites of passage (baptisms, marriages, funerals) can all be used as indicators of the decline of religious institutions and increased secularisation in Britain since the 1950s²⁶. And yet, despite evidence of secularisation from such indicators, it would be simplistic to assume a historical teleological progression from religious to secular interpretations. Suffering still remains variously contextualised and ideas and justifications overlap, as Sheila's internal dialogue demonstrates. Asad (2003:12) for one disputes the notion of some blanket secularism being attributable to the modern West. Although secularist ideology purports to be able to mediate between conflicting, heterogenous experiences (2003:5), in fact, contemporary societies are far from being the "integrated totality" (2003:13) such ideology might lead us to expect. The diversity of belief leaks through and the sacred and the secular continue to depend on each other (Asad 2003:26). "The secular", as a concept, "brings together certain behaviours, knowledges, and sensibilities in modern life", which are distinct from Christian practices and discursive grammars (2003:25). Christianity and secularism are distinct, but they coexist in Britain today. Hence the need to understand Sheila and Sara's religious interpretation of their suffering which coexist alongside other secular or medical narratives.

According to most commentators, as the meaning of suicide became progressively (although not uniformly) medicalised and secularised in the nineteenth century, so too did explanations of pain and suffering. Caton (1985:497), for instance, argues that between 1800 and 1850 anatomy and physiology developed to the point that, in the medical sciences at least, pain became purely a biological phenomenon devoid of religious connotation²⁷. However, as Sheila's story shows, religious connotations still

²⁶ Bruce (2002:71) also cites opinion polls and attitude surveys which chart a steady decline in Christian beliefs since the 1950s (although claiming beliefs, interestingly, does not always coincide with active churchgoing).

²⁷ Advocates of assisted dying would disagree with this statement, attributing the strength of the Christian Medical Fellowship's opposition to legalising assisted dying to a persistence in the belief that there is religious meaning to be found in suffering.

persist despite this generalised shift. Lavi (2005:6) also states that the law of the deathbed during this period shifted from religion to medicine. Dying in the Christian world up until that point was a “work of art” (Lavi 2005:9). Lavi uses the term “art” to indicate that in this one moment of life – dying – the whole of a believer’s life could become present in its uniqueness:

Death was a moment of truth in which the dying person... faced the ultimate truths of Christendom: immortality of the soul, sin, and God’s saving grace (Lavi 2005:10).

Methodists, for example, used to publish the details of exemplary deathbed scenes in their journals under the title of “biographies.” The art of dying on the deathbed was therefore a microcosm of how a person had lived their life, and specifically whether they had lived it in a godly way (Lavi 2005:10,14). This “art of dying” is surely reminiscent of the *Rosetta Life* artistic enterprise that recognises in the protracted dying experience of hospice patients the possibility of a space for transcendence and heightened self-knowledge. Lavi suggests, with reference to these Methodist “biographies”, that suffering was understood to have a purpose because it had the power to redeem sin and purify the soul (2005:35). To draw parallels with *Rosetta Life*’s work, I do not mean to claim that the charity finds a religious meaning in suffering, or indeed meaning in suffering at all. In fact, the charity has a principled opposition to using the term “suffering” (see Chapter Three, *p106*). Its artists focus instead on the meaning that can come through the art itself, bypassing, or at the very least minimising any suffering experienced by the hospice patient. The parallel that I want to draw between the *Rosetta Life* and the Christian interpretation is this: that the dying period offers a space for reflection, for an examination of one’s life or one’s biography, and therefore for increased authenticity of ‘self’ in the approach to death.

Pain and suffering in this Christian art of dying served a purpose. They had the power to awaken a person to their sins, and thereby to redeem those sins through their search for grace (Lavi 2005:35). Suffering was also considered to bring a person closer to Christ, who had suffered on the cross. For Bowker (1970:46), it is the crucifixion which epitomises the fearful agonies of human suffering while at the

same time signifying the ability to transcend suffering as Jesus did through his resurrection. Equally, suffering could signal that a person was one of God's chosen few because only they would be put through such terrible trials in order to reap the rewards in the hereafter (Rey 1998:48). The close association of pain and suffering with punishment of some kind persists in spite of the decline in religious beliefs. It is interesting to note that the word "pain" actually derives from *peine* in Middle English, meaning "punishment" (or similarly *poena* in Latin or *poinē* in Greek, both meaning penalty)²⁸. The etymology of the word shows just how closely associated pain was with punishment, and this linkage continues to be expressed in general sentiments such as "what have I done to deserve this?" Sara, who wants to travel to *Dignitas* to relieve what she describes as "intolerable" spinal pain, says that although she can rationalise that people have to suffer because "we live in a fallen world"²⁹, emotionally she cannot escape from the question "why me?" and the idea that "life isn't fair."

Slowly the common interpretation of pain has become 'de-Christianised', dissociated from signifying punishment for earthly sins before God or a 'test' of one's religious faith. At least on the surface there has been a weakening of religious discourses, if not moral discourses, to describe and interpret pain. Campbell (2003) argues that it was the isolation of morphine from opium in 1806 that was pivotal in the re-conceptualisation of pain in dying. Only once pain could be alleviated by analgesics could attempts to rationalise it be abandoned. Lavi's account contradicts Campbell's premising of the technological imperative. For him, the de-Christianisation of pain on the deathbed arose as a result of secularising trends and our desire to control nature, which arose in advance of the technical mastery of analgesics (2005:14). Yet both agree that once pain had been de-Christianised it was turned into a medical 'problem' instead. Once it had been medicalised it could only be understood in terms of necessitating immediate eradication:

²⁸ Random House Dictionary.

²⁹ A biblical reference to Genesis, where Eve, the first woman on earth, eats the forbidden fruit in the Garden of Eden, and so is cast out with Adam and made mortal. This is the story of "The Fall" of mankind, or "original sin" which "brought death into the world, and all our woe" (Milton 1892:43). Augustine, one of the fathers of Western Christian theology, placed responsibility for human punishment and suffering squarely on Adam's shoulders thereby defending the justice of God.

Pain became senseless precisely because the only sense that it had was given to it by the medical machinery aimed at annihilating it (Lavi 2005:74)

Of course, pain can be generally understood to act as the body's warning system, alerting one to the dangers challenging the body. Yet it becomes more difficult to apply this meaning to pain in dying because there is no longer any utility in alerting the body to its condition (Lavi 2001:152). Dr Rob George, a palliative care consultant at a London hospice and a key opponent of assisted dying, pointed out to me that the very instrumentality of pain is its unpleasantness; it alerts you to a problem, or it prevents you from doing something (for example, keeping your hand over a flame). In conversation, Dr George likened this instrumentality of pain with the instrumentality of suffering. That although pain and suffering may be intrinsically bad, the very fact of their badness may bring about an instrumental good. This instrumentality gives them meaning. For Dr George, the 'good' which could come of this 'bad' is that it can lead a patient to face the unresolved issues of their life, to "right the wrongs", and to say their "goodbyes, sorrys and thank yous"³⁰. This implies that there is some virtue in suffering, and that patients who have resolved their issues will be able to "let go" and die peacefully. This point proved controversial when he raised it in the Select Committee formed to discuss Lord Joffe's assisted dying Bill³¹.

George's view has parallels in Illich's (1976) argument that the virtue of suffering is that it makes a person more compassionate to the suffering of others. According to Illich, pain-killing technologies which do away with suffering have a corrosive effect on our humanity because they destroy "the repertoire of symbols" we have to express it and thereby "anaesthetise" our capacity to feel for others suffering (Illich 1976:132). Suffering and dying, he believes, are now treated as "malfunctions from which populations ought to be institutionally relieved." Indeed, many people for

³⁰ Rob George, personal communication, April 2007.

³¹ Baroness Hayman and Baroness Jay of Paddington both criticised Dr George for his use of "pejorative language" to describe patients who could not "let go" and die as if, somehow, it was a fault of character.

whom pain has been made “senseless” through a process of medicalisation, can simply find no instrumental “value” or “virtue” to be gained. Doctors are now expected to relieve pain, and pain that they cannot relieve represents a medical failure. This presents a major challenge to palliative medicine. If there is no meaning to be found in pain at the end of life, and that pain also resists analgesic drugs, then its persistence tends to exacerbate calls for legalising assisted dying. Whether medicalisation or secularisation came first, the pro-assisted dying lobby is founded on the principle that pain in death is “senseless”, that there is no meaning in suffering at the end of life. This is crystallised in the motto “an end to suffering rather than suffering without end.” Examining the testimony of people like Sheila and Sara highlights that people do have residual religious fears of possible punishment in the afterlife for their ‘choice’ of death, despite widespread “de-Christianisation.” Their Christian beliefs, rather than providing a source of comfort in their pain, often seemed to compound their distress:

I desperately want God to forgive me [for going to *Dignitas*]. I can only hope that he will (Sara 2008).

Can we say that pain and suffering are ever “senseless” or “meaningless” and devoid of some kind of interpretation? Questions such as “why me?” or “why did this person die of cancer and not that one?” can persist in spite of the loss of a religious moral framework. Csordas (1993) argues that pain and suffering can never be interpreted *outside* of culture because they are always experienced *in* culture so are always “socially informed”. Perhaps the assisted dying lobby’s reading of pain-in-dying as “senseless” is in itself a culturally premised view, in that it gives pain a meaning by the very fact of decrying it as futile.

The Problem of Suffering

Can we differentiate pain from suffering? And can we argue that these experiences emanate from the mind, the body, or the external social and material world? While neuroscientists recognise pain as a salient feature of the nervous system, social scientists are concerned with pain as a ubiquitous feature of human experience (Good

et al 1992:1). Jean Jackson (1994:201), in her study of a chronic pain treatment centre in New England, U.S.A, defines pain as both sensation and emotion. She argues that “the pain experience” cannot be separated from other experiences accompanying pain, and cannot somehow be viewed apart from “real” pain itself (1994:203). Pain collapses the Cartesian dualism between the mind and the body because emotional and physical pain are both experienced in the body (1994:223). Jackson’s phenomenological analysis of people’s experiences of living with chronic pain which for Sara “is always just constant”, contradicts Scarry’s (1985) view that there is a clear-cut distinction between physical and emotional pain. For Jackson (1994:225), the best way to describe pain is that it is “pre-objective” – not yet incorporating any kind of subject-object distinction, a difficult notion to grasp. Yet it is in-depth studies such as Jackson’s which challenge the widely held view that “pain is more objective than suffering” (Finn 1986:4). Both are embodied and both are part of lived experience *in* the world. It was certainly my experience when conducting research that the words pain and suffering were often used interchangeably by research participants. However, when pressed on the difference between the two they would associate pain with a physiological condition that could be pinpointed to a specific area of the body. Suffering, on the other hand, was experienced as a more diffuse condition of existence. As one of my right-to-die activists explained to me, people can suffer without being in pain. They can suffer because of a lack of choice. To illustrate the point, she told the story of a friend of hers who had to sleep on pink sheets in an “oppressively religious” hospice when she hated the colour pink and she had been an atheist all of her life. This lack of choice about her place of death caused her friend to suffer, she told me.

Cicely Saunders’s concept of “total pain”, which I outlined in my brief history of the hospice movement in Chapter Three, merges bodily experience with this more diffuse idea of suffering. “Total pain” is arguably the one original concept that hospice and palliative care have yet produced (Clark 2005:137). It takes account of physical, psychological, social, emotional and spiritual aspects. Suffering is not just ‘of the body’ or ‘of the mind’, it is also ‘of the social world’ and part of one’s personal experience and relationships. People use the idioms of bodily pain to

express more generalised suffering, which is often the result of complex inter-subjective processes (Good, Brodwin, Good, Kleinman 1992:12). Saunders's concept of "total pain" and its multiple causal factors prefigures the development in the social sciences of the concept of "social suffering", pioneered by Kleinman *et al* in their edited collection (1997).

For these authors, social suffering links personal problems with societal problems (1997:ix). They highlight the simple idea that suffering is a social experience, founded as much on interpersonal experiences as on the psychological or medical problems affecting the individual. There is an interconnectedness between the physical body and the social world inhabited. For example, the fact that Sheila did not have a family and had been abandoned by the majority of her friends and colleagues, in her own estimation, contributed to her decision to seek an assisted death. If she had family responsibilities, she told me, she would perhaps have made a different decision. Her suffering was compounded by the fact that she did not have adequate social support networks and that people did not want to "hear about her illness anymore". Yet it is precisely this multi-dimensionality of suffering that presents us with a serious analytical problem when trying to unify or classify people's experiences of pain and suffering. Understandably, we desire to find a common list of causes for and shared experiences of suffering which go beyond an individual's subjective determination that "I am suffering because I am forced to sleep on pink sheets". But as soon as we try and catalogue the causes of suffering as poverty, hunger, disease, war, bereavement and loss, social isolation, social injustice etc the list becomes inexhaustible because human events and experiences are so vast and varied. Equally, to ask what character suffering assumes becomes similarly individual specific, eventually resisting any unified characterisation. Once we say that suffering is a subjective experience, it can have infinitely variable causation and character. As Sheila said to me: "we don't know anyone else's pain."

This "burden of analytical frustration" (Wilkinson 2005:45) which besets social scientists examining the problem of suffering, also beleaguers the assisted dying lobby in its attempts to define and delimit the term "suffering" in proposed

legislation. The 2006 House of Lords Bill *Assisted Dying for the Terminally Ill* (ADTI) sets out to:

Enable a competent adult who is *suffering unbearably* as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request (my emphasis).

This term “suffering unbearably” was taken directly from the Dutch legislation³². When the ADTI Bill was scrutinised in a Select Committee, there was a great deal of concern at the term’s vague, subjective, and worryingly expansive definition (2005:48). As Hastrup notes (2003:312), there is a problem translating subjective experiences of suffering, which so often escape definition, into ‘objective’ legal measures. Lord Joffe, the cross-bench peer who introduced the ADTI Bill to the House of Lords, himself argued that a patient’s own subjective assessment would have to be confirmed as “reasonable” by an attending physician. But as a Swiss physician giving evidence to the Committee pointed out, “physicians have no particular expertise for unbearable suffering.” This is because of its multi-factorial component, as highlighted by the “total pain” and “social suffering” concepts.

There is also the fundamental problem that people who are not terminally ill could also be said to be “suffering unbearably.” For example, I am certain many of the people in Jackson’s pain clinic would describe their suffering as “unbearable”. Certainly Sheila described her suffering as such, and her disease was not terminal or life-limiting in any way (although it eventually became so because of a deliberate act taken by her). To therefore limit the scope of the Bill to people who have “a few months” left to live would be to judge their ‘right’ to have an assisted death on the grounds of prognosis rather than on whether they were “suffering unbearably.” When summing up, the Select Committee suggested that any future Bill should replace “unbearable” with “unrelievable” or “intractable” which would enable a more objective medical assessment of suffering to be made (2005:87). This suggestion returns us to the seemingly inescapable problem of whether suffering is subjective or

³² The Netherlands passed the *Dutch Euthanasia Act* in 2002, codifying the twenty-year old practice of euthanasia by Dutch doctors.

objective, 'of the mind' or 'of the body' and if it is possible to devise any external criteria of assessment.

The question of what qualifies doctors to be able to assess a person's suffering was raised by many of my research participants who expressed a wish to have an assisted death. The general view was that only they could judge their own suffering and say when it was unbearable or intolerable. Philip, who wanted to travel to Switzerland for help to die, commented:

Just because a person has a medical qualification doesn't mean that they know better what is for my best advantage.

Many of the people I spoke to who were planning their death refuted the professional's role in mediating between their suffering and their desired choice of death. When Sara requested a short medical report from her doctor for her application to *Dignitas*, they told her they wanted "nothing to do with it." While they refused this request, she also felt that they denied her any "basic" compassion for her "intolerable" situation:

They have never held my hand and said "sorry things are like this." They have never shown me any empathy. They don't like people who are chronically sick because they are persistent and can never be cured.

Indeed, the refusal of the medical profession to assure patients expressing such fears that they will help them to die when the time comes is interpreted as directly contributing to their suffering. Somerville (2001:208) writes that suffering can be experienced due to an absence of any power to control or to influence, in any meaningful way, the process of one's own bodily disintegration. Elias (1994) was the first to propose that it was the "civilising process" of the 12-18th Century which inculcated in people a sense of shame and repugnance at natural functions (sex, eating, excretion, *deterioration*) and at certain behaviours (unregulated emotion, for example). Self-control became the new standard of behaviour to adhere to and the new paradigm for social life. To then deny people an element of control over their

final years, days or hours when they have exercised self-control throughout their lives, assisted dying advocates believe, can contribute to their suffering. Yet the central paradox of this argument is that while assisted dying advocates are opposed to any medical determination of what suffering is or does, they still want to imbue the medical professional with the power to bring an end to their suffering when the time comes. They simultaneously resist medical assessment—opposing the professionalisation of death - yet they still require that doctors to meet their demands. Once again we see “senseless” suffering at the end of life given meaning through its demanded annihilation (Lavi 2005:74). Its annihilation through hastened death would ultimately become medicine’s own theodicy. This unresolved paradox also crucially leaves unchallenged the role of medical authority in shaping the convictions by which we live.

Solutions to Suffering

Assisted dying is one solution to the “problem of suffering”. However, there are other solutions advocated. Those who oppose any form of legalisation argue that energy and resources would be better focused on improving palliative care and pain relief. Life peer and palliative care consultant Ilora Finlay rationalises it as so:

During the [Joffe] debate... a huge number of people who were advocating assisted dying have had a bad experience of someone dying in the past, and it has just been straight bad care. And when they describe it, you think, that’s inexcusable, that should never have happened. But the answer to bad care is to improve care. It isn’t to kill the patient.

Baroness Finlay, a staunch anti-assisted dying advocate, regards “unrelievable pain” as presenting a challenge for palliative medicine rather than a failure. To legalise assisted dying would be to accept the current limits to medical knowledge about pain relief and symptom management and to freeze their development. Hospice care, by its own admission, has focused on symptom relief for people living with cancer, and historically neglected rarer neurological and degenerative diseases, such as MND and Parkinson’s, or respiratory diseases, all of which result in longer and less predictable dying trajectories. More research needs to be done into relieving the suffering of people living with these diseases, detractors argue, before assisted dying can be

offered as an alternative to palliative care. Another solution to “the problem of suffering” is to enable people to tell their stories. Cicely Saunders explicitly tied the concept of “total pain” to narrative and biography, emphasising the importance of listening to a patient’s story in order to understand their experiences of pain in a multi-faceted way (Clark 2005:137). Michael Jackson’s (2002:36) work on the role of storytelling in forging continuity of ‘self’ is significant here. Narratives of suffering can assuage or relieve the experience of suffering itself because they change the perception of the narrator from victim to agent. However, the therapeutic effects of self-narration can be overstated and are sometimes overly romanticised by the hospice movement, as I discussed at length in Section One of this thesis. The idea that telling someone “your story” at the end of your life can relieve all of your suffering is deemed a highly suspect and rather condescending proposition for assisted dying advocates.

One of the foremost questions of the assisted dying debate is whether these solutions to the problem of suffering at the end of life are mutually exclusive. Those who oppose legislation believe that they are. Once hastened death becomes a medical option, or a medical good, it will become the easiest form of relief to dispatch, they argue.

It is much easier to look after a dead patient than to look after a live patient in front of you, where what you have done hasn’t worked and you have to go back and you have to question your own decisions and you have to try to think imaginatively. That is much harder work (Baroness Ilora Finlay in conversation 2007).

Other possible solutions to suffering-in-dying, whether they are better drug combinations and doses, more social care support, or having someone listen to your story might be overridden if there is an easier option to hand.

Those who support a change in the law, on the other hand, argue that these solutions are all compatible and that palliative care options can exist alongside the option of assisted dying. The people who are likely to opt for each solution to their suffering will have different requirements and needs, all of which need to be catered for in the

one healthcare system. Some people need more than a recognition of their suffering, they argue. They need their suffering to end. And the sooner the better.

The Fears of the Opposition

Those who oppose assisted dying fear both the expansive nature of the “suffering unbearably” category and what they anticipate to be the inevitable restriction of the medical and compassionate solutions to suffering – the premature “throwing in the towel” by frustrated doctors as Ilora Finlay put it to me. The first of these fears relates to what is generally known as the “slippery slope” phenomenon (or what philosophers term “consequentialist” arguments), while the second relates to a fear of an irreversible change in the medical profession’s ethics and code of practice. These are the two fundamental fears that I identified during the course of countless conversations with people who oppose any change in the law on assisted dying. Of course, it should be noted that much popular opposition to the Bill is religiously motivated. These religious fears are founded on the principle of the sanctity of human life: because human life is created by God, in his own image, only he is authorised to take it. By that rationale it is, *without exception*, morally wrong intentionally to kill another human. Given that this principle no longer has any foundation in law (since the landmark Bland decision³³), I will focus my current analysis on opposition arguments that can still reasonably (according to legal reason that is) be upheld as a defence against legalisation.

The “slippery slope” argument, as it is commonly known, can be sub-divided into five categories, as helpfully outlined in The House of Lords ADTI Bill (2005). I will call these categories fears. The first fear is that, in time, the law would undergo incremental extension so that assisted dying would eventually be available for younger, non-terminally ill people. In other words, once the *principle* of intentional

³³ In the case *Airedale NHS Trust v. Bland* [1993] 1 All ER 821 HL, the judges in the House of Lords directed that Artificial Nutrition and Hydration (ANH) be withdrawn from Tony Bland, who was living in a Persistent Vegetative State, as a result of which he died. The withdrawal of ANH, which was classified as “treatment” and could therefore be withdrawn, was not considered homicide because it was classified an “omission” and not an intentional “act.” According to most commentators, the case was significant in that it marked the final switch from the sanctity of life to the quality of life principle as the basis of British law.

killing has been revoked, there can be no future principled opposition to an extension of the law. The second fear is that there will be an elastic interpretation of the law's provisions. This relates to the idea that doctors using the Act will not adhere strictly to the qualifying conditions of the Act. With regards to this fear, many opponents to legalisation like to draw parallels with the Abortion Act (1967), and the disparity between the intention of that Act (for abortion to be an *exceptional* procedure) and the reality (198,500 abortions were carried out in England and Wales in 2007³⁴). The third fear is that of "hidden pressures" which describes how people, in particular the elderly and the "vulnerable", may be made to feel a "burden" by others, particularly their relatives, and so avail themselves of the law to satisfy others. This fear seems to have an especially strong hold on the public imagination. The fourth fear listed in the ADTI Bill is of abuse of the law, which may go undetected because of the smokescreen which any, albeit restricted, law may provide. This fear has been exacerbated since the conviction of the G.P. Harold Shipman, Britain's most prolific serial killer who notoriously killed an estimated 250 patients with overdoses of diamorphine (Shipman Inquiry 2004³⁵).

The fifth and final fear listed is that there will be a paradigm shift. This ties the "slippery slope" argument to my second outlined fear that there will be an irreversible change in medical ethics. Once the law is changed, so the theory runs, an assisted death becomes a morally acceptable form of therapy; conceived of as a medical 'good'. Dr Rob George states the case like so:

You cannot sustain the idea that things are not going to change if you reclassify something. And one of my arguments has been that to dress up this paradigm shift in medical duties and society's perception of therapeutic killing, or to introduce the idea that killing can be therapeutic in and of itself, *has* to lead to the recognition that that must be available to anybody based on a best interests argument. Regardless of the capacity of the individual. You cannot get away from that. And therefore the idea that you can limit it simply makes no sense at all.

³⁴ The Department of Health Official Statistics for England and Wales
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_085508
(accessed 20th January 2010)

³⁵ www.the-shipman-inquiry.org.uk/home.asp

The opinions expressed here clearly incorporate the “slippery slope” idea, but also show a fear of the effects of legalisation on the moral framework of the doctor-patient relationship. In conversation, Dr. George was concerned that people advocating for a change in the law want the entitlements, but do not want to assume the responsibility, leaving the ‘act’ itself up to the doctors, who consequently have to shoulder the responsibility:

Do the dying have moral responsibility? The suggestion...is that somehow being given a terminal diagnosis gives people entitlements to make claims or demands which under normal circumstances no one would give a second thought to, for example, somebody saying “I no longer wish to live, in fact I want to die, in fact I want to be killed”. And somehow that translates into some kind of obligation for other people to do it... which is bizarre!

This references the central paradox of the assisted dying debate: that advocates want to resist medical determinism and the professional pathologising or romanticising of dying but yet they declare that they *need* those same doctors to enforce the proposed law and dispense the requisite lethal drugs. Dr George asked me to consider the moral responsibility of patients who ask their doctor to help them die: “is it justifiable to expect me to kill you in your “best interests?” and “Is the dying person handed a carte blanche?”

Assisting in a patient’s death, detractors argue, would contravene the medical ethical code laid down in the Hippocratic Oath:

To please no one will I prescribe a deadly drug, nor give advice which may cause his death (Mason & Laurie 2006:Appendix A).

This Ancient Greek code of practice is attributed to the Hippocratic “school” of the 5-4th Century, B.C., and was devised in order to bring uniformity and integrity to a profession beset by charlatanism (Carrick 2001:192). The guidelines laid down in the Oath include the protection of the public against charlatans, that the doctor must do good and avoid doing harm (what are now known as the principles of beneficence and non-maleficence), that euthanasia and abortion are proscribed, that the doctor must not take advantage of his patients, and that he will maintain confidentiality (Mason & Laurie 2006:12). Although most British medical schools no longer require

a reiteration of the Oath at graduation, it still holds a “persuasive influence”. Although one might have anticipated that the legalisation of abortion would have undermined the code’s other guidelines, the prohibition on euthanasia continues to be cited.

One reason for persistent references to the need to defend the Oath might be that its endurance symbolises just how long the debate about medicalised assisted death has been raging. For many doctors, its prohibition in the Oath represents a moral absolute and to break that would be a “paradigm shift” too far. There might be “collateral effects on the doctor-patient relationship” (Randall in ADTI 2005:43) which represent an unknown risk. As Beck (1992:22) points out in his analysis of our modern “risk society”, there are always “incalculables” which no expert can predict. Fear of a slippery slope, in all its forms, and fear of the unknown and unrehearsed make opponents strongly believe that the current “grey” legal situation is a better proposition than any change in the law could bring.

The Fears of the Proponents

When I began the research for this thesis, I hypothesised that when people could anticipate dying, they would become preoccupied with making choices and decisions in advance of their death in order to heighten their preparedness for dying. But during my research, it became apparent that this preoccupation with choices and decisions was actually a way in which people were managing their fears. These include fear of suffering and pain in dying, fear of bodily disintegration and loss of bodily functions, the loss of an ability to experience pleasure and to interact meaningfully with others, and fear of a loss of control over one’s life.

Our generalised fear of death can in and of itself be a cause of existential suffering.

Death and its denial – Immortality – have always formed, as they form today, the most poignant theme of man’s forebodings (Malinowski 1948[1925]:47).

Yet one of the recurring mottos of right-to-die advocates is that it is not death that people fear, but the ‘process of dying’. As Elias (1994) theorised, our concept of ‘self’ in the modern era is tied to our ability to manage our natural functions. Lawton’s hospice ethnography (2001) about the disintegration of ‘self’ as a result of ‘unbounded’ and ‘leaky’ bodies encapsulates the worst fears of the right-to-die movement. Lawton indeed is a celebrated figure among activists I met because she revealed the ‘truth’ about ‘natural’ dying - that it can be slow and painful. The ADTI Bill was targeted at just the type of people Lawton depicts in her ethnography, patients who are in the ‘terminal’ (rather than ‘life-limiting’ phase) of their disease and are suffering due to “unrelievable” pain which can be “objectively assessed” by medics. Dianne Pretty’s main concern in bringing her case to the European Court of Human Rights was that she would choke to death, which is a common fear among people living with MND. Yet fear of bodily disintegration is not the only fear of people advocating for assisted dying, or people travelling to Switzerland to get help to die. Most of the people I spoke to did not have a ‘terminal disease’ although all had a disease that was ‘uncontrollable’. And to my mind this is the key factor for those seeking or lobbying for the legalisation of assisted dying – control. This can be control over one’s body, over one’s symptoms, or over one’s destiny.

Philip’s Destiny

Philip is 90 and lives with his wife Hazel in North London. He has always had the conviction that he wants to be in charge of his own destiny, he told me. He wants to make his own decisions and not be dependent on other people’s judgment. Philip was a Jewish émigré to Britain just before the outbreak of World War II. He escaped Austria and fled through Romania, Yugoslavia, Italy and France to arrive in the U.K. Having begun to study Maths and Physics in Austria, Philip got a job as a Physics teacher in the north of England, after which he became a university lecturer. Eventually, he left the university, and went to work for the British Iron and Steel Federation, then the civil service and finally became a management consultant, travelling all over the world. He told me: “I have been bathed in luck. I was never that ambitious, I just chose work which fascinated me and I have been very lucky. I feel that I have made contributions to society and that I still do.”

In his late eighties, Philip developed colon cancer. He had an operation to remove half his colon, but he declined any further treatment. It was at this point that he started making enquiries to go to *Dignitas*, with his wife's support. A life member of the *Voluntary Euthanasia Society* (now *Dignity in Dying*), he had always made provisions in the case of misfortune. He had also been an avid sailor and climber for most of his life and, because both are dangerous sports, he deemed it part of a risk management strategy to have a "living will" and to have discussed possible eventualities with his loved ones. However, his attempt to secure a "green light" from *Dignitas* failed when tests showed that his cancer had gone into remission. There was no longer any 'objective' or verifiable reason why Philip should be helped to die. In the intervening time, Philip had developed another condition that was causing him even more anxiety. His mental faculties had begun to deteriorate. He was, in his own words, suffering from vertigo, memory loss, and feeling increasingly disorientated.

Since meeting Philip, I have followed his attempts to get help to die for about two years. He now has a date for his "accompaniment" in Switzerland. The ins and outs of his negotiations with the organisation and his liaising with psychiatrists in this country is a fascinating story in itself. Philip has had to fight hard to get what he wants and his dogged persistence is evidence enough of the strength of his will:

I have always been influenced by the two French philosophers, Sartre and De Beauvoir. That it is by one's own actions that you can change your environment. By my own actions I can meet my responsibilities. The very last thing I want is to be in the hands of others. I do not want to be dealt with as a medical object.

Like Philip, Sheila too believed that it was "her responsibility" to find a solution to her suffering. And crucially, both articulated a need to control their environment and their future. An assisted death offered a possibility for control. A staunchly academic character, Philip's greatest fear is now the disintegration of his mind and what he perceives to be an inevitable dependence on others. He says he does not want to be kept "alive" against his intentions. This, to his mind, is contrary to his sense of 'self':

I don't regret this decision, I don't feel the need to hang on to life. I was alive to see people who were 30, 35, 40 who were caught by the Gestapo and didn't get to live the full life that I have done. They were caught up in the wheels of what was happening at that time, which I was lucky enough to escape. I have had an amazing life and I don't regret anything.

The difference between Philip's destiny and that of his friends killed in World War II is that assisted dying gives him the option to control his. Just as people seek to control the accidental and the unpredictable through insurance policies, so they seek to control the predictable – death - through pre-detection. As Beck states, our "risk society" has brought the dawn of a "speculative age" where each is as well-positioned as the next to know about future risk (if to know means to have consciously experienced) (1992:72-73). Experts no longer have a monopoly on making rational judgments or predictions and people are now involved in their own "reflexive politicisation" (Beck 1992:77). Health technologies and self-surveillance of the body are increasingly applied to pre-detect or *anticipate* illness, and, more importantly, the potentiality for suffering. Not only are we responsible for our own bodies through self-surveillance, we also have a responsibility to avert potential hazards to our bodies through the maintenance of control. Elias, like Foucault, believes our attitudes towards "outward decency" have informed a distinct relationship to 'self' and therefore a distinct ethical code. Just as we do not want to be made vulnerable to the dictates or behaviour of others, we do not want to be subject to the deterioration of our bodies. If the Enlightenment gave us science by which we gained an ability to control nature by artificial means, then the "civilising process", by which we build "a wall of deep-rooted fears" around each one of us (Elias 1994), has given us the assisted dying movement.

The irony at the heart of Philip's case is that in order to get help to die at the Swiss organisation, Philip has to prove that he is mentally competent to make his own decision to die by producing psychiatric reports. Yet his very reason for applying for help to die is the onset of mental incapacity! He is stuck in this double bind precisely because he *anticipates* his own mental deterioration or "helplessness," as he calls it, through his practices of self-surveillance. For example, he has been attending the

“Cognitive Disorder Clinic” at a Neurology Hospital in order to monitor his deterioration. By maintaining control, Philip feels he will be exercising his own ethic of freedom to avoid the suffering he anticipates. This view, shared by many in the right-to-die movement, inheres a certain self-referentiality that asserts that only the individual himself has the power or freedom to determine the value of his life, and the destiny he chooses. It is when Philip’s freedom is challenged by the limits of his body in sickness and infirmity that he wants to pursue his “ultimate freedom”, the slogan used by the French right-to-die society³⁶. By opting for an “artificial” end, he believes he will be able to preserve the sense of ‘self’ he has spent a lifetime fashioning.

Conclusion

Philip’s desire for control and his resistance to being “dealt with as a medical object” are key factors in his determination to end his life. So why does he need a doctor to help him? Does involving the medical profession not run the risk of affecting a “paradigm shift” in medical ethics, as Dr George fears, or of forcing doctors to shoulder the “moral burden” of a patient’s so-called entitlement? Philip disagrees:

Doctors take a medical oath by which they agree to use their knowledge and experience to the best advantage of the patient. And that, crucially, it is for the patient to decide what that best advantage is.

Doctors have access to the drugs and the medical knowledge that could enable them to assist in a way that is “foolproof” (as my interviewee, Morna, hopes) and without any painful side-effects. Prescribed drugs could give people the “natural”, painless death they desire and envisage for themselves. Returning to the self-deliverance workshop I depicted at the beginning of this chapter, it does not take a huge leap of the imagination to envisage the potential risks for people attempting their own ‘final exit.’ Taking your own life with a helium tank or a ratchet-tie-down does not give you the same guarantee of death that a small cup of sodium pentobarbital³⁷ does. It is

³⁶ ADMD (Association pour le Droit de Mourir dans la Dignité)

³⁷ This is the drug which is used at *Dignitas*.

the doctor's technique that they want to be applied in the service of their desired end. By removing any element of unpredictability or risk associated with the act (see Castel 1991), you normalise the outcome, and also normalise the act. You also make it easier for those left behind who may have to discover a "self-delivered" body. To make the act "foolproof" through medicalisation also makes it legitimate in people's imagination. For example, Sara told me that *Dignitas* will make her death "civilised and certain." To have a medical professional facilitate one's death confers a legitimacy on the act. The fact that there is a system in place, for Sara, means that there is recognition on the part of others in society for her suffering. *Dignitas*'s "green light" shows a recognition of her suffering in a way that her G.Ps reluctance to hold her hand and tell her that he is "sorry things are like this" does not.

However, for every averted risk of a botched self-deliverance, new risks are created. Writing about the "rationalising dream of absolute control", Castel (1991:289) argues that our fears and desire for security induce a "delirium of rationality" combined with "thoroughgoing pragmatism" which aims to eradicate risk as if one were pulling up weeds. Yet for every risk eradicated, more are constructed which then constitute more targets for preventive intervention. Risks beget risks as fears beget fears, and we find ourselves on yet another slippery slope. Knowledge of the techniques of self-deliverance acts as an insurance policy for people, as does the option of travelling to *Dignitas*. This knowledge comforts people as they contemplate the end of their lives. Perhaps it even insures them against suffering. Ewald (1991:207) writes that insurance arms us against ill fortune and thus helps us to discipline the future. He writes that:

Above all, it means no longer resigning oneself to the decrees of providence and the blows of fate, but instead transforming one's relationships with nature, the world, and God so that, even in misfortune, one retains responsibility for one's affairs by possessing the means to repair its effects (1991:207)

All the people whom I interviewed who were proposing to travel to *Dignitas* were trying to avert the "blows of fate" and make their death meaningful to them by transcending the suffering which stood between them and it. Their insurance policy

would enable them to bring an end to their suffering, while also enabling them to preserve some of the essential character or quality of their lives.

CHAPTER SIX

From Euthanasia to Patient Choice

I conducted an interview with palliative care consultant, Dr Rob George, in his car as he drove around South West London making house calls. One patient he visited had died overnight, so we drove back to the hospital to pick up a death certificate to then drop off with the family. Dr George is an eccentric and highly enthusiastic character in his late 40s. Within five minutes of meeting me he suggested that we co-author an article on, in his words, “the moral responsibility of the dying.” He wears a monocle and a mobile phone earpiece by which he affects an air of being much in demand. Despite his hectic schedule, he kindly made time between house calls to discuss end-of-life issues with me. Dr George would dash out, leaving me in the car, and return 20 minutes or so later to tell me of his encounter. The juxtaposition of our theoretical, abstract discussion about what it means to be dying with his face-to-face encounters with patients, for whom our theorising was a lived reality, struck me as significant. Dr George is a tireless anti-assisted dying activist as well as a clinical practitioner and his motivation for engaging with the issue in the way that he does arises from a combination of his clinical observations and his own well-formulated belief system. It is his engagement with hospice patients over the years which has fuelled his passionate opposition and, significantly, gives him professional credibility when debating the issues.

My interview with Rob George about the pros and cons of legalising assisted dying centred on his historical reflections as to why the debate has become so prominent in recent years. For him, the calls for the ultimate control over the timing of one’s death can be traced back to the loss of “structures” – the moral structure provided by religion and the social structure determined by class – which resulted from the devastation of the First World War. To support his argument he referred me to Modis Ekstein’s (1990) historical account of the influence of the First World War on the rise of modernism and the modern aesthetic. According to Ekstein, the Great War was fought on the principles of justice, honour, dignity, and above all, duty. It was also billed as a war which would preserve these values. However, the meaning of these words was exploded by the ugliness of the combat and its casualties. Whatever

was held to be sacred or of enduring value was broken by the devastation of the war. The transformative effect of this was that the public began to question the power or moral authority of one's 'superiors' to propound and enforce such concepts and values. As Ekstein put it: "the old authority and traditional values no longer had credibility" (1990:344). Rob George calls this the dismantling of the "deontological structures" which had previously guided public sentiment and relations between people. This dismantling continued with the devastation of the Second World War, finally resulting, according to George, in a post-war "baby boomer" generation convinced that the most important virtue was to seek happiness and to resist suffering at all costs. Here, he was paraphrasing Ekstein, for whom the world wars precipitated a loss of faith in anything except the act of living, the vitality of the moment, and the pursuit of self-interest (1990:344). Dr George interprets this as the beginning of the corruption of freedoms into assertions of entitlements:

if you are in a society that says the only reason that there are structures is arbitrarily to make it possible for me to flourish as a person, then the requirement of society is *that* I flourish as a person... [and it becomes] a moral good that my life is brought to an end if I don't consider it to be a happy life. My intuition is that we have the problem we have now because the baby boomers are the people who are starting to die.

In his search through the historical record, Rob George was attempting to pinpoint the precise moment at which traditional structures began to wane and the individual and their own personal desires became paramount. He laments the loss of the belief that there is a moral structure to the universe and blames 'postmodernist' and 'relativist' trends for their refusal to entertain the notion of moral absolutes and clear statements of 'right' and 'wrong':

The words 'right' and 'wrong' are not liked in modern society because there is the idea of relativism... My position is that there do have to be a certain number of things that are true or false or right or wrong.

For Dr George, the moral absolute is that assisted dying ("therapeutic killing", as he calls it) is wrong. Citing the world wars as the events that precipitated the rise of the hedonistic, post-modern, 'baby-boomer' generation which desires above all else to

control their destiny, their bodies, and their suffering, this particular activist is trying to give historical weight and authenticity to his opposition to changing the status quo. By creating a dichotomy between then and now, between ‘traditional’ views and the modern, consumerist world, he evokes the sense of a changing society and changing values. And with change, for him, comes uncertainty:

you may know what you are freeing people from, but you never know what you are freeing them in to. And it is the same with euthanasia.

Dr George’s campaigning tactic, whether conscious or not, is to evoke a fear of a loss of values and of a line which, if crossed, will lead to fundamental values being irretrievably lost. In the last chapter I highlighted how fear shapes the arguments both for and against assisted dying. Dr Rob George’s outlining of his historical argument has the pedagogic intent of making the listener fearful of where radical individualism and consumerism will take British society and of the consequences to a loss of moral authority and certainty. Such appeals to history are generally used to validate activists’ claims. And it is a tactic employed in equal measure by both sides in this contentious debate. There is a related tendency among campaigners to claim that their argument is the more ‘rational’, ‘reasonable’ or ‘logical’. And this is often opposed to the ‘illogical’, ‘emotive’ or ‘scaremongering’ views of the other side. These claims to rationality and historical truth-telling and their juxtaposition with emotional, passionate ‘belief’ as manifested in the right-to-die debate is the subject of Chapter Seven. This chapter, however, is devoted to outlining the historical background to these tactics. If activists like Rob George premise their arguments on a certain view of history, then history is where I start my analysis.

I begin with a discussion of the modern history of the assisted dying movement in the U.K. The focus here is the *Voluntary Euthanasia Society* (now *Dignity in Dying*) and the changes the organisation underwent in the 20th Century and is still undergoing at the beginning of the 21st. The reason I focus on this organisation is because it has been instrumental in the growth of the movement for over 70 years now. As I attempt to highlight, the values at stake are not ahistorical, although they may often be

presented as such. I want to put them into context and discuss how broader historical events and societal changes have influenced the debate. In this way I hope to avoid the criticism that Anthropology's treatment of social movements has "advanced ahistorical pseudo-explanations for phenomena with profound historical roots" (Edelman 2001:309). I then move on to discuss *Dignity in Dying's* current strategies and the persistent obstacles it faces with each successive attempt at legislative change. Finally, I consider the new rhetoric of "choice" and whether this has any greater potency for securing its aims.

"Euthanasia" and its Conflicting Meanings

Rob George, in his defence of the status quo on assisted dying laws, draws on the central importance of the First World War in producing the type of person who desires control over their lives, and their deaths. Kemp (2002), in his historical account of the British euthanasia movement, also emphasises the importance of that particular war in shaping attitudes to assisted dying. The euthanasia controversy, Kemp argues (2002:11-12), really began in 1870 with the publication of school teacher Samuel Williams' essay "Euthanasia" in a rather obscure series of essays entitled "Essays of the Birmingham Speculative Club". Williams argued the case for physician assisted dying, which at that time had realistic possibilities given medical developments in analgesia and anaesthesia. This essay:

effectively introduced the ethical conundrum into popular discourse...and defined many of the parameters of the ensuing debate (Kemp 2002:12).

Tracing the origin of the debate to the mid-to-late 19th Century as he does highlights the fact that calls for euthanasia preceded the existence of intensive care units and invasive life-sustaining technology. As Lavi states, demand for euthanasia is not a response to the advance of medical technology, but the result of fundamental changes in the way we wish our lives to end (2005:163).

In the public debate which followed Williams's essay, the Christian principle of the sanctity of life was always cited as the main impediment to any real prospects of winning mainstream support. It was not until the First World War and the scale of

the loss of life in the trenches that this principle really came under attack. The war had received almost unanimous ecclesiastical backing yet the immense loss of life seemed to imply that young lives were expendable. According to Kemp, the war exposed Christian ethics to unprecedented scepticism and criticism and the Church's role as the arbiter of public morality was put in doubt (2002:76-78). A concurrent theme that arose in response to the war was that of eugenics³⁸. The intensive war effort and the economic hardship that resulted called for a prioritisation of scarce resources. As Rothman points out, in traditional philosophical terms, wartime inevitably promotes teleological, as opposed to deontological, positions (1991:50). This gave rise to a form of extreme utilitarianism or opportunity costs by which some argued that in order for someone to live a 'worthwhile' life, they needed to be able to contribute economically to society. Crude eugenics proposals were advanced that people with mental disabilities or people lacking mental capacity should be non-voluntarily 'euthanised' in order to relieve an overburdened state. Although Kemp states that such proposals had been almost entirely supplanted by 1931 with proposals for voluntary euthanasia for the terminally ill, he is also quick to point out that those proposals were distilled from the eugenics proposals:

rather than the more common assumption that proposals for voluntary euthanasia lead to the advocacy of non-voluntary euthanasia (2002:62)³⁹.

Indeed, Kemp's more general thesis is that the influence of the eugenics debate on the development of the British euthanasia movement is too often excised from histories of the debate. Analysis of the American euthanasia movement reveals the same. According to Dowbiggin (2003:15), in the first half of the twentieth century, the American movement recruited many of its members from the ranks of eugenics organisations. The most likely reason for the separation in the historical literature is to maintain the distinction that is currently emphasised between assisted dying, as it

³⁸ The term "eugenics" was coined in 1883 by Darwin's cousin, Francis Galton, from the Greek meaning "wellborn". He defined it as the "science of improving stock", and "using agencies of social control" to "improve ...the racial qualities of future generations" (Dowbiggin 2003:15).

³⁹ It is interesting to note that in the 1930s there was an estimated 12% overlap in membership between The Voluntary Euthanasia (Legalisation) Society (VES), and The Eugenics Society, founded in 1907 (an estimate which Kemp (2002:88) views as conservative).

is now known, and active non-voluntary euthanasia. If eugenics arguments in the early part of the century overlapped with arguments for voluntary euthanasia, as Kemp's analysis suggests, then discovery of the Nazi euthanasia programme after World War Two only further confused the issue in the public's mind and tarnished the word "euthanasia" for good. The Nazi programme, code named *Aktion T4*, was targeted at patients judged 'unworthy of life' by medical examination. So-called 'incurables' could be anyone deemed 'racially unsound', who, to avoid the degeneration of the population, were to be 'cleansed' from the population. The T4 programme began with an enforced sterilisation law in 1933, which aimed at eradicating what were thought to be hereditary diseases from the population. Eventually the programme extended to medicalised killing and it is estimated that as many as 200,000 people with physical and mental disabilities were killed between 1939-1945 (Burleigh 1994). Hitler's targeting of Jews was also couched in terms of "eugenics" in that Nazi ideology deemed that the Jewish race was inferior and able to corrupt the "purer" Aryan race. It was the post-war revelations of these killings and the ideology behind Nazi eugenics practices which seriously hindered the possibility of any assisted dying legislation at that time in the U.K., and, arguably, continues to prevent legislation being passed today.

The assisted dying lobby still experiences the residual effects of the association of the word "euthanasia" with Nazi eugenic ideas and their implementation. Current advocates try to combat this association by drawing an explicit distinction between voluntary and non-voluntary euthanasia, and by dismissing the implication that the one has anything *at all* to do with the other. Advocates believe that assisted dying is a fulfilment of negative liberty –freedom from interference and control by others - while non-voluntary euthanasia would entail *exactly the opposite of this* – entitling others to control when you died in an act which would negate any sense of individual freedom. One is billed as wilful release from suffering, the other simply as murder. Given what is perceived as a clear distinction between the principles motivating the two types of euthanasia, one can understand why advocates (and perhaps historians as well) may wish to keep discussion of the two entirely separate. However, in practice, the distinction is often difficult to maintain for two main reasons. The first

is that a tactic of the anti-lobby is to align the two when discussing ‘slippery slope’ arguments. For example, an article opposing Lord Joffe’s Bill appeared in the *Catholic Times* in April 2006 (Figure 1) accompanied by a photograph showing pictures of children murdered by the Nazi euthanasia programme. The tagline reads: “Warning from the past”⁴⁰.



Figure 1

This photograph/article draws an explicit parallel between the Nazi euthanasia programme and the legislation proposed in Lord Joffe’s ADTI Bill. Further connections are made in some of the placards wielded by anti-activists (see Figure 2⁴¹) and there are reports of speeches by anti-campaigners invoking the spectre of the Nazi euthanasia programme.

⁴⁰ “Legalising euthanasia turns carers into killers” *Catholic Times* 2nd April 2006

⁴¹ Designed by disabled activist Gillian Gerhardi from her website www.willtolive.co.uk

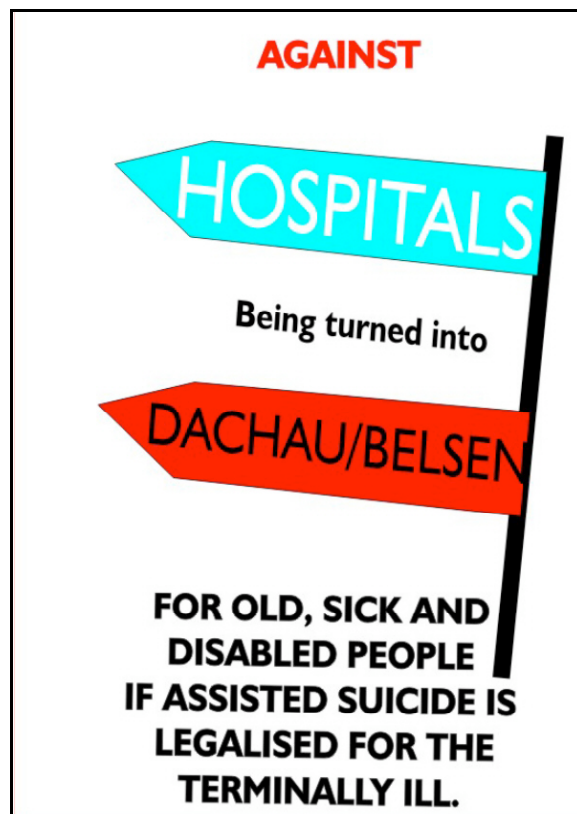


Figure 2

The second reason the assisted dying movement is haunted by the spectre of the Nazi euthanasia programme is that even among their own ranks, assisted dying supporters sometimes (perhaps unintentionally) blur the distinction between voluntary and non-voluntary euthanasia. For example, in October 2008, House of Lords life peer and vocal assisted dying advocate Mary Warnock, in an interview for the *Church of Scotland* magazine, expressed the view that people living with dementia may have a “duty to die” because they had become a “burden” on the state and on their families:

If you're demented, you're wasting people's lives – your family's lives – and you're wasting the resources of the *National Health Service*... if somebody absolutely, desperately wants to die because they're a burden to their family, or the state, then I think they too should be allowed to die.

Her comments, labelled “outrageous” and “immoral” not only by the opposition, but by charities advocating for older people's rights, was also subject to criticism from those trying to forward the case for legalisation. The Chief Executive of *Dignity in*

Dying, Sarah Wootton, for example, wrote a letter to *The Guardian* newspaper⁴², firmly disagreeing with Baroness Warnock's beliefs, labelling them "wrong" and contrary to DID's stated position. DID support physician-assisted suicide *only* for fully competent people who have been screened for mental illness and who only have "months" left to live. No doubt the organisation's Public Relations team would not have thanked Baroness Warnock for blurring the issues in the public's imagination, given the continual struggle to distinguish its aims from the eugenics links of the past. Contained within Wootton's letter is a reference to the fact that some of their supporters will always think their aims not far reaching enough. Warnock is clearly one such person. However, my research suggests that she is not alone, as I explore in Chapter Eight when I put the spotlight on *Friends at the End*.

According to Kemp, VES/DID has always been a broad church, representing a diversity of views (2002:88). Having attended two of DID's annual general meetings (AGMs), it is clear that many members would support Warnock's views on euthanasia for people living with dementia, given a prior Advance Decision having been made while the person still had mental capacity. Indeed, it is dementia which is a cause of much fear among older people, and it is older people who make up DID's membership base. A woman aged 65 in the U.K in 2007 has a one in four chance of dying with dementia (rising to one in three by 2050) (Brown 2008). But the Society's governing board is at odds with its membership. It wants to maintain a very restrictive scope in any legislation put forward, so as to distance itself from broader utilitarian arguments and not play into the hands of critics and their talk of a 'slippery slope'. This approach, however, belies the 'broad church' history of the organisation and the broad church views of its current members. There is thus a disparity that often leaves the Society, in the words of its Chief Executive, "between a rock and a hard place": caught between a hostile opposition eager to tie them to the eugenics ideas of the past and a disgruntled membership who feel their views are not being properly represented.

⁴² On the 28th November 2008
(<http://www.guardian.co.uk/commentisfree/2008/sep/28/socialcare.health>)

There is a postscript to the continued struggle of the assisted dying lobby to escape association with the Nazi euthanasia programme. At *Dignitas* in Switzerland in 2008, a new regulation in the Canton of Zurich dictated that a patient must have more than one consultation with the prescribing doctor, and that a certain amount of time must elapse between consultations. This was a prohibitory regulation because many foreigners wanting to die at *Dignitas* were too sick or could not afford to remain in Zurich for a long period of time. In order to remain in operation then, the organisation began using the ‘helium method’ which does not require a doctor’s prescription (see *p144* of this thesis for an elaboration of this technique). However, when people in the local neighbourhood discovered this change in method (the previous method involved drinking a lethal liquid called Pentobarbital or Nembutal), there are reports that *Dignitas* volunteers were verbally abused on the streets. This had never happened before. It is believed that this was because of the association of death by gas inhalation with the Nazi concentration camps.

The Voluntary Euthanasia Society (VES) Transformed

The Voluntary Euthanasia (Legalisation) Society (VES) was officially founded in 1935 by a small, elite group of physicians, clerics, scientists, and writers (Dowbiggin 2003:52). This was the first point at which an organised euthanasia “movement” could be identified (Kemp 2002:207). The first attempt to get a Bill through Parliament was in 1936, but it was defeated on its Second Reading in the House of Lords by 35 votes to 14. The main reason for the defeat of the Bill, itself quite restricted, was, once again, imprudent comments from supporters in the House of Lords noting the “consciousness of being a burden” and the possibility of later extending the provisions to people with mental incapacity⁴³. Opponents then had no trouble pointing out the “inflationary scope” of the Bill.

In the 1950s, the movement found itself under “an extremely dark cloud” (Kemp 2002:118) as it struggled mightily to avoid the taint of Nazism. It was not until the 1960s and 70s that the moral climate for legalising assisted dying became more

⁴³ Lord Ponsonby in his speech introducing the Bill to the House (Kemp 2002:110)

propitious. As in America, the euthanasia movement benefited enormously from the rise of the women's movement with its celebration of 'our bodies, our lives' (Dowbiggin 2003:xvi). In 1961, suicide was legalised, in 1965 the death penalty was suspended and finally abolished in 1969, and in 1967 David Steel's Abortion Law Reform Bill was passed. All these legal changes enhanced individuals' (negative) liberty. Life-prolonging medical technologies were also improving at a fast rate at this time which complicated medical ethics and decision-making⁴⁴. Before 1960, discussion of euthanasia had been concerned almost exclusively with those patients whose suffering medicine was unable to relieve. Thereafter, the discussion centred increasingly on cases where medical technology could maintain life, but with "poor quality" (Kemp 2002:186). The terms of the debate had shifted to a conflict between patient autonomy and the actions of an overly officious medical profession. This is the period in which the rhetoric of 'quality over quantity' of life became popular among advocates.

Of equal significance in the 1960s were the changes occurring in the relationship between the doctor and the patient. As Rothman (1991) describes in his historical account of the how law and bioethics transformed this key relationship in the United States, the discretion that the profession enjoyed pre-1960 has been increasingly circumscribed. The impact of Henry Beecher's devastating indictment of research ethics in human experimentation during World War Two not only precipitated an erosion of trust between doctor and patient (Rothman 1991:15), but ushered in a new era of a medical profession subject to outside regulation. Another reason Rothman (1991:109-117) cites for doctors becoming "strangers at the bedside" was that doctors, due to increased specialisation, the disappearance of the house call etc, were no longer *as* involved in community life, nor was there a premium placed on fostering intimacy with patients in order to guarantee their continued business. That patients are now more likely to be treated by strangers in a strange environment has turned them from grateful supplicants into wary consumers (Rothman 1991:128). Ironically, constraining one authority figure's discretion has drawn other authority

⁴⁴ Resuscitation techniques were improving with the use of cardiac massage and re-starting the heart during cardiac surgery. The artificial respirator was also developed in the 1950s and antibiotics and surgery techniques generally were continually improving and diversifying.

figures, such as lawyers, public officials, bioethicists, ‘to the bedside’ which may create further distance and distrust. Nowhere is this more explicit than in the relationship between the doctor and the dying patient, which has become regulated as much by legal as medical processes. Assisted dying, if viewed as an assertion of patient autonomy, must be analysed in the light of the radical transformation in the relationship between doctors and patients and the new rules for practising medicine.

As calls for assisted dying in the U.K. continued, the burgeoning palliative care movement pioneered by Cicely Saunders seemed to offer a direct alternative. Equally, Kemp argues, the Suicide Act went some way to diminishing the need for assisted dying legislation because those suffering through illness could end their own lives without being criminalised (2002:178). Nevertheless, in 1969, the VES sought to introduce another Voluntary Euthanasia Bill into the House of Lords. It is worth noting some of the dissenting opinions that arose in the ensuing debate, given that they prefigure those raised in the debate on the ADTI Bill in 2006. First, it was widely stated that providing more palliative care/hospice beds was the real answer to the needs of the dying. Secondly, objections were made that the Bill contained inadequate safeguards and dangerous loopholes. Thirdly, it was argued that if society wanted legalisation, it should not be medicalised because it could damage the respectability of the profession and reduce trust in doctors. The fourth and final objection was that of the “slippery slope” which, according to one peer, could lead inexorably to the excesses of Nazi Germany⁴⁵. This fear that “voluntary” termination of life would lead to “non-voluntary” termination was exacerbated and seemingly confirmed by numerous comments from the Bill’s supporters.

There was a further attempt at legislation in 1976 with the House of Lords “Incurable Patients Bill” (defeated 85 votes to 23) and a House of Lords Select Committee on Medical Ethics in 1994 also debated the issue, concluding that: “individual cases cannot reasonably establish the foundation of a policy which would have such serious and widespread repercussions” (Report of the House of Lords Select Committee 1994:48). When I discussed the recommendations of this Select

⁴⁵ Voluntary Euthanasia Bill, House of Lords Debate 25 March 1969 c.1159

Committee with Lord Walton, its Chair and a retired neurologist, he told me that, while they had concluded that any individual had the right to refuse medical treatment, the Committee had drawn the line at *active* steps being taken by a doctor to end the life of a patient:

Personally, my views have not changed since then. It is always possible to relieve symptoms, especially given advances in palliative care. Although the ‘double effect’ is a very fine line, it nevertheless can be drawn and I stick with that. I will not change my mind on that.

I asked Lord Walton what he thought about supporters’ assertions that assisted dying is an inevitable progression towards a more liberal society. He replied that it may well be, but that he is not sure he supports all the facets of a supposedly “liberal” society - same sex marriage, abortion, all the scientific advancements being discussed by the Human Fertilisation and Embryology Committee. He admitted that medical ethics is constantly being required to reflect on its assumptions and update its conclusions, but argued that the case for legalising medical assistance to die is still not fully justified. The final conclusions of this Select Committee - that it was not advisable to legislate for a very small number of dying people with “unrelievable” pain when a far greater number may be put at risk by the legislation - resurfaced again during the House of Lords discussion of the ADTI Bill in 2006:

We should not extend patient autonomy for a few by a dramatic change in medical ethics and practice, which could be detrimental to the many.⁴⁶

According to Kemp (2002), the repeated failure to secure legislation caused the VES to lose direction in the 1980s and 90s. In 1979 it changed its name to EXIT, at least in part to dissociate from the word “euthanasia”. In the same year, the society’s governance board also approved the publication of a DIY booklet entitled “Guide to Self Deliverance” (Kemp 2002:216). The guide was envisaged as a stopgap measure pending the successful passing of legislation. However, this foray into the production of reading materials of dubious legality marked a moment of radicalisation in the history of the Society, born of frustration at the lack of progress being made. When

⁴⁶ Lord Clement-Jones, who voted against the Bill

the Director of Public Prosecutions (DPP) challenged the legality of the publication and distribution of the manual, the Society refrained from further distributing the booklet (Otlowski 2000:270). The apogee of the Society's radicalisation and the impatience of members came in 1983 when the Secretary of the Society, Nicholas Reed, and long-time volunteer, Mike Lyons, were convicted for helping a number of people to kill themselves, some of whom were reputed to have been suffering from alcoholism and depression (Dowbiggin 2003:149). Although the Society immediately tried to distance itself from the actions of these two individuals, its public image was seriously tarnished. In 1992, it voted to revert back to its previous name to try to dissociate itself from the scandal. Again, it would seem that the Society was between "a rock and a hard place" – unable to gain sufficient parliamentary support to pass legislation, and unable to offer direct, hands-on advice and help to individual members without falling foul of prohibitive laws. At a pivotal time when end-of-life issues were becoming generally more mainstream, the assisted dying movement was losing its cohesiveness and factionalism was setting in.

Similar sectarian dramas were occurring on the other side of the Atlantic. In 1979, the main right-to-die organisation in America split into the *Society for the Right to Die* and *Concern for Dying*, the latter interested solely in promoting living wills, pain management and access to hospice care. In 1991, the *Society for the Right to Die* decided it too no longer wanted to continue its public advocacy of physician-assisted suicide and so merged with *Concern for Dying*. Although advocacy of assisted dying did continue with the *Hemlock Society*, founded in 1980 (disbanded in 2004) and by *Compassion and Choices* from 1993, the splintering of the national movement was indicative of a similar frustration with the lack of legislative reform, as experienced in the British movement. It also showed that there was a political place for a lobbying organisation which was concerned with patients' rights at the end of life, but stopped short of demands for an assisted death.

Dignity in Dying

When lawyer Deborah Annetts was appointed Chief Executive of VES in 2000 her aim was to transform the organisation into a credible, authoritative and

professionally-run outfit⁴⁷. She raised the membership from 12,000 to 100,000 members and ‘supporters’ (those who do not pay annual subscriptions but have in the past consulted the organisation). Her aim was to overcome the controversies of the past and make the organisation “mainstream” in its appeal. Any board members who favoured more hands-on methods or were too involved in the work of the Swiss assisted suicide organisation, *Dignitas*, were asked to leave⁴⁸. In 2001, the Society supported Dianne Pretty in her petition to the court to allow her husband, Brian, to help her commit suicide with legal immunity. Dianne was living with Motor Neurone Disease (MND) and was paralysed from the neck down, making it very difficult to take her own life. Self-deliverance was therefore not an option for her. When the court refused to give Brian immunity in advance (criminality, it was stated in the court, cannot be determined in advance of a crime being committed), Dianne took her case to the House of Lords and when that failed, on to the European Court of Human Rights. VES supported Dianne’s campaign to change the law (see Figure 3), arranging her PR and media appearances, and paying some of her expenses, including a trip to Disneyland, Paris, on her way back from the European Court.

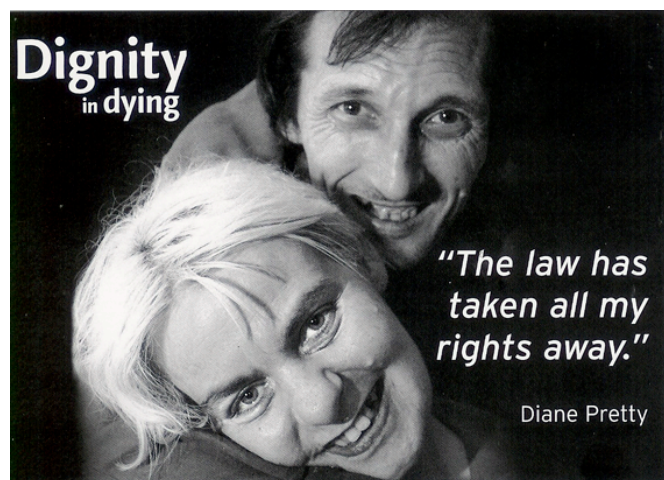


Figure 3 – a DID campaign postcard

It was Dianne’s high profile case and the representation of her suffering that raised public awareness of assisted dying once again. Although Dianne lost her appeal at the European Court and died without her husband’s help at a local hospice two

⁴⁷ *The Guardian*. 25 January 2006. Exit Strategy.

⁴⁸ Many of these expelled members joined FATE

weeks after the verdict, the VES, through association with her cause, had been rehabilitated. Her image became synonymous with the message of the right-to-die movement which was that the current legal situation was causing people to suffer needlessly. Dianne became a publicly recognisable figure. According to one member who was serving on the organisation's board at the time, the VES seized on the opportunity to highlight Dianne's plight and it was partly its successfully executed publicity strategy that made her an international 'hero' for the movement. Speakers pay homage to her efforts at international right-to-die events alongside other 'heroes' of the cause - Ramon Sampedro (from Spain) and Chantal Sebire (from France)⁴⁹. As Beck comments, in the "risk society" where politics is 'unbound' and opened up to all varieties of interest groups, the media becomes a central battleground for influencing the political agenda (1992:190,197). Although Dianne's defeat in the European Court of Human Rights dealt a blow to any immediate prospects of legalisation, it marked a new phase in the campaigning strategy of the organisation. This was to highlight the suffering of *specific* individuals with whom the public could identify. It bid to instrumentalise their suffering in the sense of giving it a purpose and channelling it to promote their 'cause'. At the same time, the courts also came to be viewed instrumentally as, possibly, a more expedient route to success as opposed to the more cumbersome parliamentary process.

By association with Dianne Pretty, the VES gained respectability as a pressure group. To cement its rehabilitation in the eyes of the public, the Society voted in 2006 to change its name to *Dignity in Dying*. The negative associations of the word "euthanasia" (the "voluntary" part too easily being omitted) had long aggrieved those who worked for and supported the organisation. However, in this debate, where the meaning of words constitutes part of the battleground of the debate, the VES's opponents strongly objected to what they viewed as the co-option of the word "dignity". *The Association of Palliative Medicine* wrote to the Trade and Industry Secretary to oppose the name change:

⁴⁹ Ramon Sampedro, left quadriplegic after a diving accident, launched a 28-year legal campaign to be helped to die in Spain. Chantal Sebire was living with a disfiguring and painful facial tumor when she petitioned the court to have a doctor assist her death. Both, like Dianne Pretty, lost their court cases, but became recognisable 'faces' in the European and World movement.

Dignity in dying is a phrase in common parlance in many sections of the population, being used by patients worried about the care they will receive... These patients are not asking for euthanasia or assisted suicide; they are asking for good care. For *The Voluntary Euthanasia Society* to seek a monopoly of a common English phrase in order to invest it with a totally different meaning is dishonest and will create confusion.⁵⁰

Dignity in Dying retorted that “dignity” was a matter for personal definition and those groups who were criticising the new name were simply opposed to patients “having any sort of choice at the end of life” (Annetts 2006). The opposition to the name change was ultimately unsuccessful and thus the VES became DID. However, throughout my research – a year after the name change – opponents would continually refer to the organisation as the VES, and in doing so registered their lingering bitterness at what they viewed as the illegitimate usurpation of the word “dignity”.

It was in the same year, 2006, that House of Lords peer Joel Joffe, brought the third draft of his Parliamentary Bill to legalise physician assisted suicide before the Upper House. I discuss the political intrigues surrounding the defeat of this Bill in the following chapter. To conclude this chapter, I would like to make a more general point about the transformation of the VES into DID. As I mentioned in Chapter Four, in the early part of the 21st Century the National Health Service, along with social care, is being restructured to fit a personalised model of care. This includes devolving budgets to individuals so that they ‘hold the purse strings’ and are given the entitlement to decide on the care services they want to enlist. This ‘personalisation’ (for which we can read individualisation) joins an already well-established rhetoric about “patient choice”. Crudely summarised, this is an agenda which asserts that patients should be given sufficient information about the options available to them on the National Health Service - treatment options, service provision, where they want to be cared for etc - to enable them to make an informed *choice* about what they want for themselves, rather than having those choices made for them by healthcare professionals. As Mol (2008:5) states, the logic of choice relies on the notion of ‘active patients’ or patient-choosers who resist being prodded and poked and made passive by the medical system. The culmination of this logic of

⁵⁰ BBC NEWS. 23 January 2006. New Pro-Euthanasia Name Row.

choice is the proposed “NHS constitution” which, for the first time, will give patients a legal right to information about the treatment options available to them (only applicable in England). The new political focus on giving patients a ‘personal budget’ and on enshrining their rights in law has created a political atmosphere in which DID’s message of assisted dying as the ‘final’ choice can firmly take hold. The organisation’s strategy is to adopt the rhetoric of “choice”, now very high on the government’s agenda, in order to make their campaign for assisted dying seem like a logical step towards the fulfilment of a legitimate choice agenda. As the Chief Executive told members at a recent AGM, “it is much more difficult to be against choice than it is assisted dying.” Indeed, the opposition, often previously labelled “pro-life”, are now increasingly labelled “anti-choice.”

Mol’s view is that the logic of choice is the new dominant paradigm in healthcare provision. This, she believes, is to the detriment of patient ‘care’. The idea that patients should be treated as citizens or as consumers when in the consulting room assumes that patients are autonomous, disembodied, clear-thinking individuals capable of comprehending all the ‘choices’ open to them (2008:40). Mol argues that this is unrealistic, given that many diseases cannot be cured but have to be ‘lived with’ and one’s conception of the ‘good life’ has to adapt accordingly (2008:41). Mol argues instead for a logic of care based on shared doctoring/patientism which does not impose value judgments on how the patient *should* be acting, but seeks to respond practically to life with a disease. While Mol does not directly address choice in death, one presumes her critique of the logic of choice might extend to demands for control over death. Certainly, Dr Rob George, whom I introduced at the beginning of this chapter, claims that giving patients the legal choice of an assisted death would destroy the logic of care prevalent in hospices. Choice may have current popular appeal but, if we are to believe Rob George, the bonds of caring doctoring may be lost forever if we endorse death as a ‘medical good’. Yet perhaps choice over the timing of death could be viewed as ‘good care’? This is what assisted dying advocates would argue. Asking for help to die is not necessarily about “throwing in the towel” (as Baroness Finlay sees it), or about shirking one’s responsibility for one’s dying (as Dr. George views it). It could be that the decision to opt for an

assisted death may come after months of ‘shared doctoring’, two-way discussions and attempts to adapt to the dying process. Perhaps if a desperate patient could foresee no other release from their suffering, they might perceive that the most caring thing a doctor could do for them would be to help them to die.

While DID may, when challenged, make the argument of ‘choice *as* care’, there is limited mention of care *per se* at their meetings and in their publications. Instead, the focus is on ‘patient choice’ and on the suppression of “enlightened” choice by the “forces of darkness”.⁵¹ The legitimating exercise which DID is undertaking through use of the ‘patient choice’ rhetoric is what Hillard & Dombrink, in their discussion of the mobilisation of the American right-to-die movement, call “frame alignment” (2001:20). DID hope this converging of their rhetoric with the government’s more established rhetoric on choice and rights will help it enter the political mainstream by winning over public and political support. In the process, DID wants to put clear blue water between its ‘legitimate’ demands and the ‘self-deliverance’ movement, now relegated to the ‘radical’ fringe. Giving hands-on advice would undermine the legitimate social reform the organisation had set its sights on by laying it open to charges of illegal practice. “We are committed to operating within the laws of this country” was their response to supporters requesting help to die *now*. Many in need were dissatisfied with this response and it led, in part, to the relative success of FATE. As one FATE member told me:

Deborah (Annetts) wanted to keep DID squeaky clean and she didn’t want anything to do with the hands on, and yet she was prepared to pay all the expenses of Dianne Pretty...

The reorganisation of DID altered the project of freedom that was originally envisaged by right-to-die supporters. As Brown writes, following Foucault, resistance in the late modern era is often incorporated *within* modalities of power rather than outside of them. This greatly affects how that power is and can be contested (1995:1):

⁵¹ Sarah Wootton, Chief Executive, at DID’s 2008 Annual Conference

The will to institutionalise freedom, to resolve its contingent character and make it permanent, metamorphoses freedom into its opposite, into a system of constraints by norms of routinisation and calculability, into unfreedom at the pinnacle of the project of rationality (Brown 1995:23).

DID wants to institutionalise the freedom to die. It is not only the Society's detractors who worry that such institutionalising or 'rationalising' of the doctoring/'patientism' (Mol 2008) which takes place at the end of life will bring about the bureaucratisation of death on demand. Radical 'hard-liners' within the right-to-die movement may also be sceptical of DID's metamorphosis. DID's new strategy of fitting physician-assisted suicide into a broader project of entitlements and rights claims certainly mirrors a wider trend of interest groups working within existing structures to achieve their emancipatory political aims. The question is whether through that process, they lose the freedom to which they were originally aspiring. For DID at the beginning of a new century, instrumentalism, not radicalism, it was determined, would win its members the 'final right'.

CHAPTER SEVEN

Suffering Made Public: A Sentimental Education?

This chapter explores further the rhetoric employed by both sides in the assisted dying debate. Just as important as the ethical and moral values and imperatives over which the two sides are battling is the representation of those values and the rhetoric in which they are wrapped. Analysing the representation and the rhetoric can reveal something about both sides' conception of the 'common good' and of the concept of the 'good life' to which they subscribe. In this chapter, I outline some of the major outcomes and controversies of the 2006 parliamentary debate on the *Assisted Dying for the Terminally Ill* (ADTI) Bill, using information gained from interviews with key advocates on both sides. This will enable me to discuss the various ways in which suffering is instrumentalised in this debate. There exists a whole spectrum of views on both sides so I also attempt to highlight the differences within the lobbies, as well as between.

Political Machinations around the ADTI Bill

The ADTI Bill was introduced to the House of Lords in March 2004 by cross-bench peer Joel Joffe in order to capitalise on the public appeal of Dianne Pretty's case. Although the defeat of her case had temporarily exhausted legal avenues for reform, DID decided the time was right to attempt yet another parliamentary Bill. The Bill itself was drafted by Annetts, Chief Executive of DID, and Joffe, a life-long member of the Society. In my discussions with Lord Joffe, he told me it was not a difficult decision to put his name to the Bill. For him, it is an unequivocal human right to be able to control one's own death:

No thinking person who looks at the evidence from a rational perspective would disagree with the Bill and the safeguards it allows.

Joffe entertains no doubts about the rightness of his cause. He told me that he wanted to approach the issue from a position of "rationality" and "logic", using only the evidence to prove his case. This reflects DID's mantra that "we must engage with the

facts”⁵². According to DID, the “facts” demonstrate that there is no evidence of a “slippery slope” in the jurisdictions where physician-assisted suicide has already been legalised. By engaging the facts, DID argues, the “forces of Enlightenment” will outweigh the “well-organised forces of darkness”⁵³. Joffe also told me that his perspective was a “detached” one and that it was the “emotive” words and use of personalised stories by the “religiously based” opposition that were responsible for clouding the public’s judgment on the issue. I found it interesting that as he told me this, he was himself displaying signs of agitation and exasperation.

The ADTI Bill, after its first reading in the House of Lords, was sent to a Select Committee comprising 13 members responsible for scrutiny and reporting back to the House on its findings. The Committee solicited responses from key organisations with a presumed interest in the Bill and also received unsolicited responses from individuals, both supporting and opposing (ADTI Bill 2005:10). Oral evidence was taken from key respondents and the Committee also visited the US state of Oregon, the Netherlands, and Switzerland, all jurisdictions with some experience of a legalised form of assisted dying. The evidence collated and scrutinised by the Committee over a period of nine months was then sent back to the House of Lords for a second reading in May 2006. After a seven hour debate, a vote was taken and it was decided by 148 to 100 that the Bill should not pass to the next legislative stage. As with the VELS Bill of 1936, Joffe’s ADTI Bill had stalled at second reading.

This defeat came as a dramatic surprise to Lord Joffe and to DID and their supporters. Joffe told me: “we really didn’t think it was necessary to get all our supporters in at that next stage. We were caught unawares.” He believes that the pro-lobby were misled by Lord Mackay, the Chairman of the Select Committee, who had intimated to them that the Bill would pass unopposed to the next stage. Clearly there had been a change of heart. The defeat of the Bill unleashed a swath of remonstrations from proponents about the “well-organised” and “religiously founded” opposition they were up against and the “underhanded” and

⁵² Ashley Riley, DID Campaigns Director, 2007

⁵³ Sarah Wootton, DID AGM 2008

“undemocratic” tactics they were prepared to employ. As one person who worked closely with Joel Joffe on the pro- campaign told me:

As a leader in society you have a responsibility to engage in grown-up debate. I don't have any respect for them [the politicians] now because they didn't live up to that responsibility.

There was a belief that the Bill's proponents had underestimated the lobbying strength of the opponents and had failed to mobilise their own supporters in the Lords to turn up and vote in favour of the Bill on the day. The opposition, on the other hand, is often depicted by proponents as being “very well organised.” In the months preceding the debate on the Bill, there was a great deal of lobbying and press interest. In January 2006, a new alliance was launched in direct opposition to DID, calling itself *Care Not Killing* (CNK). Its stated aim was to bring the “fragmented” opposition together and promote public understanding about the alternative offered by palliative care. It is an alliance which, according to its website⁵⁴, brings together human rights groups, healthcare groups, palliative care groups, and faith-based organisations (listed in that order). The use of the word “killing” became a subject of controversy, equivalent to the earlier debate over the word “dignity”, because it was deemed pejorative, emotive, and an inaccurate term to describe what in many jurisdictions was already legitimate medical practice.

Accusations of unscrupulous tactics infiltrated the debate at every point. Both sides often view the other as a homogeneous group with disingenuous aims. It was clear that in the build up to the Lords debate, and even a year on, tensions between the two sides ran extremely high. While Joffe claimed to have been “caught unawares” by their “well-organised” opponents, there were also claims that CNK had received vast injections of cash from the American pro-life lobby. In supporters' minds, this served as proof that all opposition was religiously founded. In a fundraising letter to members in 2008, DID wrote:

⁵⁴ www.carenokilling.org.uk

We are battling powerful and well-funded interest groups: we have just learnt that one faith group alone has designated £127,000 solely to undermine our campaign.

The idea of being dictated to by religious minorities perpetually provokes DID's members, to the extent that it is used as a rallying cry when they are in need of extra campaign funds. Another oft-cited accusation is that in the lead up to the debate on the ADTI Bill, opponents had received media training in how to disguise their religious beliefs when giving interviews, to avoid being stereotyped as a "religiously-led" opposition. Such alleged deception was deemed highly dishonest. Once again, right-to-die supporters categorise all opposing views as "irrational dogma", propagated by a "Catholic mafia".

Accusations also fly in the other direction. CNK believe that DID are the wealthier pressure group because they are able to afford a full-time parliamentary officer to lobby politicians. I was told by different organisations flying under the CNK banner that DID supporters have "infiltrated" doctor's regulating bodies (the *General Medical Council* and the *British Medical Association*) and that they are starting to infiltrate hospice boards. It was also reported to me on several occasions that there was a strong feeling that media reporting on the issue was biased in favour of DID. A formal complaint was lodged with the BBC concerning its reporting of the ADTI Bill debate, claiming that it was "superficial, unfair, factually inaccurate, poorly researched, one-sided and ultimately unprofessional". The campaigns director of the *Society for the Protection of Unborn Children* (SPUC) told me they had to act against "the misinformation being spread by the BBC at the behest of the VES." This "misinformation" also extended to the reporting of Dianne Pretty's case:

It was claimed that she would die a horrible death from choking and asphyxiation which is not the case. We know from the doctors who cared for her that she died a peaceful death and she died in a hospice where patients are given proper care (Campaigns Director, SPUC).

The intricacies of each side's contestation of the facts and claims to truth-telling runs parallel to the fight to claim the moral high ground. For Joel Joffe and many of

DID's supporters, non-interference is the principle which motivates them. Supporters' belief in non-interference also extends to the feeling of being "betrayed" during the debate on the Bill. There was a feeling that the opposition interfered with the fairness of the parliamentary process. As Crewe (2005:22) writes in her ethnography of the House of Lords, there is an abundance of procedural niceties in place that make the House self-regulating and egalitarian. Courtesy is prized. Yet Joel Joffe felt that the requisite courtesy had not been extended in the debate on his Bill and that peers' emotions and passions had got in the way. A Private Member's Bill had not been voted against at the second reading since 1998. Joffe and his supporters felt that an unwritten precedent had been broken. Crewe's point that, in the House of Lords, disdain for convention is akin to treachery can certainly be observed in Joffe's comments.

The opposition, on the other hand, thought that the Bill was so "morally objectionable"⁵⁵ that amendments at committee stage could not make it more palatable, therefore it would be a waste of public funds to consider it further. Lord Brennan summed up the position of many of the peers who voted against the Bill when he said:

It is wrong in principle and unworkable in practice and should be rejected now.⁵⁶

In fact, the transcript of the debate, along with the Select Committee's Report (and the transcript of the oral evidence given to the Committee) will provide an invaluable source of data for any future political deliberations. Although Joel Joffe and Deborah Annetts of DID threatened to bring the Bill back every parliamentary sitting⁵⁷, the view of the organisation now, as stated at their 2008 AGM, is that there needs to be significant momentum and public "groundswell" behind any renewed attempt. The Bill has been put to bed. For now.

⁵⁵ Lord Carlisle of Berriew, Hansard transcription of the ADTI second reading debate, 2006:1191

⁵⁶ Lord Brennan, Hansard transcription of the ADTI Second Reading Debate, 2006:1237

⁵⁷ *The Guardian*. 25 January 2006. Exit Strategy.

Personal Stories of the Disabled-Dying

One of the significant aspects of the 2006 media furore in the lead up to the House of Lords debate was its personalisation. Joffe complained repeatedly about the use of what he called “emotive” words, like “killing”, and personal stories, like Alison’s. Alison runs a charity called *No Less Human*, a division of the *Catholic Society for the Protection of Unborn Children*. Its aim is to “promote the equal status, worth and rights of disabled people.” She campaigns against assisted dying in all forms and was a regular interviewee in the media in the build-up to the Joffe debate. Alison has spina bifida, hydrocephalus, osteoporosis, and emphysema. She told me that for about 10 years she wanted to die because of the constant pain she is in. She recalls taking numerous overdoses:

I remember one suicide attempt in particular, where I had slashed my wrists and had taken a whole bottle of pain-killers and drunk a bottle of martini and I was really determined... I was then treated against my will while unconscious. And when I woke up I was very unhappy that they had treated me actually. But now of course I am glad that they thought my life was worth living even though I didn’t at the time.

After struggling with suicidal feelings for many years, she eventually found meaning and purpose again through charity work. She told me she finds the idea of euthanasia “really terrifying” because had it been a legal option for her, she would have taken advantage of it and would have agreed to “being killed”:

You know, if you see someone who is about to jump off a bridge, you say ‘don’t do it’, you don’t ask about their quality of life. There should be a presumption in favour of life for disabled and ill people, just as there is for healthy people.

Joel Joffe disapproved of Alison’s story being used as evidence during the Select Committee. Alison, argues Joffe, would never have come within the scope of the Bill because she never had a terminal disease. Her suffering is thus delegitimised in order to show its irrelevance to the proposed legislation. There is also a sense in which he views her subjective account as having little general applicability or verifiability. Yet, it was the very subjectivity of the term “suffering unbearably” in his ADTI Bill that was deemed so problematic for some (see *p171* of this thesis). There is a multi-

layered dispute over the interpretation and political representation of suffering in this debate, which I intend now to unravel.

Disabled activists spent the 1970s fighting for the recognition of a “social” model of disability over a medical model. In this account, society itself was responsible for disabling people through its oppressive and discriminatory view of those who were disabled or impaired (Swain & French 2000:571). Building on the “liberatory imperative” (Swain & French 2000:569) of this by now well-established model, activists have honed in its place an “affirmation” model of disability which emphasises the need for social recognition. This tries to set up a competing narrative to the “personal tragedy” view propagated by non-disabled people, including most health professionals, and the media. The focus here is on the positive social identities, both individual and collective, for disabled people, grounded in the life experience of actually being disabled and impaired (2000:569). In other words, there are revelatory, liberatory, therapeutic, and transformative possibilities for both the disabled individual and their community (Smith & Sparks 2005:1100). One might ask what all this has to do with terminal illness and dying. Indeed, many assisted dying advocates *do* question the relevance of narratives of disability and view their inclusion in the debate as an inappropriate diversion. And yet the ADTI Select Committee consulted disability rights organisations and disabled activists organised a large demonstration outside the Houses of Parliament on the day of the debate (see Figure 4, Figure 5, and Figure 6 below).



Figure 4
Jane Campbell outside the House of Lords on the day of the Joffe Bill Debate



Figure 5
Jane Campbell and other activists demonstrating



Figure 6

The problem of defining “terminal illness” and whether it can be classified as a disability was discussed in Chapter Three in reference to the use of the term “life-limiting illness” in the hospice day centre. However, it is clear that from a disability rights perspective, terminal illness and disability are one and the same:

The Disability Discrimination Act (1995) definition of disabled people covers people with conditions such as HIV/AIDS, MS, Motor Neurone Disease (MND), cancer, heart disease and many other terminal (or potentially terminal) conditions (Memorandum by the *Disability Rights Commission*, ADTI Evidence 2005).

Essentially, because we are all mortal we all end our lives disabled as our bodies deteriorate through disease or old age. The problem of defining “disability” without falling prey to ideas of body normativity results in an ever-expansive view of what “disability” means. It is this idea that prompted the coining of the term “temporarily able-bodied”. As Breckenridge & Vogler comment:

The designation “temporarily able-bodied” invites us to consider different sorts of vulnerability, different points of frailty, as features of our common lot and accordingly to shift our understandings of flourishing, social justice, and embodiment (2001:356).

The likely justification for defining the terminally ill as “disabled” is that they are equally subject to the same societal prejudices and negative media representations as people with other types of disability. Once people diagnosed with a terminal illness are classified as “disabled”, they can then be incorporated within the “affirmative” model of disabled people’s rights and become subject to the agenda of the disability rights movement. It is no longer just about them and their disease, so the argument runs. They are implicated in a political discourse and how they value their own lives reflects on the value of other people’s lives. When a terminally ill individual or an individual ‘living with’ life-limiting illness makes statements about their lack of quality of life, the disability rights movement suggests that they are implicitly judging the quality of life of other disabled people. This is a real concern.

Baroness Jane Campbell, a Commissioner at the *Disability Rights Commission* (DRC)⁵⁸, is another disability rights activist whose personal testimony was submitted to the Select Committee. Campbell supports the view that there is no distinction between those described as “terminally ill” and those described as “disabled”. Her justification for this is that they are interchangeable in the eyes of the public (ADTI Evidence 2005:235). Jane Campbell’s personal story of transcendence is that during an acute episode in hospital (Jane has Spinal Muscular Atrophy) her partner discovered that a Do Not Resuscitate order had been placed on her medical chart without her consent. She therefore feels that she has had personal experience of suffering under a “medical gaze” determined to judge her life based on a prejudicial understanding of the quality of disabled people’s lives. Her articulated fear comes to stand for the disability rights movement’s general fear of bureaucratic death: of being reduced to “bare life” by doctors working on behalf of a faceless state bureaucracy.

Agamben (1998) states that “bare life” is human life that is left exposed to death and is outside the protection of the law. The forms of death to which life is exposed are decided upon by the sovereign power (read state power). Agamben’s main idea, then, is that Western culture is now dominated by thanatopolitics: that is, rule by exposing the population to specifically modern forms of death and abandonment. Campbell’s experience of being judged “not worthy” of being resuscitated or “better off dead” by the hospital medics, according to Agamben, would be an example of the making of “bare life” whereby she was left completely exposed to medical and bureaucratic power. However, in Agamben’s model, “bare life” is never *actually* killed, but rather only kept exposed to death in order to make it subject to the crudest form of power. It is the “inclusive exclusion”, suspended between *zoe* (biological life – equivalent to Arendt’s “labour”) and *bios* (biographical life). By this rationale, Campbell and other disabled activists who feel their lives are judged “not worthy of being lived”, would never *actually* be killed by doctors. Instead they would be kept in a “zone of abandonment”, denied the full rights of citizenship and protection of the law⁵⁹, and

⁵⁸ The DRC merged with the Equality and Human Rights Commission in 2007.

⁵⁹ In oral evidence to the Select Committee, the prevalence of suspended sentences for mercy killings was cited as proof that to kill a disabled person not considered “murder” equivalent to killing non-disabled person.

subject to being identified only in terms of their disability and not their individual biography. In this regard, Campbell's fear of the effects of the legalization of assisted dying for disabled people are apparent in her fear that the social and legal rights, for which the movement has striven so hard, will be lost as the disabled-dying are pushed again into a "zone of abandonment".

Indeed, Campbell feels so strongly about the erosion of the rights of the disabled-dying that she has set up a small yet vocal anti-assisted dying group called *Not Dead Yet*⁶⁰. She writes on her website:

We believe individual disabled people's suicidal cries for help come from a lack of proper practical, emotional and medical support needed to live dignified lives, rather than from the 'suffering' they experience as a result of a medical condition. Individuals risk being easily exploited by the 'right-to-die' movement...their attitude is not compassionate – it is prejudiced and disablist (Accessed 02/2008).

She refutes the subjective definition of "suffering" as laid down in the ADTI Bill. Suffering, Campbell would argue, is not only a matter of individual definition, but is determined by people's preconceptions about what it means to suffer and the negative images of disability circulated through the various media channels. It is society and the media that encourage disabled people to see themselves only in terms of their medical diagnosis, rather than in terms of their potentiality, and it is this that encourages people to want to opt for death. The media, Campbell argues, depicts disability only in terms of "personal tragedy", such as the various right-to-die cases promoted by DID that depict progressive diseases as "a fate worse than death"⁶¹, and those prejudicial images feed back to disabled or sick people themselves, in a negative feedback loop. As a representative of *Disability Awareness in Action* told the Select Committee, if assisted dying were legalised "we would end up buying into what we think society wants us to do" (ADTI Evidence 2005:236).

Therefore, the argument proceeds, until resources are allocated so that disabled people have full equality of access and opportunity, any assisted dying legislation

⁶⁰ www.notdeadyetuk.org

⁶¹ DRC written submission to the ADTI Select Committee

would only serve to further discriminate against disabled people. Interestingly, at a human rights conference in London in 2005⁶², chaired by Jane Campbell, a picture of Dianne Pretty was projected onto a large screen behind the stage. Jane sat in front of this giant image of Dianne promoting the view, not that her human ‘right to die’ should be respected, but that her desire to die could have been nullified if her ‘human right’ to social care and support services was a government priority. On this platform, an image associated very explicitly with one movement was co-opted by another movement and attributed with an entirely different meaning.

The opposition’s answer to the arguments of the disability rights movement is that it is excessively paternalistic, if not discriminatory, to deny disabled/dying people the right to exercise their own autonomy, however they choose to use that autonomy i.e. even if they want to opt for a hastened death. Indeed, this was one of the central legal arguments to Dianne Pretty’s rights-claim. Her lawyers in part based her claim on Article 14, the prohibition of discrimination, in the European Convention on Human Rights. In other words, if able-bodied people could commit suicide, it was discriminatory not to aid her if she could not take her own life due to paralysis. However, the refutation of disability rights arguments is not the key issue here. Arguments come thick and fast for and against every principle at stake in this debate. What is significant in this struggle over who can define suffering and the solutions to it – whether that be a hastened death or a more equal society where people can be transformed by disability rather than trying to seek a way out – is that people’s individual, personal suffering is imbued with political and moral meaning.

The Personal Made Public

Kleinman & Kleinman’s (1991:276) view is that suffering does become “culturally patterned into recognisably shared forms” (Kleinman & Kleinman 1991:279). It becomes culturally symbolic when it is treated as political performance and moral commentary (1991:275-6). Yet suffering is also about experience and the constitution of the ‘self’. Too often, suffering is forced to undergo a “professional

⁶² *Human Rights: Transforming Services?* Conference, March 2005 (hosted by the Social Care Institute for Excellence & the Disability Rights Commission).

transformation”, whether by a psychiatrist reworking a patient’s perspective or an anthropologist codifying a participant’s experience. In the process, human experience loses its “complexity, uncertainty and ordinariness” (1991:276):

Because of the psycho-physiological grounding of experience, cultural codes cannot make of each of us precisely what they will (Kleinman & Kleinman 1991:293).

In a sense, Jane Campbell’s attempts to fit the suffering of the disabled-dying into the same overarching moral commentary on the inequitable foundations of society, flattens out individual experience in order to reinterpret it as a symbol of structural inequality. For Kleinman & Kleinman (1991:278), this caricaturing of experience is a “reductionist form of knowing which by definition distorts the existential conditions of life” and essentially dehumanises people. My research participants who have fought hard to travel to Switzerland for help to die are not so much fighting for the rights of disabled people U.K. wide as they are seeking an expedient solution to their own experiential and existential distress. When I questioned them about the position of disability rights organisations, they struggled to see the relevance to their life. This was because many did not view themselves as “disabled” but rather as sick or old or dying. They also often failed to see what effect their individual decision to go to Switzerland for help to die would have on the disability rights movement which was about well-being in life, rather than well-being in death.

In Frank’s (1995:115) work on illness narratives he discusses the “quest” narrative, which embraces a type of transcendent hope and partakes of the affirmation model of disability. The “quest” is loosely defined by the person’s belief that something is to be gained from the experience of disability. This equates with the DRC’s (and Jane and Alison’s) point that to endorse assisted dying would be to support a negative view of disability whereas, in actual fact, the experience of disability can be both individually and collectively rewarding (Swain & French 2000:574). However, another type of narrative is the “chaos” narrative (Frank 1995:97). This narrative-type is evident when an ill person never imagines life getting any better. They are “chaotic” because they lack order and discernable causality. In this sense, they are

the opposite of the clear, transcendent, transformational plot structure that Jane and Alison have attributed to their biographies-in-illness and which they articulate publicly in the media. As in Section One of this thesis where I argued that “death-talk” which does not fit a transformational narrative arc is often sidelined, “chaos” narratives, which do not conform to a positive account of disability, are often excluded. Smith & Sparks (2005:1103), who examined narratives of hope among a group of men disabled through playing sport, comment that the affirmative model of disability can “siphon out experiences of the body and its fleshy physicality in favour of a political-structural analysis.” They suggest the model “marginalises and silences” individuals who do not see themselves as part of the collective disability rights movement. It takes “disabled people” as one homogenous group which, again, flattens out individual experience. As Kleinman & Kleinman (1997:2) put it, there is no single way to suffer. Homogeneous representations deny the world in all its multiple possibilities (Frank 1995).

From the perspective of many pro-assisted dying campaigners (also not a homogenous group, it should be emphasised), personal stories are needed to elucidate the “issues”. People reveal their life stories in the media in order to add real life flesh to the bones of principle. Yet Dianne Pretty’s personal story, for example, was subject to equal but different narrative pressures as compared to the stories of people like Alison and Jane Campbell. The complexity and uncertainty of Dianne’s life with MND was blotted out of the picture in order to highlight her *one* struggle: to get help to die. She allowed her suffering to be instrumentalised for a cause that she felt was bigger than herself – she was, after all, fighting for a *human* right, extendable to all human beings. She portrayed herself, and was portrayed by those who supported her plight, as an innocent victim of the law, the inflexibility of which needlessly extended her suffering. However, in constructing her narrative of suffering, her daily negotiations of various routines, along with her relationship with her husband, Brian, whom she was asking to take her life, were reduced to one political struggle, and one singular narrative.

The day after Dianne died, the BBC broadcast a documentary entitled *Please Help Me Die*⁶³. The film crew followed Dianne for 6 weeks before her death and the documentary was intended as an intimate portrayal of the “indignities” of living with her illness. The voice-over tells the viewer:

Diane agreed to let us make this film because she wanted to help people understand what she believes is her total loss of dignity.

In the documentary, Dianne is filmed at home interacting with her family in what is depicted as normal, everyday scenarios. The film tries to evoke a sense of what Smith & Sparks (2005:1103) call the “fleshy physicality” of her experience of her illness. This they do by showing her being helped to perform various bodily functions. Her husband comments at one point: “She's a very, very private woman even to me.” And yet she had let a film crew into her home to film her last weeks, and she had launched a very public legal challenge. Her campaigning endeavours seemed to contradict her husband’s view of her as a “very private woman.”

Sennett’s arguments, which I outline earlier in this thesis (see *p131*), seem applicable here in light of these seemingly private images entering into the public domain via the media. Sennett (1977:5) argues that public life has become confused with people’s private worlds and that public matters are being worked out in terms of personal feeling. This, writes Sennett, is not so much a product of individualism as it is of individual anxieties being writ large in the public sphere. In other words, Dianne Pretty’s anxiety about dying a painful death is writ large in the highest court in Europe. The result of this blurring of the public/private boundary, argues Sennett, is that both spheres become degraded. The public sphere, since the 18th Century a site of civility and impersonal obligations, no longer inspires passion, appearing hollow, while the world of intimate feeling, once epitomised by the family unit, loses its defining aspect: a sense of private reality (Sennett 1974:18,7). In the last century, public experience has lost its connection to the formation of the social order and is now concerned instead with the formation of personality (1974:24). Despite being a “very private woman”, Dianne was willing to allow a film crew into her house to

⁶³ *Panorama*: “Please Help Me Die” BBC1, 12 May 2002.

film her up until a week before her death. Although it was broadcast the day after her death, the documentary publicly represented her intimate world in order to communicate a political message. The effect of this, as the voice-over tells us, is that Dianne “has become famous for an extraordinary reason.” Her public image is now synonymous with her conviction about the moral rightness of her cause (although it is subject to co-option, as we have seen), but also with her suffering-in-illness and the so-called “indignities” of dying, which, her image suggests to the public, may await us all.

Equally, we can apply Sennett’s comments about the blurring of the traditional public/private boundaries to the views of palliative care physician Rob George that I outlined at the beginning of Chapter Six. George argues that the loss of “deontological structures” post-World War I has given rise to a personal ethic which prizes happiness above all else and is entirely subjectively determined. These views chime with Sennett’s about the “tyrannies” of the intimate world, to the extent that both assert that an obligation to an impersonal “public” or societal “structures” no longer holds sway over people’s imaginations. Now it is the ‘cult of personality’ that motivates action and arouses belief (Sennett 1974:25).

Actually, in this debate, principles are not subsumed by personality but rather they blur with it, becoming embodied in the image of activists like Dianne or Jane. Their images and stories become symbolically potent. They are designed to appeal both emotionally *and* morally to audiences. Wilkinson (2005:138) comments on the well-established critique of news media corporations as failing to give in-depth accounts of social context when portraying suffering in sensationalist terms. This is alternatively labelled “promiscuous voyeurism” or the “commodification of experiences” (recall Moretti and Sontag’s views on emotive spectatorship outlined in Chapter Four). Kleinman and Kleinman (1997:2) share the view that the experience of suffering is often used as a commodity in news media, and as such is thinned out and distorted. Virilio (2003) has gone further, controversially arguing that the media’s sensationalism has bled into art, politics, and culture to such an extent that it has become what he terms a “mediascape” of images and sound experienced at high

speed, leaving audiences without time to criticise or even to think. Indeed, it may be true that we never really get a sense of what it is like to *be* Dianne or Jane. We may feel we are just led to pity or admire them, and not necessarily in ways directed or controlled by them. One researcher working for DID at the time of the ADTI Bill debate told me that she had lost faith in democracy because she had come to realize how manipulative and selective the media was in its representation of the “serious and complicated issues” at stake.

Yet activists do not publicly narrate their stories of disability/dying in order that they can become media commodities. Although they cannot control their representation, what is important for them is that they want to elicit a form of moral witnessing from an unknown public (as discussed in Section One). Engaging with the “mediascape” and the sensationalist press may be the only way of doing this. Fassin writes about humanitarian agents working in conflict zones who act as witnesses through providing testimonies of trauma (2008). These testimonies also seek to elicit emotional rather than analytical responses, and attempt to solicit *affects* from an audience of potential donors (2008:537). However, it is the psychological-psychiatric language of trauma employed by these humanitarian organisations which is used as a way of passing moral judgment on a conflict situation: “the diagnosis of trauma is not only clinical description but the political expression of a state of the world” (2008:532). Both Dianne Pretty and Jane Campbell talk about suffering as a way of passing moral judgment on what society should and should not allow. Both believe in the underlying moral rightness of their claims to want to live in an equal and fair world. Both project utopian ideals onto an imagined future where there is no discrimination and no suffering. And both desire to emphasise their purity of intent – that their judgment is not clouded through illness or partiality. It is this moral conviction which is embodied in their personae as Sennett’s “cult of personality” comes to be used to instrumental effect.

To try to separate moral conviction from emotive sensationalism is a false pursuit, argues Rorty (1998). The attempt to separate the two is an effect of the rationalist bias that can be traced back to Plato and Kant. This is the same rationalist bias that is

clearly evident in Joel Joffe's argument that legalising physician-assisted suicide is a "rational choice" for "thinking people". The morality to which he subscribes comprises a community of rational thinkers only. Arguments on the other side appeal to morally irrelevant considerations, we might be led to believe. "Rationality" was long cited as the shared, transcendent human attribute that grounded morality (Rorty 1998:171). Kant claimed that man was, above all, rational. But Rorty is a pragmatist, and he thinks that Kantian "rationality" is no more useful as an operating principle than Nietzsche's claim that man is defined by his 'will to power.' What matters is not uncovering some transcendental moral consciousness, but rather posing the question "what can we do with ourselves" *now* (1998:167). His views here are similar to Brown's identification of a "reactionary foundationalism" (1995:35) pervading the postmodern era. Because we feel destabilised due to the decentralisation of power in the plurality of the postmodern world, we "fetishise" tradition and take one thread and present it as if it were some indisputable good (Brown 1995:36). For Rorty, the means of escape from such foundationalism is to be future orientated and to use the tools at our disposal (such as human rights law) to make a better world, rather than orientated towards that past, consuming ourselves with the foundationalist enterprise of trying to uncover the "universals" of human nature. As Brown states:

Postmodernity poses the opportunity to radically sever the problem of the good from the problem of the true, to decide "what we want" rather than derive it from assumptions and arguments about "who we are" (1995:49).

Rorty finds Kant's view that sentimentality has nothing to do with morality "astonishing" (1998:175). It is akin to regarding the law as entirely separate from emotions, even though the law ubiquitously takes account of people's emotional states and the judge's (or jury's) compassion is constantly solicited (Nussbaum 2004:5,54). Rorty suggests that we side-step the opposition between emotion and morality by endorsing Baier's (1991) "progress of sentiments" or his own "sentimental education" whereby we allow ourselves to be moved to action by sad, sentimental stories and by a feeling of "niceness" rather than obedience to a moral law (Rorty 1998:182). Lord Joffe and Rob George may argue that it is rational principles and deontological structures that underlie the assisted dying debate, but it

is the media's portrayal of emotive stories like Jane's and Dianne's that find a public foothold, are remembered, and engage people in the different types of suffering/discrimination experienced by the disabled-dying. Rorty is not concerned with *why* moral principles no longer motivate people to action, but is rather concerned to stress that our bias towards reason and principlism can often hold us back from recognising each other's humanity, and from being that "little bit nicer to one another".

Nussbaum (2004:17) too advocates that we abandon grandiose demands for omnipotence and completeness and accept our human vulnerability. Emotions are reminders of our common humanity because this is how "we register the damages we have suffered, might suffer, or luckily have failed to suffer" (Nussbaum 2004:6). Emotions are a way of expressing an evaluative judgment and, contrary to 'rationalist' views of the law, can be deemed "reasonable" and can play a dynamic and educational role (2004:12). Both sides make appeals to emotion in the assisted dying debate (despite each lobby accusing the other of crass emotional manipulation and simplification) probably because it is "the best weapon we have" (Rorty 1998:182-3). Our "rationalist bias" against sentimentalising stories (that to *know* the evidence is more important than to be *moved* by it) does not help us to recognise the "precariousness of the other" (Butler 2004).

There is an acceptance in both the pro- and anti- movements that the "progress of sentiments" and the "cult of personality" now dominate the public realm. While they might judge this as distorting or confusing for the public, rational or irrational, both sides are adapting to this new impetus to elicit emotion. The primary struggle now seems to be whose emotions are deemed to be more authentic or sincere. Trilling (1974:2) notes that sincerity refers to a congruence between avowal and actual feeling. To prove one's sincerity is to prove one's virtue and moral value. Again, we see that even as campaigners, however hesitantly, accept the move towards making public emotionally-engaging personal narratives, these embodied narratives are still believed to represent underlying concrete principles. The external avowal and the inner core principle 'sincerely' mirror one another.

In the next chapter, I focus on these claims to sincerity and authenticity and the nature of conviction itself – how do the beliefs of the activists manifest themselves and how are we to interpret their claims? I switch my attention from the politics of emotion/sentiment in the public realm, to the activists who stand behind that emotion, and their practices of ‘self’-making. My ethnographic focus here is a group of right-to-die activists. I chose to follow them because they were more active at the time of my research. Their relationship to “the cause” (legalising assisted suicide) is much more self-defining than for paid workers at DID, who would not generally define themselves as “activist”. For them it is a job. For right-to-die activists it is a passion, a conviction that compels them to go above and beyond what most would define as conventional campaigning. In what comes next, I introduce FATE, its activities, and two individual activists. I end by asking: how does the projection of a sincere ‘self’ relate to the activists claims to personal autonomy in dying. And how do the rhetorics of individuality produce an “authentic” activist and an “authentic” death?

CHAPTER EIGHT

The Death of the Activist

Deeds not words (Emmeline Pankhurst, Suffragette).

This chapter is devoted to exploring the activities and conviction of a small right-to-die group called *Friends At The End* (FATE). I spent many months involving myself in the activities of the group and forging relationships with some of the group's most active members. To outsiders, FATE members' frank discussions about the mechanics of dying and their descriptions of different 'bad death' scenarios might sound morbid or obsessive. But for FATE activists, acquiring knowledge about how to prepare for death helps to provide certainty for themselves, give certainty to others, and assuage those fears associated with uncertainty. As I argued in Chapter Five, certainty and control are the main factors that motivate requests for aid in dying.

How does the abstract principle for which FATE are campaigning – autonomy or control - relate to their interest in the practicalities of dying? How does what they are arguing for relate to what they actually *do* through their activism? In highlighting the activities of the group and the way that *Dignity in Dying* (DID) differentiates itself, I aim to show the centrality of pragmatics for the group. How do FATE members discuss death? What is it that they strive for exactly? And what kind of people do they become in the process? In order to explore these questions, I spotlight two individual FATE activists, drawing out the relationship between their principled beliefs and practical engagement. This involves exploring the problem of belief as an analytical category in Anthropology. Finally, I describe some significant moments at the 2008 *World Federation of Right-to-Die Societies* conference in Paris that demonstrate the importance of heroes within the international movement. Heroic stories of activists being arrested for helping others die or stories about individuals-turned-heroes travelling to *Dignitas* for an assisted death forms part of a new public spectacle that fuels the passion of the activists. These 'heroes', like Dianne Pretty, are often internationally recognisable and help to connect the activists with the larger principle for which they are campaigning. Nominating heroes enables activists to put

the pragmatics of death to one side momentarily for the sake of ‘something bigger than themselves’ which would involve some sort of external guarantee. This gives them the possibility of transcending suffering and bodily deterioration through a belief in the sanctity of the autonomy of the individual. This chapter continues the themes of the struggle for recognition in dying, the desire to authenticate the ‘self’, and the quest for public immortalisation – not through art this time, but through ‘making history’ as an activist/hero.

Friends At The End (FATE)

In 1980, disillusioned with its inability to pass any legislation, EXIT (now DID), decided to publish a self-deliverance manual. A year later the Society dramatically stopped publication and distribution of the manual because of questions over its legality. However, the Scottish branch of EXIT decided to publish its own self-deliverance manual, facing less chance of prosecution in Scotland because assisting a suicide is not a crime in that jurisdiction. This manual was entitled “How to Die with Dignity” and was available only to members of the Scottish group. The group continued to operate separately from its English counterpart and, in 1993, published a new how-to manual entitled “Departing Drugs” (now updated as “Five Last Acts”).

In November 1999, after disagreements over finances and irreconcilable personality clashes, a few members, based primarily in Glasgow, split off to form a new group, which they called *Friends At The End* (FATE). Those founding members were insistent that FATE operate as a grassroots organisation, that members meet regularly, and that they organise public debates. Whereas Scottish EXIT had lapsed into inactivity, FATE set its sights on regular meetings and activities in order to give its members something to *do* and to be a visible and socially animate presence. Often, what is designated as an activist group comprises little more than a lone individual expending effort on maintaining a website which gives the appearance of activity. Activism is very often intangible and thus difficult to study anthropologically. In her seminal ethnography, Riles tries to pin down her human rights activist network by following the material artefacts generated internally (2000). This is an attempt to give a network a material reality that can then be

studied. Riles (2000) concluded that these material documents/artefacts often served only to reinforce the network rather than speak directly to its aims. The aesthetics of communication was everything, the ‘cause’ lost sight of somewhere on route.

Right-to-die societies are now understood to comprise a ‘new’ social movement (McInerney 2000:137). In the light of my historical account of the rise of the assisted dying movement beginning with the publication of Samuel Williams’ essay in 1870 (Chapter Six), the adjunct “new” might seem misplaced. However, it is true to say that the right-to-die movement as a whole has only achieved conspicuous momentum in the last four decades and its profile bears similarities with other ‘new’ social movements which have emerged since the 1960s: the civil rights movement; the women’s movement; the gay rights movement etc. Activism turned a corner around this time, shifting its focus from equality in the economic-industrial system to equality in terms of individual rights. According to Snow *et al* (2004:3), social movements arise when people organise into collectivities to give voice to their grievances and concerns about the rights, welfare, and well-being of themselves and others by engaging in various types of collective action. Whereas interest groups typically pursue their objectives through institutionalised means, such as lobbying and soliciting contributions, social movements pursue theirs mainly by non-institutional means such as marches, boycotts etc.

Although FATE members do not organise marches and boycotts and its members do pay contribution fees, the nature of their activism certainly puts them outwith any institutional support or networks and differentiates them from DID, as I seek to show in this Chapter. An examination of the differences between these two groups has enabled me to conceptualise the term ‘activism’ as requiring more than just nominal association to a group. It requires, at a very basic level, that members are *active*, because commitment to a ‘cause’, or conviction, is performative. Jean-Klein (2003:560) notes that activism has for too long been studied only as formal political association when it can also be understood as a state of being socially active or effective. Like Riles, she also emphasises activism’s “material concreteness” which provides its momentum (2003:570).

FATE's founding members determined from the start that they wanted more than a nominal association. They wanted to establish a collective group which would defy ageist exclusion from society and find a way to discuss what most concerned them: dying. The organisation has three meetings a year to which speakers (both national and international) are invited. It also produces a newsletter four times a year, comprising contributions from members. Included in the newsletter are national and international right-to-die news, the latest book reviews, and articles on new end-of-life research. Since 2002⁶⁴, the group has also been the U.K. point of contact for people travelling to the *Dignitas* organisation in Switzerland. It produces a guide which is distributed only to members and which details all the documentation and procedural requirements necessary for applying to die at the organisation. The Swiss authorities require a lot of identification, including marriage certificates or "celibacy" certificates (an Affidavit sworn in front of a public notary that you have never been married), birth certificates of spouses etc. as well as validation of a person's medical condition through up-to-date detailed medical records. People can have all sorts of problems sourcing this documentation, so FATE also offers advice by phone. On average the group receives 5-6 calls per week. These are all received on one activist's home telephone and calls are taken sitting at her kitchen table at all times of the day. In addition, two FATE council members have accompanied people to *Dignitas*. This is because *Dignitas* requires that a person have someone with them for their "accompaniment" and some people have no relatives or their relatives are unsupportive, in such cases FATE members can offer to go with the individual. Such is the "material concreteness" of FATE's activities.

DID, I argued in the last chapter, uses expedient measures to try to win mainstream support in order to become *the* bona fide organisation promoting patient choice at the end-of-life. FATE also applies expedient measures, but these are more pragmatic than political, meeting the needs of people requesting help to die *now*. DID does not give advice about either self-deliverance or travelling to *Dignitas*, which it views as

⁶⁴ The first British person known to have travelled to the *Dignitas* clinic for an assisted death is Reginald Crew, who also went 'public' with his story, inviting the press to accompany him on the journey.

short-term (even irresponsible) goals, that may jeopardise its hard-won credibility and incite accusations of illegal practice. In 2009, *Dignity in Dying* said:

We would not object to banning [Humphrey's best-selling "Final Exit" self-deliverance manual] because we don't encourage suicide without safeguards. It can be dangerous for vulnerable people.⁶⁵

This is a huge shift in approach for an organisation that at one point in time supplied this same book to its members. With the advent of DID's more "mainstream" stance, FATE has been able to fill the advice gap. This is in part because FATE is a much smaller organisation and does not aspire to become a great political lobbying force that needs to be above reproach. As of 2008, there were still only approximately 400 members, as compared to DID's 100,000 members and 'supporters'. Such a small, relatively informal group does not have the same levels of accountability or hierarchies of governance as an organisation like DID. Despite its higher profile more recently due, in the main, to its involvement with the activities of *Dignitas*, FATE remains a grassroots organisation and its focus is on regular networking and information sharing among members. It has more in common with the *Voluntary Euthanasia Society* (VES) as it was first conceived in 1935 than with DID's current 'restrictive scope' approach.

In his study of *Amnesty International*, Hopgood (2006) contrasts the views of the traditionalists – the "keepers of the flame" – for whom the letter-writing campaigns of the charity's founders should continue to be the focus, with the views of the reformers who stress the need to make the organisation more professional and more political. The traditionalists stress cool, calm documentation of human suffering. The reformists want to use the *Amnesty* "brand" (viewed as having "moral authority") to engage in more overt political lobbying (2006:14). The differences between FATE and DID are not directly akin to the split in *Amnesty International* as identified by Hopgood. DID staff are far more 'cool and calm' than FATE members, whose passion and pragmatism actually make them more akin to the *Amnesty* 'reformers'. Yet this sense of needing to 'professionalise' and to 'change in order to survive' (2006:14) is exactly DID's rationale for their switch to a patient choice agenda.

⁶⁵ Manchester Evening News 16/02/2009

FATE members are the “keepers of the flame” in that while they do not resist DID’s professionalisation and mainstreaming agenda, they would not compromise on the more ‘traditional’ goals of the right-to-die movement: receiving help to die on the grounds of suffering and autonomy rather than on the grounds of having a “terminal” diagnosis.

The difference between FATE and DID is exemplified by their views on *Dignitas*. The Swiss organisation and the vast amounts of publicity it has attracted in the international press have helped to keep the assisted dying debate in the public arena as much as any DID campaign of recent years, even Dianne Pretty’s legal case. So much so, in fact, that the phrase “going to Switzerland” has established itself as a euphemism for an assisted suicide, or even perhaps a euphemism for death! Yet DID do not support *Dignitas*’s activities. Ostensibly, the Society’s reasoning is that helping someone travel to Switzerland could be tantamount to “aiding and abetting” and therefore a criminal offence. Yet it may also have something to do with the fact that many assisted dying advocates simply do not like the idea of *Dignitas*. One House of Lords peer who lobbies strongly in favour of assisted dying legislation in Britain told me that it was “seedy” and that only “eccentric” people would go there to die. Another campaigner who worked on the *Assisted Dying for the Terminally Ill* (ADTI) Bill told me she thought it was “freaky” and dangerous because it was unregulated. These were comments from *supporters* of legalisation. FATE activists, on the other hand, do not view *Dignitas* as a last resort for desperate people. They actively support *Dignitas* and believe there would be a role for the organisation even if assisted dying were to be made legal in the U.K. It is this long-term support for different ‘types’ of assistance to die that differentiates FATE members from DID’s paid workers.

Another source of tension between the two groups arose when some FATE members grew suspicious of Debbie Purdy’s campaign (supported by DID) to attempt to clarify the law for people accompanying friends and relatives to *Dignitas*. They were of the view that “stirring the pot”, as one activist put it, might backfire and make it more rather than less difficult to accompany people under the radar of the authorities.

Indeed, an increase in international publicity for *Dignitas* and the services it offers does make it more difficult for the organisation to operate as the Swiss authorities become more and more irritated by their new reputation as a destination for “suicide tourism.” However, when FATE members publicly express cynicism about the Purdy case, this angers DID.

A further reason why FATE is prepared to offer more practical advice to members stems from the demographic of the organisation. Unlike DID, whose members tend to be over 65 but whose paid staff and Chief Executive represent a much younger demographic (they are in their 20s and 30s), both FATE’s council and membership average 68 years old (Judd 2009). Seventy Four per cent of members are over 60 years old. This demographic runs contrary to the usual association of activism with youth. The group’s key organisers are mostly retired and therefore have fewer concerns about airing ‘controversial’ views that may impact negatively on their careers (especially for people working in the healthcare professions). The fact that they are not getting paid to be active in the movement suggests a different type of commitment, not associated with remunerative reward. Some key members are also less concerned about skirting the fringes or even personally testing the limits of the law on this issue. By the age of 68, people have also generally experienced deaths of family and friends and have had time to contemplate their own. Some older FATE members feel that while they support all political campaigns to change the law on assisted dying, they do not personally have time to wait, if indeed waiting will bring the desired legislative change, and they need to make plans for their own dying in the interim. What can only be described as the general irreverence of FATE’s core members has meant that the group has retained an ethic of freedom of both action and expression that DID has lost in its desire to gain mainstream acceptance and to operate very strictly within the law.

FATE’s pragmatic mission echoes Rorty’s (1998) pragmatist philosophy. Rather than arguing one’s case from the basis of first principles or from lofty assertions about the underlying ‘truth’ of what it means to be human, Rorty argues that it is better to engage people in effective action which in a simple way makes people’s

lives better: “niceness champions obedience to moral law” (1998:182). FATE would endorse this view, seizing the tools and information they have at their disposal to help people achieve the death that they desire. Whereas DID want to institutionalise freedom to control death by focusing solely on legalisation, FATE members with whom I have spoken are open to adapting to freedom’s more contingent character. They want a change in the law, yes, but this would not remove the need to keep other avenues open or learn the techniques of self-deliverance, for example. To be free is to be free to adapt to circumstances and the means available. Relying on the state may not always be an option. This view is reminiscent of the central paradox of the assisted dying movement, discussed in Chapter Five, that to exercise autonomy in death, one needs the assistance and the conferred legitimacy of the medical profession, whose life-prolonging techniques are the very point of resistance. However, FATE’s refusal to adopt the narrower path towards legalisation and legitimacy assumed by DID mean that this paradox is less acute when surveying their activities. Their focus on pragmatics rather than procedure, morality, or legality enables them to enlist freedom’s contingency. As Foucault writes:

Liberty is a *practice*... The liberty of man is never assured by the institutions and laws that are intended to guarantee them...not because they are ambiguous, but simply because “liberty” is what must be exercised (Foucault 1984:245).

Part of the desire to resist institutionalising freedom may stem from the fact that many members’ motivation for joining the group comes from a determination to resist the societal trend towards institutionalising old people when they become frail. According to Adler, people in nursing homes are “patronised, infantilised, ignored, labelled, and denigrated” (1991:33). Her finding is supported by other nursing home ethnographies. It is the prospect of complete disempowerment which many members of FATE want to resist. They want to control their own demise, their own “falling away” as Diana Athill elegantly calls it in her autobiography of her 90th year (2008:10). Although ‘natural’ death is often deemed to be the preserve of the old, FATE’s old members would rather die an ‘unnatural’ death than be institutionalised, or forced, as they see it, to suffer the tyranny of longevity. Whether they are conforming to the stigma of old age (by fearing the ‘slow dying’ old age may bring)

or defying it (by choosing death over the infirmities of age or institutionalisation), the societal stigma around old age shapes their anticipation of death. It is interesting to note that suicide rates are higher amongst older people than any other age group, and that the suicide attempts of the old have greater lethality, and are made with no warning or requests for help (Brogden 2001:48).

The relationship between FATE and DID is at times strained. In interview, a DID representative told me that they did not want to have anything to do with FATE because mere association with the group could bring their own campaigns into disrepute:

Because FATE assist people more than they should do legally then we can't have anything to do with them, even if we wanted to. And I'm not sure we would want to (Campaigns & Press Officer, DID).

FATE's pragmatic project not only takes them onto shaky legal ground, it also makes them less controllable. They do not hold a "corporate" view to which they are accountable. Instead, they are a collection of individuals with different personal views, all seeking recourse to different methods of preparedness for death. This means that FATE council members can be unpredictable when engaging with the press or with the opposition because they have never agreed a set of "foundational principles" or "ground rules" from which to work. When embarking on my research I naively presumed that all assisted dying advocates would be united through shared goals. Yet it is often the case that internal differences *within* movements are felt as passionately and deemed as irreconcilable as differences between the movement and the opposition. Hopgood (2006) comments on similar internal diversity and division within *Amnesty International* as the reformers struggle to convince the traditionalists of their new vision for the organisation. The DID representative's qualification of "I'm not sure we would want to [have dealings with FATE]" implies that even if FATE were operating securely within the law, their lack of a corporate view and their more radical take on the types of people they endorse being helped to die, such as non-terminal cases or the "tired of life", makes them a poor prospect for collaboration. As DID's representative told me:

We don't want to come across as so passionate that we are not rational.

For DID and many of their political supporters, FATE are just *too* passionate. It is this passion that makes FATE an activist organisation rather than an interest group, which better categorises DID's role/activities. Needless to say that both are part of the same social movement.

To insist that FATE are concerned with pragmatics over and above morality or legality is simply to emphasise that conversations among members centre on practicalities of death rather than debates over the morality of their actions or their moral authority. Unlike the *Amnesty* 'traditionalists' who align their moral authority to transcendent/foundationalist principles (*Amnesty* operating as a fixed point on the moral landscape (Hopgood 2006:xi)), FATE members are more interested in tactics and *action*. Activists discuss "difficult" cases – deaths that went wrong through bad planning, examples of poor care or poor medical advice, people whose families are proving obstructive. There is little consideration given in conversation among themselves to the ethics of the type of people who should be assisted to die, or the types of advice that should be given. There is an 'ought' that goes without saying here, which is that autonomy *ought* to be respected and suffering relieved through compassionate action. It is tacitly assumed that anybody who attends FATE meetings or phones up to ask advice also takes these two principles as givens. And from that perceived indisputable point of departure, there is no need continually to revisit that moral 'ought'. It is always assumed that one holds that belief in autonomy by virtue of being a right-to-die activist. This is the *foundation*, and from here on in, pragmatics can take centre stage.

"The Cue for Passion"⁶⁶: Jean & Gwen

Baroness Ilora Finlay, a palliative care consultant and one of the most influential and prominent anti-assisted dying figures, told me that she thinks that most right-to-die advocates have had a bad experience of someone dying in the past. Her answer to this is not to deny these bad deaths, which she says show "inexcusable bad care", but rather to improve palliative care. Putting her solution to the problem to one side, her

⁶⁶ *Hamlet*, Act 2; Scene 2

assessment of the motivations of activists reflects a common assumption. Indeed, it was a question I myself posed to activists I interviewed, expecting to be told of some formative ‘conversion’ experience where the ‘bad death’ of a relative or a friend converted them to the ‘cause’. One activist to whom I spoke had a particularly shocking personal experience. Her elderly mother had a heart attack in hospital and after the medical team tried to resuscitate her for 20 minutes by “pumping on her chest”, they then told her she had died, at which point she was transferred to the mortuary. The activist phoned her mother’s friends and relatives who duly assembled at her house to pay their respects. At this point, the hospital telephoned to say that hospital workers in the mortuary had found her mother was still breathing. Her mother went on to live for three more months in a coma. This activist was so “appalled” that she became involved in the movement in order to avoid such a ‘bad’ death herself. While this conversion story is extreme, many (60%, according to Judd) activists did have a formative experience of witnessing someone else’s ‘bad death’ to which they could trace their interest in the movement. But not all. For some conversion extends from a generalised fear not traceable to any one experience, or any one death, except perhaps their own. Jean and Gwen are two such people.

Jean is a founding member of FATE. She is 82 years old, upper-middle class and a retired doctor. Her main occupation now is organising FATE activities and responding to callers to the advice line. Jean has three children and is a widow - her husband died when he was 59 (but his was “not a bad death”). She self-identifies as an activist but told me “I’m not extreme, I’ve just never been conventional.” Her background in medicine means that she is familiar with many of the caller’s diseases and has knowledge of the medication they are taking. She can also tell callers which drug concoctions will and will not cause death and the majority, she says, will not; “Unless you go to Mexico and buy a bottle of Nembutal, which is a liquid used to put horses down”. She sometimes writes the medical reports for people who want to go to *Dignitas* but whose doctors are unsupportive, or who do not have one doctor with the requisite overview of their multiple pathologies. Jean is very exact in her diagnoses of people’s problems, and incorporates both medical and social aspects of suffering to account for why people want to die.

Jean is a no nonsense kind of person. She wears her (metaphorical) medic's hat when dispensing advice to members or callers about how they can get to Switzerland, or the self-deliverance options open to them. She retains a professional distance from the people she advises so that while she feels "heartsick" for people, she says she does not get emotionally involved. Her motivation, she says, is unequivocally the principle of autonomy:

N: Jean, why death activism?

J: Oh, it's not to do with death! It's to do with autonomy.

Jean feels like her whole life has been devoted to pursuing an ethic of personal autonomy (for which we can read 'freedom'). In her earlier professional life she was "up to her neck" in the family planning movement, prescribing contraception and giving abortion advice to women living in deprived inner city tower blocks in the 1970s. She also volunteered at a drop-in clinic for prostitutes and worked in a venereal diseases clinic:

I never carried a banner or walked in processions. I just did the job in front of me. Against a lot of odds at times.

She told me that it seemed "logical" after she retired to get involved with the "battle for choice" at the end of life.

Aside from the principle of autonomy, Jean is also motivated by her "clinical curiosity". She says that through her work with FATE she has encountered diseases that she had hardly even heard of in 40 years of clinical practice. Her involvement with FATE gives her something to *do* every day, a "usefulness" by which she can also continue to satisfy her "infinite curiosity". In this sense, she is now firmly entrenched in the pragmatics of assisted dying. This became very clear in a discussion I had with her about a recent case. She had given advice over the phone to a woman with a brain tumour, the effects of which made this lady want to end her own life. The woman had already made two unsuccessful and quite traumatic suicide attempts. Jean went to visit the woman in person to do a face-to-face assessment. They discussed the options open to her and she left the woman to think them

through. A few days later the lady telephoned Jean to tell her she had decided which method she would use and they talked it through together. That same day she took her own life, but she actually used a different method to the one she had discussed with Jean. I asked Jean how she would have felt had the woman in question used the method they had talked about in advance. My reason for asking her this was to try to prompt an expression of relief that she could not be held responsible for having “aided and abetted”. Actually, her response was entirely the opposite:

Well actually I was hoping that she had [used that particular method] and that she had died with it because it would have meant that I could personally say to other people who wanted to take that way out that it worked.

Her expression of regret, rather than the relief I had expected, are evidence of an absence of doubt about her ‘cause’. Kelly (in press; n.d.) discusses the doubt that pervades human rights practitioners’ work at the *United Nations Committee Against Torture*. Here, he argues, doubt centres on the means – the procedures and the technicalities of the system – rather than on the ultimate ends – the eradication of cruelty and suffering. Yet, it is actually the means, states Kelly, which offer the requisite reassurance of “immediacy and accessibility” which moves them nearer to their goal. Jean and other FATE activists also had doubts about the ‘means’ of their mission – the efficacy of various ‘techniques’ of death - but never noted any doubts about the ends. It was the means over which they craved certainty. I had also anticipated that Jean’s encounters with people seeking help to die would be intimate and confessional, and that perhaps she might fulfil a role akin to Chris, the *Rosetta Life* artist, who acted as a “confessor” for the hospice patients. Yet in Jean’s case, it appears her encounters were purely “clinical”. She dispensed advice objectively without revealing or requesting personal details or knowledge of dispositions above and beyond what was relevant to the task at hand, whether that be travelling to Switzerland or self-delivering. While admittedly this detached attitude may have been a feature of Jean’s professionalism as a doctor, similar sentiments were echoed by Gwen, another right-to-die activist, to whom I now turn. I want to suggest that this state of detachment is a feature of the single-mindedness and ‘doubtlessness’ of their activism.

Gwen is 81 years old and also upper-middle class. Jean refers cases to Gwen when she feels overloaded. In this way, Gwen also deals with individuals who want to go to *Dignitas*, and supports their families. Whereas Jean says she does not think about her own death, or “look too deeply into the future”, Gwen’s main motivation for becoming involved in the right-to-die movement is deep fears about the prolonged period of suffering and loss of autonomy prior to death. She continually reiterated to me that her interest in helping others was “purely selfish” in that she wants to acquire all the information she possibly can to be better prepared for her own death: “control is my big want”. Gwen is far from “purely selfish”, as she puts it, she is just disarmingly honest about her own motivations. She only became active in the movement in 2004, although she had been a passive member of DID before that. She used to be a Community Care manager and her job was visiting people in their own homes to assess their care needs. Her “conversion” experience was not one isolatable incident, but rather came about through what she witnessed in these visits and the overwhelming feeling that this was not the end she wanted for herself. She told me that people used to say to her “I am just waiting for God to come and take me”⁶⁷. Gwen said she could only think to herself, “I’m not going to wait for God!”

Gwen likens old age to a car running down. She feels her own body “packing in” on her. She does not see anything to be gained from pain and suffering at the end of life. She fully supports the right-to-die mantra that an end to suffering is infinitely preferable to suffering without end.

Most people hang on to life. I can’t understand it myself. I’ve always hated pain. I’m a terrible coward.

It is not that she is opposed to hospice care; she just does not really see the point of “slow dying”. Gwen has made every effort to plan for her death. She has executed an Advance Decision (see Chapter Nine) refusing all treatment apart from comfort care and stating that she does not wish to be hospitalised, but to stay in her own home. All of her children have signed this (after some persuasion). She carries a laminated “Do

⁶⁷ Two people actually said the same thing to me in the hospice day-centre where I worked alongside *Rosetta Life*.

Not Resuscitate” card with her at all times and she has made her doctors more than aware of her wishes. Her main fear is that her wishes will not be respected and that she will be kept alive against her will:

Do you realise, Naomi, how frightfully difficult it is to die?

Gwen is so scared, in fact, that she even joked about having “DNR” tattooed across her chest so her wishes will be known even if she is unable to communicate them verbally.

When I first met Gwen I found her frankness quite unnerving. The usual feelings of sorrow at the prospect of death seemed misplaced, and trying to talk her out of her death plans would be quickly ridiculed. Yet as with Jean, her unflinching “death talk” did not require or engage any sense of intimacy. It was not a confessional unburdening of emotion, but rather a detached practical statement of intent. Yet discussions of technique amongst activists at communal events did foster their own sense of intimacy because they were conspiratorial and because they could reach a depth of knowledge sharing which would be considered morbid or “freakish” to outsiders. At the biennial meeting of European Right-to-Die Societies in Strasbourg in 2007, I accompanied Jean and Gwen to a dinner at a small French restaurant with a select group of activists from various countries. During the dinner people began to discuss the helium technique for self-deliverance in some detail. How tight did the bag need to be around the neck? Would a mask not do instead? How could you test the gas flow in advance? How could “caring friends” leave with the equipment undetected? The discussion was so frank that it prompted the wife of one activist to comment: “it’s a good job we have a table upstairs (i.e. in a secluded area of the restaurant). What would people think if they overheard this conversation?!” If we endorse Aries’s (1983) proposal that modern death is “wild” and alien to us, these secluded gatherings of like-minded people offer a forum where intimate ‘death talk’ is permissible and a particular version of death is made ‘tame’ again.

Gwen’s coveting of information about ways and means of dying, might sound disquieting to an outsider, and also rather obsessive. Her sister refuses to discuss the “D-word” with her and even Jean said of Gwen: “I sometimes think she is death

obsessed!” Like Jean’s “clinical curiosity”, Gwen has a curiosity about people’s personal circumstances and family dynamics, which is why she enjoys manning the FATE phone line from time to time. It is significant that she is an avid fan of mystery novels. Her favourite author is P.D. James. She wants to ‘solve’ mysteries as she wants to solve people’s problems. This seems to have been a theme throughout her professional life. But perhaps she also wants to remove any mystique surrounding her own death, or death in general. She thinks there is a “conspiracy of silence” surrounding death. For her, there is nothing special about the period in which one knows one is dying:

Why is there this idea that something meaningful happens because you are dying? It might happen in spite of it, but not because of it.

Like a mystery to be discovered in advance, Gwen wants to know exactly what awaits her and to make her future certain, not because dying is special, but because it is to be avoided. She has turned death into a technical issue.

Gwen told me that she keeps a bottle of Nembutal in the cupboard as an insurance policy. However, even that does not give her the watertight assurance she wants. She worries about having a stroke and then not being able to open the bottle. What if she takes the drugs and doesn’t die? Who will find her body afterwards? Her ideal death would be at *Dignitas*, to which she has accompanied two people so far. She likes the Swiss model where people are helped to die by a “caring friend volunteer” type. This way, the process is de-medicalised and the doctor does not have control, which pleases her. Yet she fears that she will not be accepted to *Dignitas*, because she does not have a clear medical diagnosis, she just has the diffuse ‘symptoms’ of old age. I have often heard her make comments such as: “if I were lucky enough to have a cancer diagnosis, then I could go to *Dignitas*.” Such comments are prompted by her overriding concern that ‘slow’ dying from a ‘leaky’ body (Lawton 2000) will be so much worse than a painless, artificially induced death.

Gwen’s fears about what lies ahead for her may be exacerbated by her exposure to all these difficult cases through her work with FATE. Right-to-die activists are often

overexposed to “bad deaths” because these are the deaths they are most keen to document in order to highlight the “horrors” of ‘natural’ death. Every horror story they hear about via another member at a meeting or on the phone from some desperate caller reinforces their passion for the cause but also reinforces their fears of “worst case scenarios”. Hence for Gwen, I get the sense that she can never be prepared *enough*.

Although Gwen cites “selfish reasons” for her involvement with FATE, like Jean, it also gives her a sense of purpose:

Doing what I do now is really what I have always done which is listen to people and try and help them get what they want. I used to help people stay in their houses rather than go into residential care. Now I help people leave their houses and go to Switzerland and die! It’s very satisfying when you’re over 80 to have something to do which is needed. We all need to be needed, not least when we are 81.

As for Jean, Gwen’s activism gives her something to *do*. This raises the question of activism’s relationship to consequence. Are people ‘active’ advocating for an issue because it takes them closer to their target or is it the taking part that counts? Kelly’s (in press; n.d.) human rights practitioners felt daunted by their utopian goal of a world without torture and suffering – it was too diffuse and too long-term an aim to be realised. Instead, it was the bureaucratic practices – the instruments – which made them feel as if they were *doing* something.

Gwen’s “doing something” includes: helping people who contact FATE because they want to travel to *Dignitas*; writing for the FATE newsletter; attending FATE events; keeping abreast of new research; and endlessly networking at public events, conferences and through email. She also sat in the public gallery for the House of Lords debate on the ADTI Bill, attended some of the Select Committee hearings (which are open to the public), as well as right-to-die court cases. Occasionally she also speaks to the media. Yet what haunts Gwen on a day-to-day basis are: thoughts about her own death; her own current and future pain; the prospect of living too long; and being unable to hasten her own death when the time comes. For a long period of my fieldwork, her biggest concern was with death by dehydration. She perceived

there to be conflicting information about its relative merits and drawbacks in the medical literature. Callers to the FATE helpline described desperate situations where relatives had taken weeks to die after ceasing eating and drinking, one of the only methods of hastening death that does not require equipment of any sort. Gwen, concerned to give callers the right advice, took every opportunity at right-to-die conferences to find out whether refusal of food and fluid could ever guarantee a ‘good death’. Just as there is no doubt in her mind that assisted dying is morally right and rational, she is also unable to entertain any doubts that her choice of method, or that which she advises to others, will bring a quick, painless, and certain death. The moral certainty of her choice of death, about which she is convinced, needs only to be shored up by the certainty of its execution.

Both Jean and Gwen are self-proclaimed activists. They are both strictly utilitarian in their ideological perspectives. Their views could be considered quite extreme, even by those who are ‘on the same side’. Comments from Gwen such as “if I had the luck to be knocked down in the street”, while perhaps sounding flippant to an outsider, are born of her palpable fear that she will live too long or be kept alive against her will. Equally, Jean’s view that people over 70 years old should not “hold on too tightly to life”, might to some constitute a very crude and arbitrary form of age discrimination (although there is a widely held view that dying is the prerogative of the old expressed in such comments as “they had a good innings”). After all, when can we say that we have had *enough* life? For members of FATE, personal views are not censored – there is no ‘corporate’ view to uphold, no designated party line. While DID management may believe that expressing extreme personal views may do the ‘cause’ more harm than good, in actual fact it is more likely that there is no *one* cause to uphold. FATE membership simply offers a platform from which activists’ radically individualistic views can be authenticated. According to people like Jean and Gwen, to execute one’s ‘final right’ is a decision made alone and in accordance with one’s individual beliefs. There can be no ‘corporate’ view on this. It is this process of authentication of their radical individualism to which I now turn.

Belief & Conviction

In her ethnography of pro-life and pro-choice abortion activists in North Dakota, U.S.A., Ginsburg (1989) connects her activists' biographical experiences to their commitment to the 'cause'. She suggests that her participants used activism to give shape to disorderly private experiences (1989:14). By focussing on the life stories of individuals, Ginsburg wants to align the reflexive project of self-construction, as famously discussed by Giddens (1991), with the women's broader ideas of social reform and culture-construction within American society (1989:129). In a similar way, one could argue that FATE activists' commitment to the right-to-die movement gives them both something to *do* – a sense of purpose and fosters social relationships between activists – and something to *be* – a social identity. They work on their 'self' as they work on their 'cause'. Certainly, most activists themselves are aware of continuity between their life story – their biography - and their current commitment to the right-to-die movement. For example, Jean understands her involvement as a direct continuation of her earlier work with the *Family Planning Association*, Gwen, as a natural consequence of her earlier work with community care and older people.

In this way, life experience gives rise to one's convictions which then guide one's further life experiences, subsequently either undermining or confirming those original convictions. This is the iterative process of self-construction and the narrative of transformation which accompanies many activists' life stories. However, while Ginsburg addressed the substance of her activists' convictions, she never analysed the nature of conviction itself. Although she explored why each individual activist was personally motivated to become involved in the abortion movement (whether anti or pro-choice), at a more basic level she took for granted the idea that belief in a 'cause' and activism go together. Why is it important that activists convince their audience of their sincerely held beliefs? Can we entertain the possibility that a person can be active in a movement without *believing* in it? Or vice versa – that one can believe strongly without demonstrating that belief publicly? What exactly needs to coincide for a person to become a right-to-die activist?

As I discussed in the previous chapter, much of the political contestation in the

assisted dying debate centres on each side trying to *prove* its moral authority by invalidating the opposition's claims to that same authority. This 'proof' consists of attempting to demonstrate publicly that one's interior convictions are more sincerely held than one's opponents' convictions. Trilling argues that 'sincerity' needs to be performed or demonstrated publicly if it is to conjure up a sense that a person is *revealing* themselves in all their specificity (1974:25). And it is this sincerity which bestows moral value on the speaker. Trilling (and Sennett (1977) and Arendt (1958)), traces this expectation that one's sincere intentions can be demonstrated in public back to the "birth of society" from the Sixteenth Century onwards. Rousseau's *Confessions*, for example, was seminal in instilling a model of disclosure, where one's intimate life is laid bare in the public realm in order to secure a very public form of witnessing of the 'self'. It was no longer just the truth of Christianity which was important, but the truth of the individual (Hansen 2009). So in the same way that Jane Campbell and Dianne Pretty revealed themselves to an unknown public in order to demonstrate their sincerity and elicit emotion (Rorty's "sentimental education" (1998)), so too is there a pressure upon right-to-die activists to prove their sincerity. They must prove that they believe in their cause, sincerely. This performance of sincerity, however, at a basic level assumes an equivalence between interior belief and action which we cannot take for granted.

Kirsch argues that there is a predominant conception in the West that 'belief' is permanent and unchanging - that it is attached to a stable interior state or being (2004). This is due to the predominance of Christianity in the West and the fact that the Christian God is conceived of as permanent and unchanging. Belief is thus associated with interiority that exists *prior to* acting, that conditions understandings in social life rather than responding to them. Such treatment of belief, which assumes a specifically Christian approach, may be a result of Anthropology's own unacknowledged Protestant ontology, identified by Cannell and discussed earlier in this thesis (see p79). Instead of viewing belief as stable, a priori, and inwardly directed, Kirsch (2004:701) argues that beliefs can attach to whichever religious practices are most efficacious. Beliefs in this context are still considered a sincere internal condition but they are also performative and are directed at the "world

outside” rather than associated with a “working on the self” type model found in Western Christianity.

Bell (1992:186) too has highlighted the anthropological evidence which suggests that belief systems are ambiguous, unstable, and inconsistent. Bell argues that ‘rituals’, for instance, have little to do with an inflexible set of beliefs and everything to do with instinctive knowledge being embedded in people’s bodies through ritual action (1992:221). Her argument is that ritual does not necessarily require that participants *believe* in what they are performing, only that they consent to the *form* of the activities. A person believes in the act, not necessarily in the ideology which gives rise to the act. In this way, we might question whether it is important that FATE activists are interpreted as having an a priori concrete and stable belief in the principle of autonomy rather than that they come to embody those beliefs through rehearsing self-deliverance techniques or attending meetings, for example. While it has to be acknowledged that people are likely to be motivated to attend meetings in the first place through a prior commitment to self-determination, it is the actions taken which cement that belief. As Hansen (2009) states, convictions have to be affective to be effective.

Clearly there are a multitude of factors motivating people to become embedded in the movement and Ilora Finlay is probably correct when she says that experience of ‘bad deaths’ ranks highly. Activism can also give people a means of sociality and a sense of purpose. It is a way to help others and ‘do good’. Many more are motivated by fears about their own deaths. Some might be inspired by morbid fascination or a simple human interest in other people’s lives and family circumstances. Or perhaps, as for Gwen and Jean, it is a matter of solving a mystery, like a P.D.James novel. One cannot distil to one causal factor people’s involvement in the right-to-die movement. What is more interesting is how people’s convictions are performed and become embodied (*a la* Bell) and the relationship of the “material concreteness” of activism to the abstract principle to which they are committed.

While ‘belief’ as a concept has been traditionally discussed in Anthropology through

discussions of religious ‘belief’ and rituals, Asad (1993), among others, has argued that no domain of human social life is belief-free and that there is nothing particularly distinctive or universal about religious beliefs *per se*. Beliefs are not necessarily transcendent or to be associated with the divine, but are rather a basis for practical engagement in the world and can be flexibly applied according to the needs of our everyday lives.

One of the central problems facing those trying to study beliefs is that they can only ever be studied through either words (and my earlier discussion of Keane is useful here, see *p84*) or actions, given that we can never empirically study a person’s interior state (Sperber 1985:45). Perhaps this is one of the reasons why scholars have reframed beliefs in terms of actions because it then enables them to become an object of study. Otherwise, a researcher is forced to trust that what a participant says they believe is what they *really do* believe, which returns us to the issue of sincerity and authenticity. As Trilling states:

Claims to perfect sincerity encroach upon the darkness of an unknowable heart (1974:70).

It is this unknowable aspect to a person’s sincerity and to their belief which ultimately aligns both with death. Belief, unlike knowledge, entails a measure of the unknown; it requires a leap of faith. Death too, however we try to experience it in anticipation, always remains unknowable.

One way of circumventing the problems involved with studying ‘belief’ is to turn instead to conviction. Hansen (2009) has contrasted two modes of ethical conviction. The first type he labels an “ethics of the other”, involving activist ways of being in the present which include tactics, acts of giving or helping, and treatment of others. AN “ethics of the other” takes place when Jean or Gwen talks on the phone with a caller to FATE. They offer callers recognition for their suffering, often denied them by friends, relatives and ‘the system.’ This “ethics of the other” Hansen contrasts with an “ethics of consequence” which is a commitment to an abstract principle located in a future time. Only abstractions (not people) can be the object of this type

of commitment e.g. ‘The People’, ‘The Nation’, or, for right-to-die activists, ‘Freedom to Die’. An “ethics of consequence” can never be realised because the goal sought is forever located in a future time. In the case of death activism, orientation to a future goal that always remains out of reach is significant because our death is also located in the future; it is that which we move inexorably towards but yet can never experience and therefore it remains forever unknowable. According to Hansen, an “ethics of the other” can be proved by your conduct and displays of loyalty to others within the movement and to those you are seeking to help. An “ethics of consequence”, however, is more than actions or conduct – it is more than the ‘self’. It is beyond the ‘self’. It is an ideal.

For Arendt (2000:448) it is only in the political and public realm that this second mode of conviction can be realised because it is here where “not life, but the world is at stake”. I propose that it is an attachment to an “ethics of consequence” - belief in a better/perfect future world – that transforms right-to-die activists’ pragmatism into a transcendent belief in the ultimate value of autonomy. This type of conviction is future orientated, and because it attaches to a value greater or beyond the ‘self’, it stretches beyond interiority (where belief is so often envisaged to reside) to a transcendent principle which takes the activist beyond themselves and out of the realm of ‘ordinary’ engagement. This belief in autonomy as a transcendent principle is brought into particularly sharp focus in the contemplation of our death. This is because our death, unlike any other cause for which we may fight, is something we face alone, and no one can undergo it in our place (Derrida 1995). Hence it is the time at which our individuality and our autonomy arguably come into sharpest focus. When right-to-die activists like Jean and Gwen challenge norms, run risks, and skirt the edge of the law it is because they are responding to both an ‘ethics of the other’ and an ‘ethics of consequence’ which is an attachment to the transcendent principle of autonomy.

Hansen ends his argument by proposing that the activist is a specifically modern type of person, a public performer of ideals who may well become a surrogate hero:

through which the community compensates for its own lacks – lack of purpose, lack of consistency, lack of virtue (Hansen 2009:42).

One might be forgiven for confusing Hansen's final proposition with a glorification of the activist as a Christ-like redeemer of collective sin. This is certainly not what I want to imply about the right-to-die activists I met. But the conviction they cultivate through their activism and shared passion transforms them into enigmatic figures who both feed off and inspire the movement in equal measure. Jean's unrelenting energy for manning the FATE phonenumber and offering advice to desperate people in need, or Gwen's relentless enquiries into research on 'death by dehydration' make their passion for their cause indisputable. And it is my view that this pragmatic engagement also connects them to 'something outside themselves', and that their activism is more than a project of self-construction – it goes beyond the self. They are making demands of "I want" rather than just "I am" which attaches their claims to a political good rather than just an expression of self-interest (Brown 1995:75).

If we take this "something bigger than themselves" to be the principle of autonomy, then it implies that a principle can stand as a point of attraction in a pure form. In fact, as we know, there is no purely 'autonomous' individual just as there is no *one* meaning attached to "autonomy." It means different things to different people, even within the right-to-die movement. Autonomy even means something different to Jean than it does to Gwen. The idea that the 'principle' outside – the "ethics of consequence" – is any more stable than the 'convictions' within or between people is misleading. The principle is more likely to be an ever-changing discourse that escapes our grasp even as we try to take hold of it. And this is why, in my view, right-to-die activists subscribe to a philosophy of pragmatics in order to achieve their 'ethics of consequence'. They *do* their activism via social networking and information sharing, rather than *think* their activism. Their conviction is manifested in their pragmatism. Both Jean and Gwen are far more orientated towards worldly matters of the diseased body and fulfilling people's 'simple' desires ("I want to go to Switzerland to die, please help me get there") than they are to abstract principles or truth-seeking. But it is perhaps a lack of a 'call to arms' that prevents their specific plea for freedom from having a wider appeal, except among the already converted.

In the final part of this chapter, I want to briefly describe FATE's involvement in *The World Federation of Right-to-Die Societies* biennial conference in Paris in 2008. Some of the themes that arose at this conference will lead us conveniently into Chapter Eight – seeking recognition in dying through recourse to the law.

The World Federation & The Right-to-Die Hall of Fame

The World Federation of Right-to-Die Societies was founded in 1980 and consists of 38 organisations from 23 countries. It meets every two years and in 2008 the conference was sponsored by ADMD France and was entitled: “Towards a Global Recognition of our Final Freedom?” The “*World Fed*” meetings, as my activists called them, present an opportunity to ‘talk shop’ with fellow campaigners from right-to-die lobby groups around the world. As one former board member stated: “there is so much to gain and learn from each other’s activities.” Different forms of assisted dying legislation can be found now on the statute books of four European countries and two American states⁶⁸. In theory, other countries can learn from their legislative successes as well as from their experiences post-legislation. However, *The World Federation* always lacks funds and there are only a few countries rich enough to host the event. As Sarah Wootton, the Chief Executive of DID⁶⁹ told me, in order to invest more in *The Federation* she would have to be convinced that DID’s members would get some return on that investment. The cultural specificities of each country’s assisted dying movement sometimes make it difficult for member organisations to see the value of expending time and effort on an international movement. This would summarise DID’s uncertain engagement. Yet for other organisations, particularly smaller organisations like FATE, the chance to network with other activists, especially from other ‘fringe’ groups, is keenly anticipated. The number of FATE delegates present at the conference (six) was disproportionately high compared to other much larger organisations (DID only had three delegates at the World conference, and only one at the European). This is testament to the greater networking needs of smaller organisations and their desire to reach beyond their own

⁶⁸ The Netherlands, Belgium, Switzerland, Luxembourg, Oregon State USA, Washington State USA

⁶⁹ Sarah Wootton replaced Deborah Annetts as Chief Executive of DID in December 2007.

limited membership and to feel part of something ‘bigger than themselves’. It is also a way of obtaining up-to-date information as well as catching up on gossip from friends in the international movement.

There were two highly significant moments during the 2008 *World Federation* conference. The first was a debate that took place entitled “Activism vs. Legalism.” Arguing on the side of “activism” was Ted Goodwin who runs the American group *Final Exit Network* of volunteers who collectively feel that “no one should die alone.” They thus act as “caring friends” who “hold people’s hands” when they self-deliver. In the words of Ted Goodwin, as a network they “skirt the law rather than challenge it.” Goodwin is also Vice-Chairman of the *World Fed*’s Board of Directors. Arguing the case for “legalism” was Lesley Martin, Chief Executive of a New Zealand organisation called *Dignity New Zealand Trust*. Lesley herself served a jail term for assisting in her mother’s death and became a minor celebrity in New Zealand, writing two books about her experiences. It is perhaps as a result of these experiences, that Lesley now thinks that directly helping people without the certainty or authority of a legal framework risks bringing the movement into disrepute. There can be no checks and balances, only the ‘conscience’ of the activist themselves to rely on. And there have been too many unscrupulous “gung ho” radicals, like George Exoo⁷⁰ or Philip Nitschke⁷¹, for example, who only make it harder to put the case for “legitimate social reform.” According to Lesley Martin, every time individual radicals incite controversial media headlines (with tag lines like “helium pushers” or “snuffers”) it makes politicians more sceptical. Martin wants to see a separation between *The World Federation* and what she calls its “rogue fringe” of activists who actually help people to die, in which category she includes Goodwin and his *Final Exit Network*.

⁷⁰ George Exoo is an American Unitarian Minister who is reported to have assisted in 102 suicides of people who were not terminally ill. In 2008, he featured in a U.K. documentary (Channel 4) called *Reverend Death* which claimed that his “clients” were mostly in need of psychiatric help. Exoo was a founding member of *Nutech*, but that network has since distanced itself from his activities.

⁷¹ Dr. Philip Nitschke is the founding member and director of the Australian euthanasia group *Exit International* and author of the DIY book *The Peaceful Pill*. When assisted dying legislation was passed in the Northern Territories in 1996 (the first jurisdiction in the world to pass such legislation), Dr Nitschke assisted the four people who ended their lives using the law before it was overturned by the Federal Parliament in 1997.

This heated discussion also spoke to the differences between FATE and DID as outlined earlier in this chapter. Ted Goodwin argued that each member organisation was responding to the culture, legal system, and social mores of their home country and that *The World Federation* could not dictate one route to the successful passing of legislation. He asserted that there were checks and balances within his organisation, that the volunteers were all professional and compassionate people, and that they should not be considered a “rogue fringe.” Legislation may never be passed, and in the meantime, people are suffering and in need of direct help. The underlying argument was that activism is often ahead of the mainstream political debate and thus has a place informing and stimulating the debate. Questions from the audience at the debate indicated that people favoured a “broad church” approach for the *World Fed* and that much could be learned from different organisations with different *modus operandi*. At one point, Gwen raised her hand to offer her perspective. She asserted that FATE members considered themselves activists but that their work in assisting people to go to *Dignitas* and the publicity gained was helping to change the law in the U.K. In other words, pushing at the limits of the law would eventually change the law by highlighting its inconsistency.

There are two important post-scripts to this debate. First, Sarah Wootton, the Chief Executive of DID, approached Gwen after the debate and angrily told her that she and FATE had nothing to do with the recent spate of publicity and that it was all due to DID’s work on Debbie Purdy’s legal case. Gwen was taken aback by this comment, and tried on several occasions for the remainder of the conference to ‘patch things up’ with Sarah Wootton. Wootton’s aggravation at Gwen’s comment stemmed from the very antagonism between the mainstream and the fringe which was the subject of the *World Fed* debate. What I infer from the altercation is that DID views FATE’s activities as *harmful* and counterproductive in their campaign for legitimate social reform. While the two organisations may ostensibly be on the same side, their aims are actually quite different, and this is symbolic of more generalised splits in the international movement.

The other postscript to this debate is that on the 25th February 2009, Ted Goodwin was arrested in the U.S. state of Georgia on charges of assisted suicide, tampering with evidence and violating Georgia's RICO (Racketeer Influenced and Corrupt Organizations) Act. He was arrested, along with four others from *Final Exit Network*, after an undercover police officer posed as a dying person requesting help to die. As Goodwin was rehearsing the helium self-deliverance technique with him police stepped in and arrested him. Goodwin faces years in prison if found guilty. The police have also raided the homes of other *Final Exit Network* volunteers in seven other U.S. states⁷² and the case has attracted vast amounts of national press coverage. While Goodwin's arrest could be interpreted as confirming Lesley Martin's view that the fringe damages mainstream legitimacy, the right-to-die blogs post-Goodwin's arrest suggest that other activists in the movement are hoping that the court case may be a productive 'test' of the law. In a sense, the arrest makes him a cause célèbre for the movement, consolidating his reputation and authenticating his commitment. The response of *The World Federation* was to express concern for Ted whom it regards as "a most compassionate individual."

In the absence of rational laws, organizations such as *Final Exit Network* sometimes may get close to the line in challenging the law, as perceived by opponents of the right to choose⁷³.

While I am certain that Ted Goodwin did not wish to get arrested for his "compassionate" actions, he has (inadvertently) validated his own convictions. For other activists, there can be no doubt now about his passion for and devotion to the cause. The ensuing controversy will make him a hero within the movement and as a result he has entered the right-to-die hall of fame, along with other individuals like Dianne Pretty and, more recently, Debbie Purdy.

The second significant moment during the conference relates to Debbie Purdy herself. The conference took place just a few weeks after her judicial review at the High Court of Justice in London. Clearly news of her case had spread to right-to-die

⁷² The Atlanta Constitution. 26 February 2009. 4 arrested in Ga. assisted suicide sting: Operation by GBI results in accusations believed to be first of their kind in state. By Christian Boone

⁷³ Statement from the Board of Directors, printed in the World Right-to-Die Newsletter 2009, No.56

activists around the world. On the second day of the conference *The World Federation's* board decided it would like to invite Debbie to come to Paris to speak to the conference as the latest international 'star' of the right-to-die movement. The invitation came at too short notice for Debbie to make the journey, but this courting of her new-found media status and the lauding of her plight, suggests to me, that, only a few weeks after her case was heard, she had also entered the right-to-die hall of fame. Debbie Purdy, Ted Goodwin, and British activists like Jean and Gwen are all seeking public authentication by performing their conviction on various stages. They are also seeking authentication of 'self' through what they view as a self-made death. This may be at FATE meetings or a *World Federation* conference, where authentication comes from the already converted, or it may be a court of law, where one must convince a judge in order to win that authentication. But on any of these stages, the intensity of the conviction directly correlates with the authentication of 'self'. As Eagleton writes, nobility lies in the intensity of one's commitment, not in its content:

Being more purely oneself is more daring than being merely good or merely right (2003:231).

The public nature of that authentication is also important. Walter *et al's* view is that it is the media that brings death out of private homes and hospital wards and makes death present in public (1995). But it is also the passion and conviction of right-to-die campaigners that brings death, once more, onto a public stage.

Conclusion

Do right-to-die activists ask to be judged on their convictions or on their actions? In this chapter I have argued that while autonomy and self-determination are held up by activists as the beliefs which initiate their involvement, once they are immersed in the movement, it is their actions that make these beliefs both affective and effective and it is pragmatics which will enable them to secure the death that they desire. There are two ends to which they are committed: the end of their own individual existence and the end which is the final triumph of the legal recognition of a human right-to-die.

The practices in which activists are engaged, whether talking on the phone with callers to the helpline, or the “material concreteness” of writing leaflets and rehearsing self-deliverance techniques, all serve to bolster their commitment to a more abstract “ethics of consequence.” When Gwen stood up in *The World Federation* debate and argued that FATE, through its pragmatic engagement with *Dignitas*, had done just as much for the ‘cause’ as DID had accomplished through lobbying in the Houses of Parliament, she was asking to be judged on her actions. Both organisations are ostensibly part of the same social movement, and yet campaigning for a right-to-die means different things to both.

The moral rightness of their cause, as FATE members see it, is self-evident. Now they want to get on with the task at hand – helping people who are suffering to die. Can we say that they embody a notion of radical freedom in a way that Foucault would have advocated? That freedom from death comes from embracing death on one’s own terms? In Chapter Five I discussed how, for Foucault, suicide was the ultimate means to reclaim one’s own agency and work against disciplinary power (1996). Freedom for him did not involve conforming to socially sanctioned rules. Right-to-die activists challenging the law do not conform to such rules either. The fact that the leading lights in FATE are all over 70 allows them a freedom and an irreverence that the younger members of DID cannot afford. Old age and activism do go together after all. Tierney suggests that neither fear nor anxiety help us to undo the modern regimen of self-preservation (1999:252). Only by “laughing ironically” at the lengths to which medicine and we ourselves often go in the pursuit of health can we actually begin to reflect on what is *worth* preserving (1999:253). While many FATE members, like Gwen, are clearly motivated by deep fears about their own deaths, I also encountered irreverence among these activists which reminds me of the ironic laughing suggested by Tierney. The “U.K. Guide to *Dignitas*” produced by FATE provides some evidence of this irreverence. Its final paragraph states:

Travelling to Switzerland to end one’s life is arduous and demands strength of purpose. The person accompanying you must also be focused and strong willed. A sense of humour in both parties is a great help!

This reluctance to institutionalise freedom is also demonstrated in FATE's lack of a 'corporate' view. Each individual is in a unique relationship with their own death. Death activism is closely linked to individualism to the extent that it is the activist's view that each individual faces their own death alone, and no one and nothing can stand as a substitute. The way that they choose to die is seen to validate their own sense of 'self' in the same way that their activism also authenticates their sense of themselves as a unique individual.

In this chapter, I have also drawn a link between the pragmatics of fighting for a cause and the principle which transcends the death of individual activists. I described how anthropologists like Bell (1992) and Kirsch (2004) have rejected an understanding of belief as interior and static, choosing instead to emphasise the role which practices and affects have in conditioning the 'self' into a believing 'self'. In other words, rehearsing self-deliverance techniques cultivates a belief in a right-to-die. I also explained how Jean and Gwen's attempts to find practical ways to hasten death and put an end to suffering anchors their beliefs in materially concrete solutions. Yet, to focus only on practices and affects is to omit the fact that these are clearly attached to a will: the human will to make decisions. When Jean exclaimed to me: "Oh, it's not to do with death! It's to do with autonomy", she was declaring her conviction in an "ethics of consequence". In the right-to-die movement, this "ethics of consequence" is the transcendent principle of autonomy. It is the transcendence of this principle which extends from one activist finding certainty in death to that certainty becoming a guaranteed right for all.

The right-to-die movement has its own momentum, further propelled in recent years by the activities of *Dignitas*. So much so that the phrase "going to Switzerland" could now be said to be a euphemism for an assisted death. Switzerland has appeared on the horizon towards which our 'being-towards-death' is orientated. Some people have travelled to *Dignitas* and invited the media to follow them and report their story, in order to help the 'cause' after their death. The most famous example of this was Anne Turner, a doctor from Glasgow, who invited the BBC to accompany her to

Switzerland. These public testimonies in anticipation of death have no doubt improved the social acceptability of “going to Switzerland” as an “authentic” way to end one’s life. And they have made people heroes for the cause, often now mentioned alongside Dianne Pretty and Debbie Purdy. All are activists of one shape or another, and all, in fighting for their own ‘controlled’ death, are also fighting for other people to die in a ‘controlled’ manner. During my fieldwork, a woman named Jane Tomlinson died aged 43. Tomlinson had ‘lived with’ cancer for seven years and in that time she ran four marathons, three triathlons, and completed a 4,200-mile bike ride across the U.S., raising a total of £1.75 million for charity. Her death prompted a Diana-esque outpouring of gushing tributes (e.g. Hughes 2007), the Prime Minister calling her a “daily inspiration”. And yet, as journalist Mary Riddell commented in *The Observer* newspaper (2007), the darker undertone of Jane Tomlinson’s story is the implication that one can stave off death through superhuman effort. Tomlinson made her death public, by trying to postpone it through a rigorous health regimen. But, asks Riddell, what about other brave ways to die, like “going to Switzerland”?

FATE activists argue that people can have “heroic” deaths by opting for an assisted death, not just by staving off death, which to their mind only extends suffering. Both Jane Tomlinson and Anne Turner embody types of public dying. But whereas Tomlinson might have been a living authentication of the hospice principle of “live until you die”, for right-to-die activists like Jean and Gwen, Anne Turner is the most authentic “hero” because she elected to die on her own terms against societal expectations of superhuman endurance.

SECTION THREE

Continuing the theme of transcendence that emerged in my discussion of *Rosetta Life's* activities in Section One, Section Two focussed on a different group of people and their desire for a different kind of transcendence. For some of my research participants, the dying phase does not yield any profound insights or heightened awareness of 'self', instead, it is only anticipated as a time of intense suffering, disintegration, loss of social-connectedness and increased and unwanted dependency on relatives. These people's attention is fixed not on what can be gained from the period between diagnosis and death, but rather on what is feared and what will have to be endured without purpose. It is this "demise", about which Heidegger wrote so disparagingly, that my participants are trying to transcend. People like Sheila, who plan to travel to Switzerland for help to die, and the activists and politicians who lobby for legalisation in this country, all believe that to romanticise and sentimentalise the dying phase ignores the fact that "hell can be here on earth as well" (Sheila). Talk of silver linings, and prescriptive notions about "letting go" and about the instrumentality of pain (Dr Rob George) do not fit these people's experiences. Not only do they want to transcend their "demise", they also want to transcend the romantic ideology of a cathartic deathbed scene. As Gwen says: "Why is there this idea that something meaningful happens because you are dying? It might happen in spite of it, but not because of it."

Involvement in activism also offers a mode of transcendence. This is partly because it attaches believers to an "ethics of consequence" – the transcendent principle of autonomy - and partly because it offers a form of immortalisation or heroism that transcends time. The FATE activists whom I encountered were committed to an "ethic of freedom" which is in danger of being lost in the movement's rush to enter the mainstream. After a chequered history of association with eugenics and falling foul of the law, DID is now forging ahead with its campaign to align assisted dying with patient choice. They are also using individual stories to give their cause a compassionate face. Those waiting for the "green light" from *Dignitas* are awaiting a willed-for death of a very personal kind. They long for future certainty and control.

Those campaigners pressing for “legitimate social reform” are trying to establish future guarantees of a different kind, not for themselves but for the “generalised other”. They are appealing for legal recognition of a human right-to-die.

In this deeply divided debate, both sides are appealing to human rights: proponents to a right to privacy, opponents to a guaranteed right to life for vulnerable members of society i.e. those who are in danger of being judged only in terms of their *zoe* and reduced to the condition of ‘bare life’ (Agamben 1998). As Douzinas (2000:367) writes, the utopian value of human rights is that they “inscribe futurity in law.” They must always remain a “not yet”. Proponents and opponents are both future orientated, either to a world where requests to die are honoured, or a world where the prohibition on the intentional taking of life is upheld. In the next section, I continue this story of the “conflict of rights” through examining bids for two new laws – one to recognise the “extraordinary” demand to be assisted to die and the other to recognise the “ordinary” demand to refuse life-prolonging treatment when one has lost mental capacity (now on the statute books). Not only does this next section revisit the principle of the transcendent power of human rights, it also raises the question of how the law can recognise an individual’s demands for a hastened death while also accommodating and safeguarding the needs of others.

CHAPTER NINE

Legal Recognition of Extraordinary and Ordinary Dying

Life and death are not properly scientific concepts but rather political concepts, which as such acquire a political meaning precisely only through a decision (Agamben 1998:164).

As I outlined in the previous chapter, the right-to-die movement has a host of celebrated figures in its “hall of fame”. Anne Turner’s or Dianne Pretty’s ‘struggle’ to die combined conviction in an ideal (autonomy) and conviction in the action required to execute that ideal (death by lethal barbiturates). An assisted death made aesthetic sense to them: a reflection of their views on the ‘good life’ and a reflection of their determination not to die in a way that compromised their sense of ‘self’. The stories of these right-to-die heroes inspire others who feel a similar existential imperative: that the way they die needs to be in accordance with the aesthetic dimension of their lives. Debbie Purdy, whose legal challenge I focus on in this chapter, first heard about assisted dying through Dianne’s story. It was the death she could envisage for herself. When Dianne Pretty told her story publicly, when she appeared on Panorama and revealed details of her intimate daily routines, or when she appeared at the European Court of Human Rights in Strasbourg while her lawyers pleaded her case, little did she know that the death for which she was fighting would become the death to which Debbie Purdy and others would aspire. Making her dying public she became the very subject of politics. She became a hero and a symbol for a whole movement.

Yet Dianne Pretty and the other figures of the right-to-die movement are dying ‘extraordinary’ deaths in the sense that they are managing their illness and their dying under a media spotlight. Even going to *Dignitas* is still an ‘extraordinary’ act in that there are relatively few people who make that journey compared to the thousands who die in Britain every year (509,090 in England and Wales in 2008⁷⁴). However, what pro-lobbyists, like the FATE activists, really want is to make assisted dying an ‘ordinary’ possibility. How will they achieve this? They argue that assisted dying will become an ‘ordinary’ option (rather than an extraordinary achievement for

⁷⁴ Office of National Statistics <http://www.statistics.gov.uk/cci/nugget.asp?id=952> (accessed 20.01.10)

which heroes are commemorated), once it is made lawful and becomes a right enshrined in law⁷⁵. The path toward making assisted suicide an ‘ordinary’ death is the path towards legal recognition.

A recent focus for pro-campaigners has been Debbie Purdy’s legal challenge to the 1961 Suicide Act. Her anticipation of her death and her fears surrounding the suffering she may experience caused her to initiate the highest-profile legal challenge on this issue since the Pretty case in 2002. Debbie Purdy, who may yet be a long way from death, but who is nevertheless experiencing her death in anticipation by trying to plan for it, is making her death ‘extraordinary’ by, like Dianne, inviting the media into her private life to speculate on her disability and her relationships. The public and the private are blurred through this process as she uses public instruments and engages public debate to attain a death that, in the final instance, she wishes to be kept very private. It is through the public debate which her case has stimulated that people have been able to reflect on and anticipate their own dying and ask the question: what would *I* want? What plans should *I* make? Debbie Purdy may be fighting for what she perceives to be an ‘ordinary’ right - an ‘ordinary’ request to make of one’s government – but the nature of her fight has made her (as yet only anticipated) dying quite extraordinary. Victor Turner (1986:35) distinguished between experience in general and “an experience”. The latter he identified as a life-cycle event or a dramatic performance of some kind. Debbie’s battle for legal recognition has not only made her dying extraordinary but has also turned it into “an experience” of dramatic significance.

What are the prospects of making the medically hastened death the “ordinary” death? One piece of legislation which has been passed by Parliament and which goes some way towards recognising a person’s right to control the manner of their death is the *Mental Capacity Act* (MCA) 2005⁷⁶. This Act is by no means solely focused on the

⁷⁵ Both FATE and DID campaign for a positive right to an assisted death, which would be instituted as a result of new legislation, such as Lord Joffe’s ADTI Bill. This would mean that people would have the legal right to ask their doctor to help them die. The alternative to this, which Debbie Purdy’s case has taken the U.K. a step towards, is that assisting a dying person’s suicide is effectively ‘decriminalised’ i.e. no longer subject to criminal prosecution. This does not have the same attraction to activists as a positive right enshrined in statute.

⁷⁶ The Act only applies in England and Wales.

regulation of death and in fact it is more generally concentrated on empowering people to make decisions about aspects of living or to provide for substituted decision-making when capacity is lost. However, its provisions for ‘death-decisions’, as I call them in this chapter, are still significant and centre on the formal recognition of the ‘living will’, now known as an ‘Advance Decision.’ This gives citizens in England and Wales the right to refuse life-prolonging treatment *in advance*, so safeguarding people who lose mental capacity at the end of their lives. In this chapter, I highlight some of the tensions between the state as enabler and the state as regulator that I regard as inherent in this legislation and the rights it confers. Inevitably, this will lead me into discussions of the place of law in regulating private decisions at the end-of-life.

The overall aim of this chapter is to look at legal decision-making and claims for legal recognition of our dying. How does our knowledge and use of the law affect our preparation for our deaths? Why is there a need to regulate death at all? What interests are at stake? Dianne Pretty’s lawyers framed her legal case in terms of a human right-to-die. Debbie Purdy’s lawyers did the same. Yet opponents believe that to accede to these women’s wishes would be to abandon the disabled-dying to the category of “lives unworthy of being lived”, or what Agamben (1998) calls the condition of ‘bare life’ and nothing more. In this chapter I ask: what is the value of claiming a human right-to-die and where does its ideological appeal reside? I also interrogate the relationship between human rights and the concept of “dignity”, a term that appears frequently in the slogans of the right-to-die movement. Finally, I ask if we can ever make generalisable laws that can respond to, or offer recognition for, the specific circumstances of each individual’s suffering and death. I begin with Debbie Purdy’s story.

Debbie Purdy’s Predicament

“I think the reason people find it hard to talk about death is that they just find it horribly embarrassing” (Debbie Purdy 2007).

Debbie Purdy is certainly not embarrassed about death or disability. She has been living with primary progressive Multiple Sclerosis (MS) since 1995 when she was first diagnosed. Strictly speaking, she is not ‘dying’. She has lived with her disease for a long time now. She comes under the category of the “disabled-dying”, which I described in Chapter Seven. She is aware that her life may be foreshortened by her disease, but by how much, she does not know. In the meantime she must get on with living with her disability. However, the not knowing causes her a degree of anxiety. Debbie has always been politically aware and an agitator of sorts. She says it is in her nature. Whereas other people who have “gone public” with their stories of travelling to Switzerland had never been particularly political, Debbie has always been a campaigner for a variety of issues. At the moment, for example, she works as a “simulated” patient for a medical school, a project that aims to educate doctors about how to engage appropriately with disabled patients. She thinks that disabled people should have the same access to services as everyone else, but crucially, she also thinks that disabled people should be allowed to decide what they want for themselves, even if that deviates from what is expected of them. She doesn’t support the paternalism she encounters in the disability rights movement and resents being called “vulnerable”:

If you are going to argue for disabled rights [for disabled people], then you have to argue for their right to decide what they want. It’s easy to say you support free speech with someone who is agreeing with you.

By this rationale, Debbie Purdy feels strongly that disabled people should be able to choose an assisted death, without needing to be “protected from ourselves.” Assisted dying first entered Debbie’s consciousness through the media coverage of Dianne Pretty’s case. It was then that she joined *Dignity in Dying* (DID) and won its support for her legal challenge. DID arrange her legal representation and it ‘manages’ all of her media appearances (see Figure 7 below).

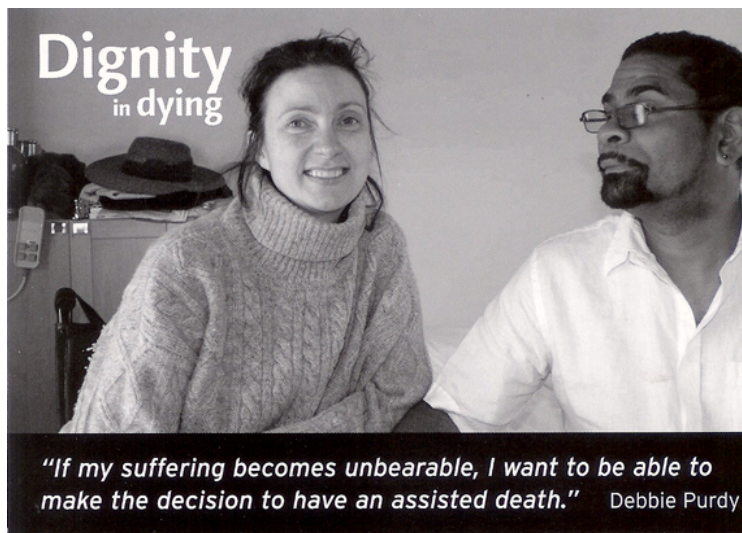


Figure 7 – a DID campaign postcard

Debbie’s case is this. In the future, as her body deteriorates from her MS, she fears her suffering may become “unbearable”, at which point she may feel the need to travel to Switzerland for help to die. However, by such a time, she may be physically unable to make her own travel arrangements. Her option then would be to ask her husband, Omar Puente, to help her to make the journey. If he were to agree, there is a possibility that he would be found guilty of breaking Section 2 of the 1961 Suicide Act. This Act makes it illegal for anyone to “aid, abet, counsel or procure” the suicide of another, and is punishable by up to fourteen years in prison. Debbie is not seeking immunity for Omar, as in Dianne Pretty’s case where Dianne sought immunity for her husband, Brian, to help her die. Instead, Debbie is asking for the Director of Public Prosecutions (DPP), on whose discretion a criminal case against Omar would be brought, to specify exactly what counts as “aiding, abetting, counselling or procuring” suicide. She says that she is seeking a “clarification” of the law. Her lawyers claim that a refusal by the DPP to make clear the factors he will take into account when deciding whether to prosecute Omar amount to an “interference” with her right to respect for private life: Article 8 of the European Convention on Human Rights (ECHR)⁷⁷. If she is not 100% certain that Omar will not be prosecuted after her death, then she will not allow him to accompany her: “I’ve got to be certain that my decision will not hurt him.” She will therefore be

⁷⁷ The U.K. was an early signatory to the ECHR and, in 1998, the U.K. Parliament incorporated the principles of the convention into U.K law in the form of the *Human Rights Act*.

forced to travel to Switzerland and die earlier than she wishes while she still has the physical capacity to travel alone, and can go without Omar's help. For this reason, Debbie Purdy frames her claim not as a 'right-to-die' but as a 'right to live longer'.

Debbie characterises herself as a "loudmouthed, obnoxious" pro-choice activist: "I'm not the type of person who can just drift into the background." She wants to argue for her case while she is still able to do that. Some people might wonder why Debbie gives so much of her diminishing energy to seeking a change in the law. She told me: "I don't want my life to be without purpose". She certainly has not shied away from the press interest in her story. She has done countless media interviews on TV and for newspapers and magazines and her legal case has been reported all around the world (hence the *World Federation*'s interest in her speaking at their biennial meeting in 2008 - see Chapter Eight). There is symbolic capital to be gained from association with her case making her the current poster girl for the right-to-die movement. Although there is a very clear personal motivation behind her legal challenge – protecting her husband from any repercussions resulting from her death decision– she is also fighting a campaign, the ultimate aim of which is the legalisation of physician assisted suicide in the U.K. Her case may be based on wanting to "clarify" the law by asking that the DPP publish clear and unequivocal guidance on what constitutes "assistance", but the undisputed sub-text is that she wants to apply pressure on Parliament to change the law. In this way, it is as much a political as it is a legal challenge. It is as much about substance as it is about procedure (Parker 2003:46).

What is intriguing about Debbie's case is that although she is the focus and she has brought the case, it is her husband's potential actions that are the subject of the legal dispute. This mirrors the Pretty case in which it was Dianne's husband, Brian, whose potential actions were being judged. Debbie's husband Omar is the one who risks prosecution for helping her to make the journey to Switzerland. Yet he says he will go with her regardless of the risks. It is Debbie who refuses this offer out of a desire to protect him. This is an odd twist for someone committed to a choice agenda and so vocally anti-paternalist. He may still choose to accompany her despite not winning any legal assurances, but she will not allow him to do so. The two are

mutually implicated in her death decision. The right-to-die movement would have us believe that demands for help to die are purely a matter of individual choice. Advocates argue that such demands are made by individuals who want to determine the end to their own lives through their own subjective assessment of whether they are suffering “unbearably”. This focus on the individual as the locus of decision-making is part of liberal philosophy’s glorification of the unimpeded individual and its denial of our dependence on the world and on others. In demanding a human right to have her private life respected, Debbie’s decision depends on her husband and his support. Despite the fact that it is she who is in the media gaze, in truth it is *he* who will feel the effects of the law. As Strathern argues, much of the motivation to act comes from claims binding people to others:

To an age that thinks of itself as individualistic, the revelation of relationship can come as something of a surprise. The person as an individual turns out to be the person as a relative (2005:10).

Omar is locked into Debbie’s decisions. He must anticipate her death, not because he chooses to, but because Debbie is determined to be prepared and her relationship with him is part of that preparation. They are invested in each others’ lives, or as Strathern writes, “we own one another” (2005:133). Her case makes explicit her dependency on her husband for making her death decision, and in the process makes plain her day-to-day dependency on him in her life-with-illness.

Another crucial but often over-looked factor in her case has been the many hypothetical circumstances at stake. *If* she finds life “unbearable” at some point in the future, she *might* want to have an assisted death at *Dignitas*. Perhaps she is anticipating the worst, but she wants to be prepared anyway:

I don’t want to make the decision now. Until you are in an unbearable situation you don’t *really* know what is unbearable. When I was 21, I thought being in a wheelchair would be the most terrible thing that could happen – that I’d kill myself if that ever happened. It’s not that bad! You learn to cope in a different way, you learn to see yourself in a different way. You are not prevented from being you.

This idea of wanting to have the option available, even if one does not ultimately make use of that option, is evident in the statistics from the U.S. state of Oregon's *Death With Dignity Act*. Every year, the number of prescriptions written for lethal barbiturates under the Act is more than the number of deaths from making use of those prescriptions. In 2008, for example, 88 prescriptions were written, but only 54 patients ended up taking the medication⁷⁸. The evidence suggests that, for many, simply having the prescription eases suffering because it offers an "insurance policy". The prescription itself has a palliative effect. Debbie's legal case is about demanding fixed assurances at a time when her disease seems to be denying her control over her life.

Her recounting of her life story for the media is also a way of trying to establish control over the events of her life (although once her story is in the public domain, she relinquishes control over its representation). This is the existential imperative, or the "necessary illusions", by which we imagine that our actions and words make a difference in determining the shape of our lives (Jackson 2002:14). In her own words, her legal battle gives her life purpose. It gives her dying quite an extraordinary aesthetic. She says that she hopes the legal process will recognise her desire for "clarity", (by which I read "certainty"), but in talking to her, it seems she also desires more general recognition of her disability, the difficulties of maintaining her relationship through her disability, and her fears about her dying.

Seeking Legal Recognition

Honneth (1995), following Hegel, identified the "struggle for recognition" existing at the heart of the cumulative acquisition of self-confidence and self-esteem. In Chapter Four (see *p119*) I discussed the three ways that Honneth identifies that the bonds of mutual recognition are fostered: familial love, legal recognition, and solidarity. I argued that *Rosetta Life* focuses on fostering "solidarity" between participants in their art projects and those who witness them. These three forms of recognition proceed from the view that people act not as isolated subjects but from a framework

⁷⁸ <http://www.oregon.gov/DHS/ph/pas/ar-index.shtml>

of ethical bonds. People become reconciled with difference through recognition of their own particularity (1995:15). In terms of legal recognition, Honneth contends that it is only once we have taken the perspective of the other person, and recognised that person as a member of the community and thus as a bearer of rights, that we can understand *ourselves* as legal persons, in the sense that we feel sure that our own claims will be met (1995:108).

Yet the struggle for recognition of the right-to-die has not yet been won. How is Debbie to convince the judges and the public that her legal demands are based on morally responsible claims (Honneth 1995:114)? And how is she to convince them to take her perspective and understand the world from her point of view? Honneth argues that only through symmetrical recognition can an individual know that they are valued and respected and therefore gain self-esteem and a sense of self-worth. But if Debbie's right-to-die is not legally recognised, does it then follow that she loses all her self-worth? In Chapter Four, I highlighted that recognition implies that one has knowledge of and can understand the object of recognition. Witnessing, on the other hand, does not require that one understands what one sees, or that what one is asking for correlates with what is actually being recognised. Witnessing implies a less idealised form of communication and assumes less knowledge on the part of the witness. In this regard, Debbie may be asking for recognition, and whether or not she is successful in this, her experiences will be witnessed. The judges sitting at the front of the court witness aspects of her life and her dying which are extraneous to the legal facts of her case. Additionally, in making her case in a public court, she is also witnessing her own future death and Omar, her husband, is witnessing his own anticipatory grief at her death.

The multiple "what ifs" around which Debbie's case revolves show that it is predicated on an unknown future. Debbie is asking the law to make anticipatory decisions, given certain 'hypotheticals'. Using the language of Heidegger, we could say that she is running ahead to her death and then 'coming towards herself' again out of the future (1962:373). As Toombs (1995:20) points out, for people with progressive disability, time may be disturbed in that the future, rather than the

present, assumes overriding significance. The future also becomes inherently problematic because of its unknown aspect. The ‘extraordinary experience’ of making her dying public in the courts entails both an envisaging of her and her husband’s future and an assessment of their past. They are trying to determine the freedom of their future selves. Yet the criminal law is retroactive, not anticipatory. It responds to things that have already happened. Herein lies the conflict. Human rights, like Debbie’s and Omar’s demands for certainty, are also future oriented in that they symbolise a utopian hope for a better future (Douzinas 2000:318). In their temporal aspect, human rights are also at odds with the law as a retroactive mechanism of regulation. It is this difference which enables human rights to retain a critical distance from the law in the sense of transcending their present application. Only when human rights become law do they bestow their symbolic character of transcendence onto the legal application of reason and logic (Douzinas 2000:367). The power of human rights is, therefore, their potential to inscribe futurity in law. There is a correlation between Debbie Purdy’s anticipation of her future death as certain and knowable, and her appeal to human rights and their anticipation of a utopian future. Both are future orientated, and both offer the potential for transcendence.

However, if the criminal law (not human rights law) is retroactive in that it responds to crimes that have already taken place, can it offer Debbie the future certainty she is requesting? In Dianne Pretty’s case, the DPP refused to give her an assurance in advance that her husband would not be prosecuted if he were to help her to die. And when, in the final instance, Dianne appealed to five Articles in the European Convention on Human Rights, the European court in Strasbourg determined that none of those Articles had been breached. The European judges were understandably wary of giving sanction to an action that would effectively legalise assisted dying in the U.K.⁷⁹. Human rights declarations, despite their universalist rhetoric, are still founded on the principle of national sovereignty and non-intervention (Douzinas 2000:118). As I highlighted in Chapter Six, both the British Parliament and the

⁷⁹ Appeals on human rights issues can be taken from the U.K House of Lords (now the Supreme Court) to The European Court in Strasbourg. Consequently, decisions made by judges there “trump” decisions by the Supreme Court.

Judiciary (perhaps in deference to Parliament's position) are reluctant to permit assisted dying for fear that it will undermine the right to life of the disabled, the elderly, and vulnerable members of society more generally. Hobbes (1971) thought that the social contract was based on innately self-preserving individuals willing to bind themselves to the powers of the sovereign (the Leviathan) for the sake of protection against others (and because of a generalised fear of death). His was a contractual justification for the sovereignty of the state. It was not just 'vulnerable' members of society who needed state protection, but all subjects beset with a fear and mistrust of others who needed to be saved from a war of 'all against all'. The right to life, for Hobbes, was the foundation of the social order. The view supported by the Strasbourg decision is that the interests of certain strong-willed individuals, like Dianne Pretty or Debbie Purdy, are to be sacrificed for the sake of protecting the majority from potential harm. The prohibition on killing must be maintained as a principle in law. For Hobbes, this is the one certainty that is expected of the law.

Debbie's lawyers argued that there is a need for "foreseeability" in how the law will be applied. Their view is supported by Mason and Laurie (2006:623), in their classic text on law and medical ethics, in which they argue that leaving the decision to prosecute up to the sole discretion of the DPP could lead to inconsistency and uncertainty, which they state is "something the law should avoid." These arguments, among others, were put forward by Debbie Purdy's lawyers in their application for Judicial Review, at the subsequent Appeal, and finally before the House of Lords, the highest court in the U.K., in July 2009.

Dying to go to Court

Outside the Royal Courts of Justice in London I stand in a throng of T.V. cameras and journalists. Debbie and Omar are fashionably late for their Appeal. Debbie's solicitor, Saimo Chahal, seems quite agitated, obviously keen to see that things run smoothly on a day of high media exposure⁸⁰. I see the Chief Executive of *Dignity in*

⁸⁰ Saimo Chahal won "Solicitor of the Year" at the Law Society's Excellence Awards in 2008 due to her cutting-edge work and use of the Human Rights Act on the Purdy case, among others. <http://www.bindmans.com/index.php?id=135> (20.01.10)

Dying giving a T.V. interview. Most of the newspapers today featured a headline about the 100 Britons who have now been helped to die at *Dignitas*. The organisation chose today to release its figures for maximum publicity. Finally, Debbie and Omar advance down the street towards the journalists who rush to form a scrum. The couple is instructed to stop someway off to pose for the cameras. Omar crouches down next to Debbie in her wheelchair and leans in for a kiss. The photographers shout for them to repeat the kiss. They oblige. They smile for the cameras. It is a display of solidarity and love. As they continue along the pavement, the cameras and journalists break the scrum and encircle the couple. I doubt Debbie can see sky. She tries to answer the barrage of questions put to her. After five minutes they move off, accompanied by the lawyers and DID staff, in search of the disabled entrance to the court.

The courtroom is small with only two rows of benches available to the general public. The aesthetic of the room – vast amounts of wood, a high podium for the judges - stresses tradition, authority, and hierarchy. Debbie sits in her wheelchair at the side of the room and Omar sits next to her. The two judges enter wearing their wigs and gowns, and everyone rises (except Debbie). The first matter the judges allude to is the application made by *The Society for the Protection of Unborn Children* (SPUC) to be appointed an “intervenor” in the case. Such an appointment allows an organisation to represent the interests of people who are not party to the actual proceedings, but may be affected by the outcome. SPUC, in its written statement of intervention, states that Debbie Purdy’s case is based on an “incomplete understanding of the material facts”:

The Claimant’s apparent fear of a painful and undignified death is against the overwhelming weight of the evidence about the efficacy of terminal palliative care in MS (Intervenor’s Skeleton Argument 2008:2).

This intervention shows that from the outset the stakes are high. The outcome, in terms of the decision made by the court, will have a very real effect in terms of changing the law on assisted dying. This was something that in previous decisions has been declared by judges to be a “matter for Parliament” (Lord Hobhouse in House of Lords decision on the *Pretty* case). But occasionally, even very slight shifts

in the framing of legal judgments, even down to their specific wording, can have a knock on effect in relation to future decisions. SPUC has made its intervention in order to remind the court that there are broader interests at stake than Debbie Purdy's individual relationship with her own future death.

Proceedings begin and Debbie's counsel puts her case forward. He states that all Debbie wants is a "dignified death". I assume that by this he means an assisted suicide. But, he states, she needs "information" in order to delay that "dignified death" for as long as possible. It is only meant to be a last resort. Debbie is entitled, via Article 8 – the right to private life - of the ECHR, to know the particular circumstances which the DPP will take into account when judging whether to prosecute her husband Omar. If a law exists, in this case, the 1961 Suicide Act, then people have the right to know precisely what "factors" will be taken into account so that they can regulate their conduct accordingly. The legal case, as her lawyers put it, is that to rely wholly on the DPP's discretion without any formal guidelines could result in "arbitrariness" or "inconsistencies" in the application of the Suicide Act and would be in breach of Article 6 – the right to a fair trial.

The DPP's counsel then put their case. Their main legal argument is that the current situation upholds the "delicate balance" between giving people clarity and retaining flexibility in the application of the law. They quote at length from a previous legal decision:

...while certainty is highly desirable, it may bring in its train excessive rigidity and the law must be able to keep pace with changing circumstances. Accordingly many laws are inevitably couched in terms which, to a greater or lesser extent, are vague and whose interpretation and application are questions of practice (*Sunday Times v United Kingdom* para 49).

It is proper, the DPP's lawyers argue, that the DPP has discretionary powers via the Suicide Act to charge unscrupulous associates who may have something to benefit from helping a person to take their own life. They concluded:

The DPP does not have the power to give the clarification which the defendants' desire.

One of the judges presiding commented during the proceedings that he could not envisage a code being drafted which could take account of all the “infinitely various” scenarios which might occur. He qualified that “perhaps the real answer to this is to amend the [1961 Suicide Act].”

The Judicial Review lasted for a day and half. Debbie gave countless media interviews in that time and told me afterwards that she was exhausted by it all, but that she realised “you have to make hay when the sun shines”. She also told me later how surprised she was at how positive the judges were and was encouraged by their hints that Parliament needed to look again at reforming the Suicide Act. When the court issued its decision some weeks later, however, it found against her. Debbie and her legal team decided to appeal, but this too proved unsuccessful. The Appeal decision stated:

The DPP cannot... offer the kind of case-specific indications which would provide her with the absolute security of mind she is seeking.

And later:

Notwithstanding our sympathy for the dreadful predicament in which Ms. Purdy and Mr. Puente find themselves, this appeal must be dismissed.

However, in July 2009, Debbie’s case was heard by five law lords in the House of Lords who voted unanimously to overturn the decision of the lower courts. The outcome of her case means that with regards to Section 2 of the 1961 Suicide Act, the DPP is now required to produce an offence-specific policy identifying the facts and circumstances which he will take into account in deciding whether or not to consent to a prosecution. These guidelines are due to be published in Spring 2010. Debbie and Omar appeared jubilant outside the House of Lords on the day of the verdict. Standing alongside their lawyers and Sarah Wootton of DID, Debbie and Omar smiled and kissed each other affectionately for the cameras. Their legal victory was the leading story on every T.V. news channel and the couple appeared on the front cover of every newspaper in the country. Headlines focused on Debbie’s point, which I cited earlier, that she sees her case not as a ‘right-to-die’ but as a ‘right to

live longer’: “‘This has given me my life back’”⁸¹; “‘I feel like I have my life back’” – Right-to-die victory for Purdy’⁸²; and “‘We’ve got our lives back’” – Debbie Purdy Triumphant’⁸³. The five law lords, in the end, determined that the law needed to give citizens clarity, and that in this instance, that clarity was unjustifiably lacking. Their sympathies clearly rested with Debbie and Omar:

It cannot be doubted that a sensible and clear policy document would be of great legal and practical value, as well as being...of some moral and emotional comfort to Ms Purdy and others in a similar tragic situation (Lord Neuberger para 101).

In the weeks following the law lords’ final decision, the DPP produced his “interim guidance”. He stated that factors against a prosecution included: that the “victim had a clear, settled, and informed wish to commit suicide”; that the “victim had: a terminal illness; a severe and incurable physical disability; or a severe degenerative physical condition”; and that the person suspected of assisting in the suicide was a “spouse, partner, or a close personal friend” who was “wholly motivated by compassion.” The existence of such a policy undoubtedly moves us a step closer to effectively decriminalising assisted suicide for the disabled-dying. What is more doubtful, however, is whether this policy will contain the fears of either the pro- or the anti- lobby. Proponents will continue to fight for a “positive” right to a medically assisted death, while opponents will continue to fear the devaluing of the lives of the disabled-dying.⁸⁴

Law as instrument

Debbie Purdy’s case centred on giving her clarity and security of mind about her death decision. The question is whether it is the role of the law to give this, especially when it comes to death? Is suicide not the ultimate private decision? The Stoic view of suicide was that it was the ultimate act of resistance to state

⁸¹ *The Daily Mail*, 31 July 2009.

⁸² *The Guardian*, 31 July 2009.

⁸³ *The Independent*, 31 July 2009.

⁸⁴ This is the legal situation as it stands up to the submission of this thesis. Developments are ongoing and the DPP’s guidance may change further.

domination. What struck me as I sat in the court listening to the lawyers present their very precise and erudite arguments was that what was really being discussed was the law, not Debbie's life, and certainly not her death. Her death constituted an absence despite references made to it. Only the very bare bones of her "dreadful predicament" as the appeal judges called it, were alluded to. There seemed to be a disparity between the law, as it was being interpreted during the hearing of her case, and her real life dilemma. The gap between her real person and her legal persona became visible during the proceedings. Perhaps it was because her death remained so remote, both in terms of timing (indeterminable future time) and location (Switzerland). This is not to say that death needs material form to be present. Armstrong (1987) argues that the materiality of death can be framed and produced through discourse and even through silences. Death is present in the public domain in many ways, not just materially. Her dying was absent, rather, because the case was not really about the specifics of her dying. It was about the law.

The British legal system has a common law tradition which means that the law develops by establishing precedents so that "the ends of one analytical practice become the means of the next" (Riles 2004:783). Jurisprudence develops by building on previous decisions in an expertly crafted game of legal logic, which Debbie knowingly referred to as "legalese". According to Greenhouse (1989:1640), while the common law seems to reflect a logic of linear time with its reliance on precedent, and its commitment to reform, its reclaiming of past judgments for the purposes of present claims and its essential reversibility also make it decidedly non-linear. It gives the aura of completeness but is always subject to change. The common law is both in time, as the product of human reasoning, and out of time, in that it has no definite start or end point. It stands outside of specific human interests, but must also respond to them. This particular temporal relationship, according to Greenhouse, gives law a mythical dimension, an "all-times" quality (1989:1642).

The volume of legal details submitted to the court and the level of analysis given them made court proceedings all but impenetrable to non-experts. It was quite surreal to imagine that these intense discussions about logic and precedents among people dressed in gowns and wigs would decide the timing of Debbie's (possible) suicide.

Perhaps it was such “anti-everyday practices” (Valverde 2003:88) as the wigs and gowns themselves that lifted Debbie’s death-in-waiting out of the realm of the ordinary. Anthropologists have classified “the ordinary” as everything that is not “spectacular, large scale, institutional, or formal” (Kelly 2008:353). Whereas anthropologists used to focus on such extraordinary experiences as major life cycle events or pivotal dramatic performances, they now give ideological preference to the study of the ‘ordinary’ or the ‘everyday’, valorised as the concrete and commonsensical aspects of life (Marcus 1993:237,244). Interestingly, Debbie is trying to make her death both concrete (certain) and commonsensical (she even used that term) which I interpret as her attempts to make her assisted death “ordinary”. Yet her death-in-waiting in the court is undoubtedly extraordinary due to its very public nature. Although Shokeid (1992:241) asks why we cannot find the “extraordinary” in people’s private lives and in unexpected events, and by extension, why we cannot identify the “ordinary” in the public and the planned, it seems clear that Debbie’s case is not a good illustration of these terms being successfully applied to their opposite. Certainly, in their turn towards the ‘everyday’, some anthropologists have argued that the law is not always engaged with as some radical ‘Other’ which can offer symbolic recognition, but actually plays a constitutive part of people’s everyday experiences. However, in this instance, Debbie’s legal, political, and media campaign was directed precisely towards that symbolic recognition, making her dying experience far more extraordinary than ordinary.

When I asked Debbie after the event whether she also found the courtroom experience surreal, her response showed a remarkable awareness of the function of the law. She told me that she always knew the lawyers could only interpret the law and that it was not about her specific situation. In addition, she had become sceptical about the ability of the law to apply ‘common sense’, as she viewed it. Riles (2006:54-55) comments that some legal scholars, bureaucrats, and activists share a “profound and sophisticated scepticism” about the claims, practices, and subjectivities of human rights law. Part of this scepticism arises from the idea that human rights work is often less about helping “victims” and more about legitimating the human rights regime itself: its institutions and the people who work in those institutions (2006:56). Debbie’s scepticism was just as “sophisticated” in that she

realised that the legal game of logic wrapped up in elegant legalese had very little to do with her own anticipated dying. Success in using the law requires that one hide one's scepticism, as Riles's human rights activists and lawyers are acutely aware. Similarly, Debbie did not reveal her scepticism about the law's capacity to speak directly to her predicament in her interviews with the media. Her legal case was represented in the press as a very personal plight with details given about her private life and her relationship with her husband, Omar. It was through the media that Debbie's 'being-towards-death' was recognised in its specificity, not in the court with its focus on the "technocratic rationalities of law" (Riles 2006:59). This is not to argue that legal recognition is neither possible nor desired for Debbie and Omar. Only that if this recognition *is* given, it will be a collective recognition of a general right-to-die, and not a recognition of the specificities of her dying or death. These are perhaps too private, emotional, and still uncertain for the law to make an impact on.

It is the media that offers a more immediately gratifying and personalised form of recognition. This supports Walter *et al's* (1995) argument that the media is now where death is made public. Confusingly, Debbie seems both sceptical about her chances for personal recognition, but at the same time she is occupied with harnessing the law's symbolic power for her political ends. Certainly it is easy to be cynical about the instrumentalisation of the human rights regime. Riles's legal sceptics might feel particularly cynical knowing that efforts to have a right-to-die recognised as an officially sanctioned human right has cost the taxpayer millions of pounds in legal aid⁸⁵. One would be entitled to question what the 'ends' of the human rights discourse actually are.

Relying on the courts to give recognition to one's suffering has further problems. What a claimant is usually appealing for is justice, as they perceive it. But the law is not necessarily just; it is more like an economy (Derrida 2002). Law is appealed to in order to calculate the "infinite idea of justice" (2002:244). As Riles has emphasised (2004:781-2), 'doctrine' is what emerges from cases for lawyers, not relations

⁸⁵ Legal aid is provided by the state to people of modest financial means to enable them to obtain legal advice and representation. Legal aid is only given if the case is considered to be of general public importance. Debbie's case received legal aid.

between people or the practical effects of decisions. The legal person that emerges in court is the product of an institutional performance, of theatrical artifice (Douzinas 2000:19). In the iterative process that is the common law system, lawyers have a pragmatic orientation “focused on the way in which legal texts index their contexts of production and use” (Mertz 1996:233). Doctrine, and all that it contains, is paramount and the social world is contextualised by lawyers in terms of doctrine. The result of this is that the law is largely conservative because it is so relentlessly self-referential. Hence why, according to Gearty (2006:12), the legal profession should not be relied upon to carry the ‘radical’ project of human rights forward:

Which great social movement has ever before put the lawyers in its front line? (Gearty 2006:12)

Riles, who is more familiar with ‘sceptical’ lawyers who may also be less conservative, thinks that lawyers *are* interested in social problems, but that they engage with them through an analysis of legal doctrine:

The social world beyond the law is relevant, but in a specific way. It is the end, and the law is the means (Riles 2004:783).

This is the argument for viewing the law as an instrument, which is exactly how Debbie Purdy sees it. She is using the law to achieve political ends (legalising assisted dying). But if human rights law becomes subject to too much instrumentalism, it turns into an “iron cage” which destroys its relationship to its ends (Riles 2006:60). The means become the ends. Gearty (2006) made a similar point when he argued that human rights have reached dizzying heights in the world of politics and law, but in the process have become dislodged from any sound philosophical base or inquiry. If they are to survive, they need a better answer to the basis of their authority and they need much more certainty and clarity (2006:11,19). It is perhaps ironic, then, that human rights, which according to some critics themselves lack clarity and certainty, are being invoked by Debbie Purdy’s lawyers in an attempt to give her and her husband clarity and certainty about her death and its consequences!

Human rights and human rights law are not the same thing, and while the law may be instrumentalised, many would argue that human rights may not. As a pure concept, rights stand apart from law. Hobbes was the first philosopher to make this idea plain: “law and right differ as much as obligation and liberty” (Hobbes 1996:172). Human rights as, arguably, the modern version of ‘natural rights’, are inalienable and exist outside of the law. This is exemplified in Dianne Pretty’s declaration, after she lost her case in Strasbourg, that “the law has taken away my human rights”. The instrumental value of the law was lost when it failed to deliver her desired ‘end’.

Predicting Future “Unbearability”

Before ending my discussion of Debbie’s case, I want to make some final comments about her and her husband’s “dreadful predicament”. First, some members of FATE and people I spoke to who were planning to die at *Dignitas* were concerned that Debbie’s case could have the opposite effect to that intended and actually make it more difficult for people to travel to Switzerland to die. Sheila, whose story I outlined in Chapter Five, felt angry that there was so much publicity given to *Dignitas*. She was initially given the green light by the organisation, but by the time she felt ready to die, the organisation had introduced tighter restrictions in response to adverse publicity and internal political pressures. Her “green light” was revoked because she did not fulfil the new requirements. Sheila was eventually helped to die by another Swiss organisation. Although Sheila understood why campaigners wanting to change the law would use *Dignitas* as leverage, she thought that it was to the detriment of people who desperately needed to make use of its services *right now*.

This leads me to my second point. Debbie only wants the *possibility* of using the services of *Dignitas* at some unspecified future date. She told me that Omar “has a total belief that I will never find life unbearable.” In other words, her husband doubts that she will ever travel to *Dignitas*. There is a lot of uncertainty in her approach to her future, but she wants the law to help her keep her options open. In contrast, for a number of the people with whom I spoke who want to go to *Dignitas*, it offers the very best option for bringing an end to their suffering. Far from being the “dignified

death” of last resort, it was their most desired choice. Phillip, whom I also introduced in Chapter Five, was battling for three years to get the green light from *Dignitas*. Whenever I met him during this waiting period, he told me of his desperate bureaucratic struggles and his misery at the delay to his plans. The urgency that accompanies many people’s desire to go to *Dignitas* is qualitatively different from Debbie’s desire to use the law simply to keep her options open. The additional publicity her case (among others) gives to “suicide tourism” in Switzerland makes some concerned that it jeopardises the very existence of this “last resort” option. Adverse media attention on Switzerland as a destination for suicide has resulted in the Swiss government reconsidering its laws on assisted dying. There is now a proposal currently before the Swiss parliament that would require patients to supply two medical opinions stating that they only had months to live and that they had mental capacity to make the decision to die. Given that many British doctors are still reluctant to write medical reports for patients they suspect of wanting to travel abroad to die, such a measure would present a new significant obstacle.

The third significant point is the response of the opposition. They view her claim to want “clarity” as disingenuous, given that none of the ‘accompaniers’ of the 100-plus Britons who have gone to *Dignitas* have been prosecuted. Her case, as they see it, is part of DID’s cynical political campaign to legalise assisted dying by stealth. SPUC’s intervention put forward the “material fact” that terminal palliative care for people with MS was wholly effective. Just as her husband thinks Debbie will never find life unbearable, so those who oppose her legal case also believe that she will never find life “unbearable”, given the appropriate care and support. During the case, I wondered how other people living with MS might feel watching Debbie on T.V. appealing for a human-right-to-die when life with her disease becomes “unbearable”. The majority of the media reports began with the phrase: “MS sufferer Debbie Purdy...” Do people living with MS always feel as if they are suffering? Do media reports which represent them as suffering undermine the value they find in their life with illness?⁸⁶ Or do others living with MS share Debbie’s desire for certainty and

⁸⁶ I recall here *Rosetta Life*’s reluctance to use the word suffering (see Chapter Two). The stated reason for this was that the term disempowers the person who is living with the life limiting illness and casts them as a victim in their narrative.

security of mind? These are tantalising questions that this research project cannot answer. The point I want to make, however, is that the opposition's argument that one person's claim for a "right-to-die" undermines the value of another person's life by proxy is something which needs to be considered. In Sheila's case, for example, when a friend from her internet support group who was living with the same disease found out, after the fact, about her assisted suicide, she was very distressed and made a formal complaint to the Swiss organisation that had helped her to die. This action was born of more than just grief. The woman felt that Sheila's suicide contained within it an implicit judgment about *her* quality of life. They had been living with the same disease and had the same symptoms, yet one had decided to end their life early because they felt they were "suffering unbearably." Even for Sheila, who considered herself to be 'unattached', her death decision affected other people.

The media in the main endorsed Debbie's plight. Was this because journalists could imagine the future "unbearable" quality of Debbie's life, or because they imagine living with MS to be "unbearable" in and of itself? Imagining future states is incredibly difficult, as much for Debbie as for the public which judges her claim. The concern is that the many hypothetical "what ifs" around which her case revolves and the future determination of what she considers to be "unbearable" may not be sufficiently emphasised in the media coverage of her case. Hausmann's (2004) discourse analysis of press coverage of assisted dying found that illness was nearly always seen as a decisive factor in justifying a sympathetic response to assistance in dying:

Whereas this sympathy cannot be openly expressed by stating categorically that "serious illness is enough to justify the killing of people", it can be argued that this same sentiment is expressed more subtly by making extensive reference to the poor health of the patient (Hausmann 2004:215).

The representation of Debbie's life with MS is just as important as the representation of her projected fears about her future dying. Debbie herself is aware that she is a representative of disability as well as of the assisted dying cause. For example, she told me that her district nurse always wants her to talk about incontinence and sex

whenever she does an interview in order to raise awareness of those issues for people with disabilities. Her high media profile gives her a platform for talking publicly about both disability and dying, but in trying to align the two strands of her activism, she finds herself in conflict with those sections of the disability rights movement (and it is by no means all⁸⁷) which view assisted dying as a serious threat. As I have attempted to demonstrate throughout this thesis, once people's private stories are shared publicly and become part of public discourse, their narrative can take on a life of its own over which the subject of the narrative has limited control.

Legal Inconsistencies?

Debbie Purdy's legal case attempted to challenge the seeming inconsistency between the law, which as it is written makes it a criminal offence to assist with someone's suicide, and the reality, where no one has yet been prosecuted for facilitating another's journey to Switzerland. What is of anthropological interest here is not the rule of law *per se*, but rather the way society creates "exceptions" to rules.

The greatest exception to the rule of law is the law-makers themselves. In Agamben's (1998) theoretical analysis of the relationship between death, state power, and the law, it is the sovereign power's *exception* from the authority of the law that gives him the ultimate power to decide who should die and who forced to live. In totalitarian regimes, it is state power's exemption from the rule of law which can leave people subject to arbitrary, extra-judicial death decisions. This is why democratic nations support the principle of a separation of powers, to maintain the independence of the judiciary against the authority of government. But what happens when an individual does not apply to the law to be *protected* from death, through appealing to a right-to-life against the state's death decisions, but rather applies to the law in order to request their own deaths? For those who make an application for a right to be helped to die, Agamben's totalising sovereign power is felt not in being condemned to death, but in being condemned to live. Instead, they want to be made

⁸⁷ While the Disability Rights Commission (DRC) and Disability Awareness in Action (DAA) both oppose assisted suicide on the grounds that it would reinforce existing public prejudices, Tom Shakespeare of the Policy Ethics and Life Sciences (PEALS) Research Institute argues that "disabled people are [not] dupes...they are not going to be trotted off to die." (ADTI 2005:51)

an exception to Article 1 of ECHR which grants the right to life. However, in demanding the power to determine their own death decision, paradoxically, this requires that they hand back this decision to the state/government/doctors.

In the U.K., it was the case of *Re C (adult: refusal of medical treatment)*[1994] that established the right of patients to refuse treatment, including life-sustaining treatment⁸⁸. This is based on the seriousness with which the law views any invasion of physical integrity, and the conviction that everyone has the right to self-determination with regards to his or her body. This upholds what Berlin termed “negative liberty” – freedom from interference (see discussion *p149*). The legal consequences of unauthorised invasion of that bodily integrity include civil actions for damages and criminal liability for assault (Mason *et al* 2005:349). This right was made unequivocally enforceable with the case of *Ms B (adult: refusal of medical treatment)*. Ms. B was paralysed from the neck down and sustained only by a ventilator. She requested that the ventilator keeping her alive be switched off. The dilemma for the doctors was whether she had legal capacity to make such a decision when the inevitable result would be her death. After conflicting psychiatric reports about her mental capacity, her case went to court and the judge presiding attended Ms. B’s bedside to hear her story and assess her ‘capacity’ in person. Ms. B was found competent to make the decision and the ventilator was switched off. As a symbolic gesture, notional damages of £100 were awarded in recognition of the technical assault that the health carers had committed by continuing to treat Ms B against her wishes (Mason *et al* 2005:377). The law upheld Ms B’s own death decision.

Given the success of Ms B’s case, a number of commentators saw fit to draw comparisons between it and the case of Dianne Pretty which was progressing concurrently through the courts. Biggs (2003:299) argues that it is “clearly

⁸⁸ The case involved a 68-year-old man with paranoid schizophrenia who had developed gangrene in a foot while serving a prison term. Despite being told he had only a 15% chance of survival if his lower leg was not amputated, the man refused the operation saying he preferred to die with two feet than to live with one. The hospital questioned his capacity to exercise his autonomy in this matter, but the court held that although his general capacity to make decisions was impaired by his schizophrenia, he understood the “nature, purpose and effects” of the treatment being refused and so was within his rights (Mason, McCall-Smith, Laurie 2006:375).

anomalous” for the courts to let Ms. B die by switching off her ventilator, but refuse Mrs Pretty assistance to reach the same conclusion. The fact that Mrs Pretty was terminally ill but Ms B was not seems to add further to the perceived “anomaly”. However, as Boyd (2002:211) points out, the two judgments are not inconsistent in the eyes of the law, despite what some view as pure sophistry⁸⁹. A legal distinction is made between acts and omissions. Legally, treatment can be passively withdrawn (omitted), even if that results in the death of the patient, but a person cannot be actively killed, even with the consent of the individual concerned. This again reflects Berlin’s (2006[1958]:369) view of “negative” liberty as the principle of non-interference from the state. In other words, a person’s right not to be subject to unwanted medical ‘interference’.

McGee (2005:384) advances the idea that the ability to reason in this way rests on a nature/human action distinction, whereby once human interference (or artifice) ceases, the patient can be left to die “naturally” from the underlying medical condition. What is interesting is the way law is used to create such distinctions in order to guarantee certain outcomes, in this instance, the prohibition on deliberate killing. Lock (2002) draws attention to another instance in which legal reasoning is employed to justify a particular outcome. The ‘brain death’ category, as the uniform, statutory definition of death, was created in no uncertain terms to facilitate organ transplantation. In an application of consequentialist ethics, the determination of this category of persons enabled an expanding number of patients to be considered “as-good-as-dead” and to be harvested for their organs. In the assisted dying movement, many think that the legal reasoning which renders omissions legal and acts illegal is ‘illogical’ and amounts to legal fudging or “intellectual and moral nonsense” (McLean & Britton 1997:95). What such perceptions of inconsistency suggest is that there is a more general discrepancy between legal reasoning, as understood by non-legal actors, and its effects on people’s real lives. Rosen comments on this:

The categories made available to the decision-makers, the analogies that one shares with colleagues, the need to mask the substantive through the technicalities of the procedural may all contribute to a style of logic that

⁸⁹ Sheila McClean, in debate at the Royal College of Physicians, Edinburgh, 3 October 2007.

separates law from an ordinary citizen's idea of commonsense reasoning (2006:133).

Dianne Pretty wanted to be classified an “exception” to the rule prohibiting intentional killing. In her eyes, she was not protected by the law, but rather abandoned to her disease. To use Agamben's terms, she was ‘made to live’, but in a state of “bare life” or pure *zoe* (mere existence). But active assistance to die is where the law currently draws the line, and Debbie's Purdy's challenge, as yet, has not shifted that line. For Agamben, both deliberate killing or ‘making live’ are manifestations of the state's ultimate power over subjects, the power to reduce life to pure *zoe* (mere life) and forsake a life's *bios* (ethical and political life). Agamben describes *homo sacer*, an obscure figure from Roman law, as someone who “it is not permitted to sacrifice, yet he who kills him will not be condemned for homicide” (1998:78). *Homo sacer* is therefore outside the protection of law and left exposed to death. This could in fact be “the exception” represented by assisted suicide, in that life which is deemed “unbearable” is authorised to be killed with impunity. In other words, the person requesting assistance to die desires to be designated *homo sacer* - to be judged only for their ‘bare life’. It seems that Agamben's choice of words: “bare life”, “zones of abandonment”, not to mention his continual references to the concentration camp as the paradigmatic “state of exception” where people can be killed with impunity, play squarely into the hands of the anti-assisted dying lobby who fear the erosion of life's innate worth. That life hangs on a political or legal decision is an idea that many, particularly those who believe in a higher spiritual authority, find hard to swallow. Such decision-making powers make life and death vulnerable to the vagaries of human intention and motive. Is it advisable to have court endorsed views about quality of life and what constitutes “unbearability”? The pro-lobby argue that life *already* hangs on such decisions, that ‘nature’ has not decided death for a century or more (anthropologists would argue that ‘nature’ alone has never determined death), and that legalising assisted dying would simply make decision-making more morally consistent and “honest”. For Calibressi and Bobbit (1978:26), honesty may be considered a virtue, but it also exposes the “tragic choices” at the heart of such decision-making.

Could Dianne Pretty and Debbie Purdy become legal exceptions to the prohibition on killing? The problem of making exceptions in the common law system is that exceptions establish a precedent, which can then ground the logic to establish further exceptions. Recall that “the ends of one analytical practice become the means of the next” (Riles 2002:783). A so-called “threshold decision” (Agamben 1998) may never be reached. Herein lies the idea of the “slippery slope” which drives the fears of the anti-lobby. Some suggest it is perhaps better to live with a legal ‘fudge’. Lord Phillips, in debate at the Royal College of Physicians, said: “the illusion of our age is that law can replace moral and collective responsibilities.” The only certainty a new law would bring, he argued, would be the creation of more legal specialists.

Rights and Relations

Throughout anthropology’s history, law has been studied as rules, ideology, culture, and resource. The instrumentalist perspective, as examined by Riles, is often juxtaposed to the constitutive perspective which takes account of the law’s effect on what people think and do un-self-consciously (Sarat & Kearns 1995:11). Law helps to shape consciousness, by both initiating and constraining actions in people’s everyday lives. Rosen (2006:7) argues that law acts as a framework for ordered relationships; it is a way of putting things in their place. If this is the case, it is reminiscent of Strathern’s concept of kinship as knowledge of, and different ways of, verifying connections between people (2005:46). It validates certain relationships. How has the law verified the connection between Debbie Purdy and her husband Omar? The legal case has caused them to discuss their hopes and fears about Debbie’s dying, and make plans for her dying, more than they otherwise might. In part, it is their relationship that has been on trial, and Debbie is aware of this: “I think people sympathise with me, but they empathise with Omar”. The appeal judgment described Omar’s potential assistance with her suicide as a “final act of devotion” and “the culmination of a lifelong loving relationship” motivated by “raw compassion and devoted love” (Para 7,10). By making these comments in spite of refusing their appeal, the judges publicly recognise the couple’s intimate inter-dependency.

So, while anthropologists, like Rosen, view the law as a framework for ordering relationships, others disagree claiming that legal definitions cannot explain us fully as persons. Berlant (2002:125) asks what the relation is between the authoritarianism of juridical categorisation and other, looser spaces of social life and personhood? The law only recognises certain acts, identities, and subjects that fit its classificatory order. In a similar vein, Brown (1995:27) argues that the law's categories fix people's identities and deny their natural indeterminacy and ambiguity. Once people feel that their identity is fixed, they argue from a vision of essentialised individual identity ("who I am") rather than of the common good or inter-subjective relations. Rights rhetoric, variously traced to the Reformation, the Renaissance, the Enlightenment, the French Revolution and the Industrial Revolution (Lukes 1973:14), has been the handmaiden of individualism and according to Brown (1995:51) it is still founded on unreconstructed private interest. For critics like Glendon (1991:x-xi), rights discourse fosters an exaggerated absoluteness and a hyper-individualism that destroys the prospect of mutual understanding and compromise. It is only concerned with "placing the self at the centre of the universe". Butler (2004) has argued that we have an unavoidable dependency on others, which the law does not always recognise. She writes:

Although we struggle for rights over our own bodies, the very bodies over which we struggle are not quite ever our own (Butler 2004:26).

Whether we agree or not that rights language takes account of our relatedness and the ways in which we are implicated in other people's lives it has now become the primary mode by which people seek to promote an interest or advance a cause, and especially to make claims upon the state. One of the main reasons Debbie gives for wanting to pursue her 'human-right-to-die' is that if it was a legally recognised right, it would give people a way to *talk* about death. Rights language certainly appeals because it "shifts claims out of the realm of the merely desirable into the domain of the morally essential" (Jones 1994:4). Its appeal also lies in the fact that it gives people a way of talking about their actions, motivations, and relationships, albeit in a way that puts the individual at the centre.

Dying for Dignity

The concept of ‘dignity’ has been central to the assisted dying debate and is also central to conceptions of human rights. In Chapter Six I noted the controversial renaming of the *Voluntary Euthanasia Society* to *Dignity in Dying*. Internationally, the term has a long history as a slogan in the right-to-die movement, cemented further by the name chosen for the Oregon Act legalising physician-assisted suicide (the *Oregon Death with Dignity Act*). The term is also firmly associated with human rights. For example, Article 1 of the *Universal Declaration of Human Rights* tells us “all humans are born free and equal in dignity and rights.” The ascendancy of human rights since the end of the Second World War has determined that where once ideas like “social justice” or “fairness” won support, now “human rights” are expected to do all the moral work (Gearty 2006:8). As Rajagopal (2003:165) states, human rights have gained hegemonic status as the “sole approved discourse of resistance.”

Human rights are the late modern equivalent of ‘natural rights’, which in turn developed from natural law theory. The premise of this theory was that law did not derive from an external power, but from human nature (Douzinas 2000:50). Like evolutionism, natural law was considered to transcend time and place (Rosen 2006:64). Right, according to nature, is “what contributes to a being’s perfection, what keeps it moving towards its end” (Douzinas 2000:30). For a long time, Christianity was the main driving force behind natural law theory, which confirmed the idea of God’s law on earth as immutable and eternal. Eventually, with the growth of individualism, natural law morphed into natural rights, first championed by Thomas Hobbes. Rights, according to Hobbes, were not only innate to the individual and therefore to be subjectively determined, they were also the individual’s defence against sovereign power. All these properties natural rights share with human rights. Both are conceptualised as powers that belong to the individual, essential attributes of the subject, and often used as a defence against the encroachment of the state.

This transition from natural rights, connoting “rightly ordered”, to human rights, considered to inhere equally in all, reflects a parallel change in the conceptualization of “dignity”. “Dignity” used to connote rank and status (*dignitas*), a meaning still given in dictionary entries for the term (Waldron 2007). To be “dignified” was, historically, to be granted privileges or status according to one’s nobility. It was a hierarchical differentiation of the “worth” of humans. This early equation of dignity with “dignitary” flies in the face of its current meaning in human rights discourse. Here it signifies something innate and inalienable. However, in the “death with dignity” debate it is conceived as something which can be lost through experiencing unmitigated pain and suffering. This begs the question, if people are born with dignity, how can it then be lost? Or why do we need to assert a ‘right’ to it? This seeming contradiction has spawned extensive critique of the concept, most famously from Bentham (1948). The concept inhabits a circular or tautological reasoning (Waldron 2007:235). Whereas assisted dying proponents argue that “dignity” can be lost through disease and suffering and only restored by hastening death, opponents insist that it cannot be degraded in such a way. In addition to this confusion over its inalienable quality is what substance the term actually conveys. Most commentators agree that it is so ill-defined, as to convey no substantive meaning at all (Macklin 2003). Waldron can only fall back on the Kantian notion that dignity is a respect owed specifically to humans by virtue of their autonomy (capacity for self-regulation) and that people should always be treated as ends, not just means (2007:206). But what of dignity that can be lost through suffering? What, then, of its content? If we lose our capacity for self-regulation (which includes bodily functions), do we automatically lose our dignity? Philosophers comment that this is a more transient version of dignity that is tied to our sense of personhood. It is what Pullman (2002:76) calls “personal dignity”, as differentiated from “basic” dignity. “Personal dignity” is dependent on the question of what constitutes a person.

Anthropologists, by virtue of their focus on local contexts, are suspicious of universalist claims about the inherent dignity of persons. One need only think of the social stratification of the Hindu caste system, for example. Rabinow (1996) discusses “dignity” through the optic of the legal case, *John Moore v The Regents of*

the University of California. Moore's biological cells were used, without his consent, to create an immortal cell line patented by the University of California. Although he lost his case when it was found that no property rights existed in surgically removed body parts, the judges noted that the commodification of the body was distasteful because it violates the "dignity and sanctity of the human whole" (Judge quoted in Rabinow 1996:145). Rabinow (1996:147) finds that assumptions about the indivisibility of the person and the body are embedded in popular beliefs as a result of early Christian teachings. He reminds us that in the 2nd – 5th centuries, belief in the resurrection of the body was held very literally. Hence the vital importance of the completeness of the body at burial. This contrasts with the approach to the body found in biotechnology which fragments the body into an exploitable reservoir of molecules and biochemical products (Rabinow 1996:149). It also contrasts with non-Christian worldviews studied by anthropologists. Strathern (1999), drawing from experiences in Papua New Guinea, developed the concept of the "partible" person. This is the idea that people are not indivisible but rather are constituted by property, goods, and substances exchanged with others. People can literally give parts of themselves away. In Papua New Guinea, even sickness can be detached from the afflicted person in the same way as a man gives away a pearl shell in an exchange (1999:148). This notion of divisibility undermines not only the link between the person and the body but also the concept of inalienability, so central to current definitions of dignity and human rights. In death, people's divisibility becomes even more apparent as people are 'disassembled' to reveal all their constituent parts. As Strathern writes:

At death, the multiple constitution of the socially active person...is displayed, then deconstituted and then taken apart (1988:291).

Lawton (2000) recognised an equivalent disassemblage in the deaths she observed at a British hospice. The bodily disintegration of patients was not always synchronised with their diminishing social connectedness. Patients often lived too long or died too soon (2000:148). She argues that the idea of "dying with dignity", if dignity is understood as the indivisibility of the body and the person, ignores the realities of

bodily dying (2000:179) where boundaries are transgressed as the dying body becomes 'leaky' and a person's functions uncontrollable. Debbie Purdy herself told me that dignity for her was about control. In an era where a healthy body has come to operate as a symbol of personal, internal order, dignity too has become synonymous with bodily control. Debbie says that although dignity for her is about control, it is a matter of individual determination. Dignity is whatever people say it is. In other words, it is entirely individually specific. This leaves its substantive content or quality unknowable. Perhaps, like good health, we only become aware of 'dignity' when we lose it.

Like rights, 'dignity' is a problematic concept to identify in the abstract but it is used as a way to talk about our wants and our needs and the aesthetic shape we want to give to our lives. The demands for 'dignity' are of greater ontological significance than its actual content. The slogan "dying with dignity" is firmly entrenched in right-to-die discourse, despite the opposition's sense of ownership. Like human rights, dignity as a term has symbolic and rhetorical force and will continue to be used, despite being considered a "useless concept" by some (Mackin 2003). Both concepts have infinite possibilities and offer a way of transcending the uncertainties of the present. The idea of dignity as something both inalienable by virtue of one's humanity and also as specific to the person is mirrored in the competing appeals to law to recognise both one's collective claim to a 'human-right-to-die' and to recognise the specificity of one's life lived and death anticipated.

The Mental Capacity Act

The Mental Capacity Act 2005 (MCA) is fundamentally a piece of equality legislation and in this respect it appeals to dignity rhetoric about the inherent worthiness of all persons. The Act establishes a legal framework for deciding whether people have the mental capacity to take decisions for themselves and for making decisions on behalf of people who do lack mental capacity. It is intended to both empower and protect people who have a mental "impairment" or "disturbance" of some kind: people living with dementia; learning disabilities; mental health issues; and brain injuries. The majority of people who use the Act will be older people with

dementia (700,000 people are currently diagnosed with dementia, but 1 in 3 over 65s will die with some form of dementia⁹⁰). “Capacity” is judged to be when a person can comprehend and retain information that they believe in and that they can weigh in the balance with other considerations. Crucially, the Act applies not only to financial and property matters, (previously covered by a patchwork of mental health and social security law) but, for the first time, it applies to health and welfare decisions. This includes everything from decisions about how one wants to be washed or fed, to consent to medical treatment.

The Act also enables individuals to make advance provision for the end of their lives in the event of their own mental incapacity. They can do this either by executing what is known as an Advanced Decision (previously called a ‘living will’) stating clearly what treatments they do and do not want, including life-sustaining treatment, or by nominating others to make decisions on their behalf. This is called substituted decision-making and it is the first time the medical profession have formally had to deal with this. It is these end-of-life decision-making provisions that are pertinent to the assisted dying debate. The Act attempts to make advanced care planning routine and bring death decisions into people’s lives in order to reduce the number of disputes coming before the courts. If the Act is successful in encouraging and facilitating the making of end-of-life care plans, then the anticipated death may become the “ordinary” death. The Act is also of general interest in relation to the themes discussed in this thesis because it appeals to the new public demands for personal choice over one’s care, equal rights for people with disabilities, and the state’s role in enabling its citizens to flourish. Demands for rights, choice, and personalised services coalesce in this Act.

Moves to establish the Act began in 1989 when it became clear, according to Penny Letts, who played an influential role in drafting the legislation, that the law was “just a vacuum” when it came to health and welfare issues. There was no framework for making decisions about where people should live, for example, or for making healthcare decisions about consent to medical treatment. Although the common law

⁹⁰ <http://www.alzheimers-research.org.uk/info/statistics/> (accessed 20.01.10)

had built up around various high-profile legal decisions, and ‘living wills’, as they were known, were already enforceable, there was a sense of confusion and hesitation and people wanted comprehensive guidance contained within one piece of legislation:

Some people were turning to their solicitors and saying – will you draw up a ‘living will’ for me, and solicitors were saying they’d never heard of this. Cases were going to court to see whether or not such documents were valid and could be enforced (Penny Letts)

An umbrella group called the *Making Decisions Alliance*, comprised of thirty nine charities lobbying for the rights of older people, people with mental health issues, people with disabilities etc was set up to spearhead the campaign. However, the first draft bill was not presented to Parliament until 2003 – a delay of 14 years. According to Penny Letts, this was down to the religiously motivated resistance to the end-of-life provisions in the legislation. The Lord Chancellor had various discussions with the Roman Catholic bishops trying to allay their concerns that it was effectively legalising assisted dying by the “backdoor.” One of the concessions made was to create a specific clause within the Act (Section 62) that states that:

For the avoidance of doubt, it is hereby declared that nothing in this Act is to be taken to affect the law relating to murder or manslaughter or the operation of section 2 of the Suicide Act 1961 (assisting suicide).

The MCA only managed to scrape through Parliament. Although the end-of-life provisions dominated in the press at the time (some tabloids calling it “euthanasia by the backdoor”⁹¹ or referencing “tick box to die”), the majority of the Act is not concerned with dying at all, but rather with ensuring equality and freedom in decision-making throughout life.

Section 1 of the Act lays out a set of guiding principles all broadly devoted to ensuring the equal treatment of persons. The first principle is that there is a presumption in favour of capacity and an obligation to assist individuals to make their own decisions as much as is practically possible. This means that people are not

⁹¹Daily Mail “We’ll fight backdoor euthanasia and risk jail say doctors”
<http://www.dailymail.co.uk/health/article-445585/Well-fight-backdoor-euthanasia-risk-jail-say-doctors.html>

to be judged “incapable” just because they have dementia or because they have learning difficulties. Further to this, the Act also stipulates that decision-making capacity must be assessed on a decision-by-decision basis. Just because someone is judged incapable of deciding whether or not to sell their house, does not mean that they are also incapable of refusing chemotherapy. The Act puts the onus on the carer, whether that is a relative or a professional, to facilitate the decision-making capacities of the individual concerned. Deborah Bowman, a medical ethicist at a London hospital, told me that this principle means that doctors and carers will have to think imaginatively about how to help people to make decisions. For too long, she says, doctors have been allowed to make pejorative judgment calls (like “she’s lost her marbles”) when assessing capacity or to make decisions on behalf of others without taking any steps to include the patient in the decision-making process. All paternalistic justifications are rejected by the Act, further enshrining the primacy of patients’ rights.

If a person is found to lack capacity to make a particular decision, then a form of “substitute decision-making” takes over and a person’s “best interests” must be determined. Further underlining the emphasis on equality and non-discrimination, the Act states that a person’s “best interests” must not be judged according to age, appearance, condition, or behaviour. It also states that their “wishes and feelings” and “beliefs and values” must be considered (MCA s4). There is no mention at all of clinical “best interests”. This represents quite a radical shift. For some, this is a shift too far. *The Society for the Protection of Unborn Children* (SPUC), for example, lobbied fiercely against the Act for the reason that it further degrades the principle of the sanctity of life. By allowing such subjective ideas as “wishes and feelings” to be the basis for turning off a life-support machine, for example, disregards “the intrinsic value of the human person”:

There is an idea that law is something that can be constantly changeable and doesn’t have to be linked to any timeless principles... [that it is] only there is satisfy passing social concerns. It’s a misunderstanding or a failure to recognise the basis of positive human law and natural or moral law (Campaigns Director, SPUC).

SPUC have now created the *Patient First Network* whereby members receive a card and a medallion to alert medical staff that they want to be treated in the event of incapacity. This is to avoid any confusion over their “wishes and feelings”⁹². What is of anthropological interest in these determinations of “best interest” is that it requires the medical professional or relative to assume the perspective of the person whose interests they are deciding. They are required to enter their worldview and “see through the eyes of another”. This could be a form of perspectivism or alternatively of “asymmetrical reciprocity” (Young 1997:41) in which one takes account of the other but cannot directly assume their perspective because life histories and social positions are so divergent. Deborah Bowman thinks that this presents a fundamental challenge to the way that doctors think. Doctors have to evaluate non-medical factors, but yet this is not their area of expertise. Bowman told me that many doctors would feel that to include other perspectives would be “poor medicine” and an erosion of their expertise. Fundamentally, it is a translation exercise between different forms of knowledge.

Advance Decisions

Another key principle of the Act is that a person is not to be judged incapable “merely because he makes an unwise decision.” This means that even if a person makes a decision that may be considered “irrational” by those caring for that person, they are not permitted to overrule that individual’s decision. This subverts the link, discussed in Chapter Seven, between rationality and autonomy. A person’s decision does not have to be deemed ‘rational’ in order for them to be allowed to act autonomously. For example, those who assert a Hobbesian ‘self-preserving’ view of human nature may argue it is “irrational” or “against nature” to want to intentionally bring an end to one’s life by refusing life-sustaining treatment. However, within the principles of the Act, one is entitled to execute any logic one sees fit. The normative category of the “reasonable man” identified in legal decision-making (Nussbaum 2004:11) does not necessarily hold when assessing capacity under the MCA. Additionally, a decision made (in writing and in the correct format) in *anticipation* of

⁹² Salford council received negative national publicity for producing a so-called “right-to-die” card to publicise the Advance Decision provisions in the Act.

an end-of-life situation, say, in twenty or thirty year's time, has the same legal effect as a decision made at the time when the question arises (MCA Section 26(1)). Similarly, a decision made by a nominated health and welfare "attorney" (or proxy: a relative, friend, or carer) on behalf of an individual, even the decision to refuse life-sustaining treatment, has the same legal effect as if the individual themselves had made it. In Kaufman's ethnography about modern hospital dying she shows that all too often 'choices' about treatment of dying patients are displaced onto relatives who lack the basic medical knowledge to make informed decisions and who often struggle to penetrate the complicated system of rules in hospital culture (2005:28). Testimonials received from patients and relatives showed that often they did not know what they wanted, other than recovery or an end to suffering in a general sense (2005:34). Their views were much less purposeful and much more muddled than the clear-cut goal that patient autonomy in decision-making suggests (2005:39). Kaufman's research shows that while patients may now have a legal right to nominate someone to make decisions on their behalf, it may still not be clear for that health and welfare attorney exactly what course of action best reflects their relative or friends "beliefs, wishes, and feelings."

The Advance Decision provisions within the Act, however, have not satisfied either assisted dying supporters or those who fear "euthanasia by the backdoor". For the right-to-die lobby, the need within the Act to specify *exactly* which medical treatments one does or does not want raises fears that if a doctor does not agree with a person's decision (if he is a devout Christian or Muslim, for example), he will be able to find a loophole and thereby disregard their Advance Decision. On the other side of the debate, opponents fear the opposite: that medical developments may occur between the time a person creates an Advance Decision and them becoming ill. The concern is that had the person known about the medical development, they would have altered their views. For one side, the wording is too precise, for the other, not precise enough.

Another criticism of Advance Decisions is that they do not take account of the idea that people change their life expectations and make different quality of life judgments at different stages of their lives. Predicting future feelings is an inexact

science. Christensen-Szalanski (1984) researched the discrepancy between a group of women's stated desire and intention not to use anaesthesia in childbirth and their eventual reversal of that decision. It was likely that this was down to their underestimation of the intensity of the pain. Research into people opting for aggressive cancer treatment is also indicative. When different groups of respondents were asked whether they would accept a gruelling course of chemotherapy if it would extend their lives by only three months, 42% of cancer patients said they would, but only 10% of healthy people, 6% of oncologists, and no radiotherapists said they would opt for the treatment (Slevin *et al* 1988). These surveys highlight that there may well be a discrepancy between how people predict they will feel and the feelings they ultimately experience (not to mention the difference between lay and professional views) (Loewenstein & Schkade 1999). These predictions are often affected, the opposition argue, by negative images of disabled people in the media as lives "not worthy of being lived." According to Loewenstein & Schkade (1999:97), such negative projections ignore the ubiquity of humans' ability to adapt.

A similar line of argument that works to discredit the ethics of advanced or substituted decision-making is that the competent person who makes the Advance Decision is not the same person as the incapacitated person to whom the instrument applies (or could even be considered a non-person). For example, a man living with dementia may not be recognisable to those who knew him as the same person and he may have very different interests to those he had when fully mentally competent. The ethicist Dworkin (1993:226) distinguishes "critical" interests - the values and projects we consciously adopt - from "experiential" interests - eating an ice-cream or watching T.V. To allow a person to die whose experiential interests are met even if their critical interests have been lost is to some morally reprehensible. For Dworkin and other, on the other hand, it is our critical interests that should take precedence. Critical interests, in a sense, survive the person in the form of the written directive. Although Advance Decisions are treated as objects, in a Strathernian sense (1999) they actually come to be extensions of the person: their continued will in written form.

The idea that the Advance Decision provision allows a person to judge their own future quality of life and make decisions about whether they want to continue in that life is in strange contrast to the other non-judgmental provisions of the Act. On the one hand, all of the tenets of the Act further enshrine in law the principle of autonomy. It gives people the ‘right’ to plan for their deaths. Yet at the same time, the Act makes non-discrimination a pre-requisite for any substituted decision-making. It specifies that everyone is equal and every decision equal before the law. People’s quality of life ought not to be judged. It is only our own that can. The Act straddles the assisted dying debate by appealing to both disability rights activists, and pro-assisted dying activists, as Debbie Purdy herself tries to straddle both interest groups. What is also significant is the extreme subjectivism encouraged by the Act. On the one hand, no one can assume to know what is best for another person, in which respect we are all very much treated as isolated individuals with our own discrete wants and needs. On the other hand, to make decisions for others, or even for our future ‘self’, we have to enter another person’s perspective (or our own perspective at a future time, when we are arguably a different person). In this regard, the Act is both radical and idealistic but also, no doubt, susceptible to major implementation difficulties.

Conclusion

The Act provides a legal framework so that in the final instance, people have recourse to the law to question how others have made decisions on their behalf, including their death decision. As the co-chair of the *Making Decisions Alliance* told me, the Act ‘has teeth’ in as much as it can force people to comply. It is a stick not a carrot approach. For Derrida, the force of law is what gives it its vitality and it is the only way in which justice can be calculated (2002:244). If it is proven in court⁹³, for example, that a hospital has not respected an individual’s Advance Decision to refuse life-sustaining treatment then a court can force the hospital to do so and the doctor responsible could be prosecuted and banned from practising. The Act reflects the new anti-paternalism which views rights as “trumps” (Dworkin 1984) which

⁹³ The Act has established a new specific court – the Court of Protection – to enforce its rules and procedures.

safeguard the individual's interests against majority views about what would be best for them. In a post-modern turn, each individual's choices are valid and absolute.

Like Debbie and Omar's legal challenge, the *Mental Capacity Act* is future orientated. The ability to nominate "attorneys" (proxies) to represent one's future 'self' and to make legally enforceable written statements about one's future wishes, will, it is hoped, give people clarity and certainty, the two things that Debbie craves. However, these abilities or instruments imply a continuity of 'self' into the dying phase; that one knows one's feelings in advance of experiencing them; and that more rights can create better deaths. While the criminal law is retroactive so it cannot make anticipatory decisions, the MCA is future orientated, in that it is intended to guide future action and assuage uncertainties about dying. Indeed, the MCA will actually affect far more people's dying than any law permitting physician-assisted suicide that, by anybody's calculation, will only be used by a very small number of people. The provisions in the MCA intend to make the planned and anticipated death the 'ordinary' death.

Critics of the Act argue that it displaces all responsibility onto individuals and families to direct their own dying, removing medical professionals from the equation and reducing them to the role of managers or bureaucrats. As Kaufman found in her American hospital, families rarely wanted to shoulder the medical decision-making responsibility and had seldom been meaningfully forewarned of the issues despite ubiquitous accounts in the media (2005:59). They had simply never imagined themselves in that situation. As one lawyer told me, the fact that 60% of people do not have a will does not bode well for people making Advance Decisions. Yet patient choice and patient rights agendas have won the day and the duty is now on patients to know, or at least to be informed of, their rights. Critics argue that those who don't risk being abandoned. For patients who are sick or dying, it may be very hard for them to agitate for their rights (Mol 2008). Supporters plead that the legal recognition contained within the Act will help avoid disputes which are costly and corrosive for families by bringing 'death talk' out into the open and into family discussions while a person still has capacity and can voice their wishes. Equally, the

Act forces people - medical professionals, carers, lawyers and families - to address themselves in the “language of the other” which for Derrida is the condition of all possible justice (1992:17).

The MCA goes some way to appeasing demands for control over death. However, it has not countered the persistent calls for a legal entitlement to an assisted suicide. It also remains to be seen whether the Act will work in practice. As one specialist lawyer reflected, there is an assumption that families actually *get along* and that they talk to one another whereas it is often the case that they disagree and withhold information from each other. This raises the question of how far law and legislation directs behaviour. Without legal assurances, will Debbie and Omar still make the trip to Switzerland? While legal recognition of a ‘human-right-to-die’ may offer a secular version of transcendence (Douzinas 2000), of transcending the dying process, legal *regulation*, on the other hand, ends up involving the state in private decisions. Baudrillard (1993:177), the French theorist, has a unique take on the late modern trend towards regulation. For him, it creates the “myth of security”. This is epitomised by the legal requirement to wear a car seat belt. Baudrillard argues that such security precautions dispossess a person of their own death by robbing them of the risk of dying while simultaneously smothering them with the very idea that they are at risk of death:

This is the secret of security, like a steak under cellophane: to surround you with a sarcophagus in order to prevent you from dying (1993:177).

Perhaps death ultimately represents a limit to legal regulation. This may be because some things do or should remain ‘beyond’, whether because they are too emotional, too uncertain, too individual, or too private.

CONCLUSION

According to Baudrillard (1993), the more we try to exclude death, by creating mass cemeteries outside cities, for example, the more death threatens to invade our whole culture. What we try to ignore becomes an obsession and fills us with anguish as we interiorise our fears (1993:145). In a sense, death is everywhere and nowhere. It is simultaneously invested with secrecy and stripped of privacy (Riddell 2002). For Baudrillard (1993:176-7), our demand for a comfortable, personalised, ‘designer’ death is analogous to the industrialised world’s obsession with accumulation, with administration, and with suppressing death through the myth of security.

As I sought to show in Section Two and Three of this thesis, the desire to make life and death certain perpetuates this myth of security. For advocates of assisted dying, the best way to make sure that death is both “civilised and certain”, as one participant described it, is via the administration of a lethal dose of barbiturates. Cross-culturally, a ‘good death’ is usually considered to be one that can be foreseen, prepared for, and controlled (Bloch and Parry 1999:15). For supporters of assisted dying, that control can come only in the form of legalised medical assistance to die. The consensus among supporters is that the procedure requires the involvement of a medical professional not only because of their access to the “foolproof” drugs, but also because their professionalism, which, according to Friedson (2004:122), has “transcendent value”, confers legitimacy on the patient’s decision. But for detractors in the debate, who refuse the right to an artificially procured death, a desire for control that turns death into a ‘designer’ good and makes it subject to administration by an anonymous and bureaucratic state further corrupts our relationship to our death. To apply Agamben’s terms to this counter argument, state sanctioned deliberate death would expose human life to the condition of ‘bare life’ as envisaged in the ancient figure of *homo sacer*, a person who could be killed without the commission of homicide. Once such a ‘state of exception’ has been established, so the detractors argue, it would result in a “paradigm shift” whereby whole sections of society could end up being classified as unworthy of life or worthy of being killed. Offering people a choice would soon turn into an imperative to choose (Rose & Novas 2005:451).

It is the different and equally real fears of both proponents and opponents which affect their anticipation of dying, and these were the subject of Section Two of this thesis. For the pro-lobby, the main fear is senseless and needless suffering in death. This loss of meaning has come about as a result of multiple factors, not least the experiences of massive numbers of casualties in the two World Wars, and because of the gradual de-Christianisation of suffering. As Lavi states, the only sense that pain now has is given to it by the medical machinery which aims to annihilate it (2005:74). Those who demand a legal right to an assisted death fear being kept alive through medical interventions long after their life has ceased to hold any value for them. As Gwen, a right-to-die activist said to me: “Do you realise how frightfully difficult it is to die?”

Another fear, particularly among older proponents of assisted dying, is that they will be subject to a slow and protracted “falling away” (Athill 2008:10) in which they may well end up institutionalised in care homes and forced into a state of complete dependency. Longevity is considered by some to be a curse. The case of dying in old age is not quite as dramatic as Debbie Purdy’s or Dianne Pretty’s high profile legal challenges, but it is older people who form the bulk of subscribers to the U.K.’s two main right-to-die societies, and, in the U.K., it is older people who form the largest proportion of the dying population. The vast majority of FATE activists, as I showed in Chapter Eight, are over the age of 65 and it is their anticipation of their own demise, helplessness, and dependency on others that motivates them into action. Unabashed utilitarianism accompanies many of the right-to-die activists’ discussions and I have suggested that this is the main way that they try to eliminate their fears surrounding death. They learn the techniques of self-deliverance or join the organisation *Dignitas* as insurance policies against an unmanaged death. Like Gwen and her P.D.James novels, activists hope that in removing the mystery surrounding the mechanics of dying, it will become knowable to them and they will be able to approach it wilfully and without fear. To be allowed to make their own death decision is also a way in which they can authenticate their lives. For some, how we die gives our life its aesthetic shape. As I discussed in Chapter Five, this is an

aesthetic which challenges Christianity's valorisation of suffering by asserting that suffering in death is meaningless and therefore should be bypassed. Yet underlying this, there is an indication that people who demand a right to an assisted death are inadvertently imbuing suffering with meaning when they infuse it with a fear that is all-consuming in their anticipation of their own death. As Lavi states, the demanded annihilation of suffering becomes medicine's own theodicy (2005:74).

The fears of the anti-lobby, also discussed in Section Two, are by no means all based on religious 'sanctity of life' arguments, but most do stem from consequentialist reasoning. They fear that: the value of life will be degraded; that we will lose the ability to find compassionate solutions to suffering (encapsulated in the motto "kill the pain and not the person"); that it will erode patients' trust in doctors (as well as trust between doctors); and that it will result in patients' not taking responsibility for their own lives, and deaths, by involving a third party in their death decision. The fears of both sides mount all the time, not least because of the political manoeuvrings and posturing of key individuals and organisations within the debate fan the flames of distrust. Accusations of emotivism, peddling of misinformation, instrumentalising of individual's suffering or grief and general foul play (espionage, defamation, backstabbing etc) fly back and forth all the time. Words such as "dignity" and "compassion" are fought over as if they are objects to be owned, such is the symbolic capital attached to them. But, as I sought to show in Chapter Seven, there is mirroring of methods by the two sides in this debate. Both use personal stories to convince the public of the 'rightness' of their cause and the strength of their conviction. Stories of individual suffering now prove more persuasive with a public accustomed to the media sensationalism surrounding celebrity deaths than making foundationalist arguments which speak of uncovering some "universal principle." Such arguments fail to strike a chord in an increasingly pluralistic world. As Brown argues, it's no longer a question of "who we are", as much as a question of "what do we want? (1995:49)"

What we want is increasingly framed as a rights-claim. Section Three of this thesis looked at how we claim rights as a way of seeking recognition in advance of our

death for our suffering, or for the life we have lived. I examined the high-profile legal case of Debbie Purdy and her husband Omar Puente who wanted clarification of the law so that they can better plan the timing and manner of her death. Debbie asserts that it is her human right to be able to die in a controlled manner and to escape unbearable suffering. She seeks the kind of security that Baudrillard (1993) thinks is a myth. The “rationalising dream of absolute control” (Castel 1991:289) over one’s life and one’s body, according to Elias (1994), has gradually come to dominate standards of behaviour and social life in the western world since the 12th Century onwards. The determination to want to control one’s bodily processes, which include the bodily process of dying, has now combined with a post World War II human rights discourse to produce a claim for a ‘human-right-to-die’. The question I sought to answer is not whether such a human rights claim is valid, but rather what is left out of the story when we speak only in terms of ‘rights’. Many commentators argue that such rights-claims foster an exaggerated absoluteness and a hyper-individualism (Glendon 1991:x-xi) which ignores both the grey areas of human interaction as well as the fact that we are all implicated in one another’s lives. In Debbie’s case, she is often the focus of journalists’ discussions of the case, yet it is the legality of *Omar’s* actions which are actually being decided on. Debbie says that while she will take his feelings into account (and he has said that he does not want her to travel abroad to die), it is ultimately her decision as to when she has ‘had enough’. However, it is clearly the support that he has given her in living with her illness which has delayed her making this determination thus far.

Her anticipation of “unbearable” suffering overrides her desire to have her husband at her side. The pain may be more than their relationship can withstand. In reality, this may not happen and she may never feel that she is ready to travel to *Dignitas* to die alone. Many people wanting to make the same journey also believe that this is a decision that they make alone. Yet among the people whom I interviewed who were planning to travel to *Dignitas*, it is clear that their relationships, whether with relatives, friends, a doctor, or with God, affect their death decision just as the decision will unavoidably affect other people. The philosophical adage that “we all die alone” did not hold for my research participants. In Morna’s case, her grown-up

children have prevented her from travelling to Switzerland on several occasions because they did not want her to defy God by committing suicide or risk bringing shame on the family. In Sheila's case, she thought her lack of relatives made her decision to travel abroad to die much easier ("if I had children, my decision might be different" she told me). But even Sheila's death decision implicated others. The friend from her internet support group felt so angry and upset when she heard of Sheila's death (Sheila's notified her by letter, timed to arrive after her death) because she felt it passed judgment on her own quality of life, living as she does with the same disease. These entanglements with other people, no matter whether we view them as an inconvenience, support Levinas's comment that "my solitude is not confirmed by death but broken by it" (1987:74).

In trying to anticipate our future suffering and make plans for our death in advance, we are attempting to limit the "incalculables" to which our lives are subject. We deny the interference of others because this complicates our decision-making and muddies the crystal-clear waters of autonomous action. Our personal sense of dignity and our personal aesthetic are believed by many to be purely subjectively determined: "no one can know anyone else's pain" (Sheila). Yet if this is the case, how can we institute a generally applicable law which legislates against "unbearable suffering" if such a thing can never be objectively determined? This was considered to be a weakness of Lord Joffe's ADTI Bill and continues to be a sticking point in all discussions about who should be entitled to help to die. Should assisted dying only be for people with a terminal illness? Or should it be an option for people with non-terminal but life-limiting conditions like MND or MS? What about people living with long-term mental illness? Or even people like Sheila who suffer from incurable long-term but not in any way life-limiting conditions? Although medicalised assisted dying appears to have mainstream support (if we are to believe the opinion polls⁹⁴), there are still difficulties finding a public forum for certain end-of-life narratives. Learning "self-deliverance" techniques for terminating one's own life, for example, are considered too morbid, too messy, or simply too hands-on for many people. Equally, *Dignitas* is considered "seedy" or "freaky" even by some supporters of legal

⁹⁴ See data in ADTI Bill

reform. Such contradictions within the movement suggest that some experiences are too private or too complex to be regulated by laws which turn the grey of relationships into the black and white of a legal decision. It is the *particularity* of people's suffering which makes it so difficult to objectively verify and to apply the type of general rules which legislation would undoubtedly require.

It was the particularity of people's experiences with life-limiting illness which I discussed in Section One of this thesis, in relation to *Rosetta Life's* work in hospices in the U.K. In contrast with the right-to-die activists for whom death is often anticipated as a technical issue or a "bad encounter" at most, *Rosetta Life* operates from the principle that death is what gives life its ultimate meaning. This I labelled a Heideggerian view of life and death. For Heidegger, it is our 'being-towards-death' – our contemplation of our future non-being - which heightens our sense of our own individuality and gives authenticity to our lives. In my discussion of the work of Chris, a *Rosetta Life* artist-in-residence working in a south London hospice day centre, I described how he encourages patients to think or verbalise themselves into an 'authentic' existence in advance of their death. He encourages explorations of selfhood just at the moment at which that 'self' is about to come to an end. In assuming a Heideggerian understanding of the ultimate significance of death in structuring people's lives, *Rosetta Life* places great emphasis on the possibility of transcendence through the dying process. However, as I showed in Chapter Three, not everyone in the day centre supports or believes in transcendence through the creative arts. Some patients are happy to "take it on the chin", some simply complain about the hospice food, others are content to enjoy non-purposive boredom, and others still to remain silent.

Chris endeavours to elicit testimony and a confession of the 'self' but in order to have these authenticated he has to find witnesses who are receptive to patients' stories. As Derrida writes, testimony can never be guaranteed in advance because it requires to be witnessed (2005:68). However, guaranteeing a receptive audience is difficult in an atmosphere of "jollification" and the careful management of patients' emotions in the hospice day centre. Day centre staff are responsible for the emotional

buoyancy of the whole group and sometimes this prevents individual stories and “incalculables” from emerging. *Rosetta Life* wants to carve an alternate path which involves facing up to the complex emotions arising from our ‘being-towards-death’. But it was my conclusion watching Chris at work making films or writing poetry with patients that he is often caught between the impetus to allow unconstrained narratives to flow and the impetus to make those narratives conform to a redemptive arc focusing on some kind of transcendence. According to Seremetakis, in Inner Mani in Greece the silent death is the worst kind of death, akin to total abandonment. A death needs to be witnessed in order that your “singular and irreplaceable” (Derrida 2005:77) experience is recognised. Witnesses do not necessarily have to understand what they see but they are needed to “stand alongside” (Benner 1996:148). This fear of a silent death or a death without a witness is what motivates the work of *Rosetta Life*. But it is also what encourages its artists to use redemptive or cathartic narratives. They fear that to present someone’s story otherwise would be to risk that audience switching off and turning their back on their role as witness. The *Rosetta Life* artist often finds himself turning unshareable private experiences and suffering into bearable fictions.

The other aspect of the *Rosetta Life* enterprise, which I discussed in Chapter Four, is to use the arts to deliver a public message: that the dying have much to teach the living. The charity projects the view that the dying should be enabled to have a public presence in our death-averse society. They want to help patients turn outwards from the ‘self’ and move from the specific to the general in order that, like the FATE activists, they are connected to something bigger than themselves. They try to create “public geographies” by improvising plays in front of an audience or arranging public debates about the future of hospice care. They try to deprivatise people’s experiences by finding mediums to tell their stories in the public realm. As Arendt states, it is only in the public realm that things can “appear out of the darkness of sheltered existence” (1958:51).

Rosetta Life do not seek to promote “emotive spectatorship”, but neither do they manage to entirely avoid recourse to the intimate register which Sennett argues is a

“tyranny” of the modern age. For Sennett, our world has become “uncivilised” since the compulsion to reveal ourselves to our neighbour became widespread. Why should we feel compelled to have our personal pain or personal stories witnessed in the first place? Arendt and Sennett think there is something very amiss with wanting to force the public to listen to our most private fears and desires. Yet this is the most persistent theme of my thesis: seeking recognition through making our private fears and wishes public. The overwhelming desire of many of my research participants to gain recognition in death involved opening up their life to public scrutiny of one form or another, whether from fellow day-centre patients or from five judges in the House of Lords. My research participants in all my research sites wanted the particularity of their deaths to be recognised while at the same time trying to make Rosetta Stone templates to help to ‘script’ the death of others.

In this thesis, I have examined our relationship with our death and the way in which this relationship is mediated by professional artists, activists, and lawyers. Sontag’s view that “people like to feel they can anticipate their own experience” (2003:98) has resonated with the views my participants shared with me. Anticipation now includes the way people plan for a hastened death, or the way they consciously sculpt a living memorial of themselves before they die. The strength of our desire to anticipate sometimes means that, like Nick, we become the third man at our own funeral. However, the intensity of this anticipation can also increase people’s fears of dying and create unrealistic expectations of what *can* be recognised. There are some things which cannot be filmed, legislated for, or campaigned for. Some experiences resist intellectualisation, rationalisation, or regulation because they are too private, too emotional, or too individually specific. When Arendt (2000:448) wrote: “it is not an individual life, but the world that is at stake” she was denying the individualising trend which had already taken root. Now it is the individual’s life which is at stake, despite the fact that death is common to us all.

APPENDIX 1

Rosetta Life: Using Film to Reflect on and Give Voice to the ‘Good Death’ Experience

ABSTRACT

This research funded by the Economic and Social Research Council will examine how we negotiate the experience of dying with those around us. Anthropological interest in dying has traditionally focused on how *others* die and only recently has become interested in the way in which *we* die or anticipate dying in a western biomedical context. Through combining documentary-making skills with a participatory ethnographic approach, the researcher will align herself with the work and principles of Rosetta Life in order to gain an insight into how we think, feel and act as we face the end of our lives, and how we do that, not in isolation, but with reference to our social networks and extended kin groups. Dying is generally viewed by society as an intensely private experience, but yet it is continually made public through people’s desire to communicate their subjective experience. By sustained immersion in the Rosetta Life Project and the lives of the participants, the research will embed the personal narratives and “voice” revealed through the filmmaking experience in the broader socio-cultural context of how we anticipate death and dying the in U.K. This research has been approved by the University of Edinburgh’s Research Ethics Committee and defended before a rigorous academic panel.

METHODS

This anthropological study will combine the innovative methods pioneered by Rosetta Life through their arts-based engagement with patients, and the ethnographic approach designed by social scientists to help reveal an 'insider's' worldview. I will work closely alongside Chris Rawlence, Head of Production at Rosetta Life, in order to engage with patients in the hospice who have expressed an interest in working on collaborative film projects. The research will be contextualised within the established practice of Rosetta Life at GBCH. Chris Rawlence, who has built up a relationship of trust with staff at the day centre, on the wards, and in the community, over a number of years, will identify potential participants to the research. Chris is very familiar with working practices at GBCH, as well as how to sensitively recruit participants to Rosetta Life projects. He will be responsible for identifying Rosetta Life participants who may be interested in becoming involved in my research. He will give a brief summary of my research to the participant, and if they resister an interest, he will initiate an introduction. Chris will continue to supervise my contact with the participant until I have succeeded in establishing my own relationship of trust and he sees fit for me to work alone. He will continue to supervise the development of the film project and my relationship with the participant(s) until completion of the project.

I will inform Rosetta Life participants that the process of making the films and the stories they choose to reveal about their lives and experiences will form a part of my PhD research. I will explain my research in the terms outlined at the end of this document. Because some patients may be unaware of their status as "terminally ill" or receiving "palliative care," I will refrain entirely from using phrases such as "end-of-life" and "death and dying" unless they are explicitly and persistently used by the patient themselves to describe their situation.

Once participants have agreed to being involved in my research, they will be given a written consent form that specifies the nature of the research and

gives me permission to use and quote participant contributions (see attached Consent Form). All the data that I collect will remain confidential, in that any information imparted by the participants will be solely for the purposes of the specified research. I will also make it clear that participants have the right to remain anonymous. This will involve falsifying names and, if necessary or specifically requested, personal signifiers (such as age, gender, physical characteristics etc) which may enable others to identify them. If I wish to include one of the Rosetta Life films as substantiating documentation for my PhD, I will get the explicit consent from all those people who feature in the film and will make clear to them who will be watching the film (PhD supervisors and Viva panel academics) and why. If consent is denied, I will not include the film when I submit my thesis.

Rosetta Life participants will be informed that they can withdraw consent at any stage prior to completion and for any reason that need not be stipulated. I will reiterate my research intentions and calls for consent at various points throughout my interactions with participants. In the event of the death of a participant during the research process, relatives of the deceased will be kept informed about the course of the research. If consent cannot be properly established (for reasons of capacity or communication difficulties), I will refrain from including the participant in my research. There may be some instances where staff are present and are informally observed or involved in a research encounter between a participant and myself. In these situations, the context and nature of the research will be explained to the staff member who will be offered a modified consent form that indicates his/her willingness to be present during, and potentially contributing (informally), to the research.

I will make my research findings available to all participants at the conclusion of my PhD. While I may use the phrases “end-of life” and “death and dying” in my writing, I will use them sparingly and sensitively in order not to cause offence through their usage. I will write my account with my readership in mind.

Ultimately, my research will be based on mutually-agreed aims and interaction between myself and participants, through the medium of film, as facilitated by Rosetta Life. I seek neither to impose any views on participants, nor to challenge their own views. I will listen to and engage with participants in a sensitive and discrete manner at all times, taking only *their* lead when probing them about their beliefs and perceptions. I will pay close attention to their emotional and physical state and will consult with Chris and other members of staff should I have concerns about their suitability for the project. If any of the participants display signs of distress, I will notify a member of staff immediately.

I will defer to Chris Rawlence of Rosetta Life at all points, as well as to hospice staff and volunteers who have a deep, everyday understanding of patients' circumstances. Throughout the duration of my research, I will be embedded in Rosetta Life, and as such, my first port of call for support will be Chris Rawlence. Chris has many years of experience supporting artists working in hospices, and as an artist-in-residence himself, he is aware of the emotional support required. I will also have support from my academic supervisors in Edinburgh and my peers, also undertaking anthropological research on sensitive topics. I will keep everybody informed as the research progresses and discuss any difficulties which may arise. The results of my study will feed into the evaluation of the Rosetta Life project and will inform planning of future projects.

The main focus for the participants will be the film project. My research will concentrate on their response to the process of creating the film and the impressions I gain of how they are coping with their illness, how this is impacting on their relationships, and how they come to reflect on their past and contemplate the future. A recent BMJ article⁹⁵ argued that often it is

⁹⁵ "Key challenges and ways forward researching the "good death": qualitative in-depth interview and focus group study" (BMJ. 2007 March 10; 334(7592): 521.)

societal taboos around death and dying that inhibits researchers from asking patients to become involved in research. I hope to be able to work alongside Rosetta Life in an unobtrusive way, creating a safe space for hospice users to become involved in end-of-life research while maintaining a primary focus on a creative and collaborative film project.

Explaining My Research to Participants

I am undertaking a research project as part of my PhD looking at the perceptions and experiences of people receiving care in a hospice environment. I am an anthropologist but I am working alongside the charity Rosetta Life in a film-making capacity, because I want to understand how collaborating on film projects in particular helps to structure and give an outlet to people's experiences of illness and hospice care. I will be looking at both the efforts of Rosetta Life to facilitate patients' expressions of wishes and feelings and at patients' general experiences of being in a hospice environment.

I would like to learn about your individual reflections and insights and about how you think your relationships with your family and friends might have been affected by your illness. I will be working alongside Chris Rawlence for the next few months and over that time I hope to gain your trust so that you will feel able to share your story with me. Hopefully, we can then turn the collaborative experience of making a film together into something that can be beneficial and empowering to you and to others.

**GREENWICH AND BEXLEY COTTAGE HOSPICE
RESEARCH APPLICATION FORM**

Name	Naomi Richards	Job Title	Social Anthropology PhD Researcher
Department/ External party contact details	Tobias Kelly, School of Social & Political Studies, The University of Edinburgh, Adam Ferguson Building, Edinburgh, EH8 9LL toby.Kelly@ed.ac.uk		
For external applicants – please also record name of GBCH contact	Christopher Rawlence, Head of Production, Rosetta Life chris.rawlence@rosettalife.org		
Title of Research Project	“Rosetta Life: Using film to reflect on and give voice to the ‘Good Death’ Experience”		
Proposed Start/ Completion Date	July-December 2007		
Briefly describe the purpose of the study	The research will examine the role and efficacy of the Rosetta Life Project in the lives of its participants at the hospice. It will explore how the personal narratives and “voice” revealed through the Rosetta Life filmmaking experience relates to the broader socio-cultural context of how we anticipate death and dying in the U.K. This study will thus provide an insight into how we think, feel and act as we come to terms with terminal illness and how we do this not in isolation but with reference to our social networks and extended kin groups.		
Rationale for Study Including background literature	<p>The experience of dying in the U.K. has generally been under-theorised (Kellehear 2007). This embedded study of the work of one arts-based charity aims to contribute to the Anthropological/Sociological literature on death and dying in the U.K. The study will also make a vital contribute to the evaluation of the Rosetta Life project.</p> <p>Literature:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Fabian, J. 1973. "How others die - Reflections on the anthropology of death" in A. Mack (ed) <i>Death in American Experience</i>. New York: Schocken. <input type="checkbox"/> Kaufman, S. R. & Morgan, L.M. 2005. "The Anthropology of the Beg and Ends of Life". <i>Annual Review of Anthropology</i> 34:317-41. <input type="checkbox"/> Kellehear, A. 2007. <i>A Social History of Dying</i> Cambridge: Cambridge University Press <input type="checkbox"/> Kendall, M., Harris, F., Boyd, K., Sheikh, A., Murray, S.A., Brown, D., Mallinson, I., Kearney, N., & Worth, A. 2007 “Key challenges and ways forward researching the “good death”: qualitative in-depth interview and focus group study” <i>British Medical Journal</i> doi:10.1136/bmj.39097.582639.55 		
Methodology	<p>Participant-Observation & Ethnography</p> <p>The researcher will be directly involved in a Rosetta Life project at the hospice – from conception through to evaluation. She will establish personal relationships with the project’s participants, enabling them to give voice to their own thoughts and emotions. She will endeavour to maintain an unobtrusive presence, observing interactions, and taking the lead from the participants</p>		

	<p>themselves. The researcher seeks neither to impose any views on participants, nor to challenge their own views. She will pay close attention to their emotional and physical state and adapt the project accordingly. She will be working under the auspices of Chris Rawlence at all times. She will also commit to working within the Rosetta Life operating ethos.</p>
Sample	4 people
Method of Analysis	<p>Qualitative analysis of ethnographic data, using InVivo software package (to analyse recurrent themes). Link ethnographic data to wider theoretical debates/ ideas about death and dying within Anthropology and the Social Sciences more generally.</p>
Ethical Approval	<p>(If received, enclose; if applied for, details of timescale)</p> <ul style="list-style-type: none"> <input type="checkbox"/> Ethical Clearance from University of Edinburgh, September 2006 (see attached confirmation letter). <input type="checkbox"/> Submitted to Clinical Governance Committee Meeting in June
Proposed Dissemination	<p>The data collected will be used for the researcher's PhD Thesis and potentially for publications thereafter. Copies of the thesis and all published work will be given to all participants and to GBCH. The Hospice & Rosetta Life will be fully credited in the research and in all publications. Rosetta Life may also choose to use the findings for benchmarking purposes.</p>
Funding	PhD funded by the Economic and Social Research Council
Sponsor/ Other Organisations involved in the project	See attached letter from PhD Supervisor, Tobias Kelly at the University of Edinburgh

APPENDIX 2

MY JOURNEY WITH A LIFE-LIMITING ILLNESS – Consent Form

My name is Naomi Richards and I'm doing a research project at Greenwich & Bexley Cottage Hospice with people who are living with life-limiting illness. Part of my research involves working alongside Chris Rawlence of *Rosetta Life*, helping hospice users bring their personal stories to life through video, photography and poetry. In my research, I would like to learn about your experience of the hospice and to ask you about the journey you are on, how illness has affected your attitude to life, how things may have changed – for better or worse, and how you now see yourself. The idea is to get a picture of what it's like to be living with a life-limiting illness and, by putting some of your experiences on to video and into a written report, to help others.

I would like you to contribute to my research but in order that you may do so you will need to sign a consent form. Among other things, this emphasises the confidentiality of your contribution, gives you the option of anonymity and the right to withdraw at any stage. Here it is:

I consent to Naomi Richards using my contribution to her research PhD "My Journey with Life Limiting Illness".

- I understand that my contribution will remain CONFIDENTIAL in that any information imparted by me will be solely for the purposes of the specified research.
- I DO/DO NOT wish to remain ANONYMOUS (please delete as appropriate)
- I understand that I have a right to withdraw from the research at any point for any reason. In which case my prior contribution MAY/MAY NOT (please delete as appropriate) be used.
- I agree to tell my next of kin about my involvement in the research (Please tick)
- I understand that Naomi Richards will offer me copies of the research on completion.
- I CONSENT/ DO NOT CONSENT (please delete as appropriate) to any footage that we film together being submitted as part of the research.
- I understand that Naomi Richards will show me all the footage we film together, and should I not like some of the footage, she will not use it in a film and will agree to dispose of it
- Each participant will be given a DVD copy of their filmed contribution.

Signed:.....

Date:.....

Address:.....

APPENDIX 3

INTERVIEWEES IN FAVOUR OF A CHANGE IN LEGISLATION TO PERMIT SOME FORM OF MEDICALLY ASSISTED DYING

NAME	POSITION, ORGANISATION	TYPE OF CONTACT	DATE OF CONTACT	DURATION OF CONTACT	HOW RECORDED?
Rev. Paul Badham	Professor of Theology and Religious Studies at the University of Wales	Email, informal face-to-face conversation	February 2008	N/A	Notes After
Jo Cartwright	Human Rights Officer, Dignity in Dying	Face-to-face interview	October 2007	40 mins	Digitally
Chris Docker	Head, EXIT (Scotland)	Face-to-face interview (x2)	November 2006 & November 2008	1 hour, 1 hour	Notes During
Libby Drake	Former Secretary, World Federation of R-t-d Societies	Face-to-face interview	November 2007	1 1/2 hours	Notes During
Evan Harris	Lib Dem MP (former GP)	Face-to-face interview	July 2007	15 mins	Digitally
Joel Joffe	House of Lords Life Peer, sponsor of ADTI Bill	Face-to-face interview (x3), phone conversations	January 2007, April 2007, December 2007	1 hour, 3 hours, 40 mins	Notes During
Elaine Murphy	House of Lords Life Peer, Professor of Psychiatry of Old Age	Face-to-face interview	May 2007	40 mins	Notes During
Ludwig Minelli	Founder & Chief Executive, Dignitas	Informal face-to-face conversation	December 2007	15 mins	Notes After
Sophie Pandit	Daughter of Anne Turner	Face-to-face interview	September 2007	45 mins	Digitally
Jeremy Purvis	Lib Dem MSP	Face-to-face interview	December 2006	40 mins	Digitally
Debbie Purdy	Activist who has brought legal case	Face-to-face interview, phone conversations	February 2008	1 hour 45mins	Digitally
Hanne Stinson	Chief Executive, British Humanist Association	Face-to-face interview	February 2007	1 hour	Notes During

I formally interviewed five committed members of *Friends at the End* (FATE), two more than once, but these interviewees remain anonymous. I also had informal conversations with numerous international activists at the European and World Right-to-Die Conferences I attended, including Sarah Wootton, Chief Executive of Dignity in Dying. I also had long (over 1 hour) conversations (recorded via note-taking) with two people affiliated to Dignity in Dying who remain anonymous.

INTERVIEWEES OPPOSED TO A CHANGE IN LEGISLATION TO PERMIT SOME FORM OF MEDICAL ASSISTANCE TO DIE

NAME	POSITION, ORGANISATION	TYPE OF CONTACT	DATE OF CONTACT	DURATION OF CONTACT	HOW RECORDED?
Jane Campbell	House of Lords Life Peer; Chairperson, Not Dead Yet U.K.	Written Correspondence	October 2007	N/A	N/A
Elsbeth Chowdharay-Best	Honorary Secretary, ALERT	Face-to-face interview	February 2007	45 mins	Digitally
Alison Davis	No Less Human	Phone interview	February 2007	40 mins	Notes During
Jim Dobbin	MP, Chair of All-Party Parliamentary Pro-Life Group	Face-to-face interview	April 2007	40 mins	Digitally
Ilorra Finlay	House of Lords Life Peer, Palliative Care Consultant	Face-to-face interview	May 2007	1 hour 15 mins	Digitally
Rob George	Palliative Care Consultant	Face-to-face interview (x 2)	April 2007, August 2007	2 hours, 1 hour	Digitally
Brian Iddon	Labour MP	Face-to-face interview	March 2007	40 mins	Digitally
David Jeffrey	Former Palliative Care Consultant	Written Correspondence	March 2007	N/A	N/A
Mary Knowles	Organiser, First Do No Harm	Face-to-face interview	February 2007	1 hour	Notes During
Anthony Ozimic	Political Secretary, Society for the Protection of Unborn Children	Face-to-face interview	February 2007	1 hour 25 mins	Digitally
John Walton	House of Lords Life Peer, Neurologist	Face-to-face interview	November 2007	1 hour	Notes During

OTHER INTERVIEWEES NOT (DIRECTLY OR INTENTIONALLY) RELATED TO ASSISTED DYING DEBATE

NAME	POSITION, ORGANISATION	TYPE OF CONTACT	DATE OF CONTACT	DURATION OF CONTACT	HOW RECORDED?
Julia Abrey	WithersWorldwide (law firm), specialising in Probate, Succession and Post-Death Planning	Face-to-face interview	June 2007	40 mins	Notes During
Carolyn Black	Humanist Funeral Celebrant	Face-to-face interview	March 2007	1 hour	Notes During
Deborah Bowman	Senior Lecturer in Medical Ethics & Law, St George's University	Face-to-face interview	November 2007	1 hour	Notes During
Kenneth Boyd	Professor of Medical Ethics, Edinburgh University	Attended his "Personhood & Rights" tutorials in 2006. Sustained contact over 6 weeks.	January – March 2006	12 hours	Notes During
Saimo Chahal	Bindman's (law firm), specialising in Public Law & Human Rights	Face-to-face informal meeting, volunteering in her offices on Purdy case	November- December 2007	30 mins, 2 days	Notes After
Rosa Curlin	Assistant Solicitor for Richard Stein, Human Rights Department, Leigh Day & Co Solicitors	Face-to-face meeting	April 2007	40 mins	Notes During
Glennys Howarth	Director & Founder of the Centre for Death and Society, University of Bath	Face-to-face meeting	March 2006	1 hour	Notes During
Tom Gordon	Association of Hospice and Palliative Care Chaplains, Chaplain, Marie Curie Centre, Edinburgh	Face-to-face interview	March 2008	1 hour 20 mins	Notes During
Sarah Holmes	Medical Director, Marie Curie Hospice, Bradford	Face-to-face interview	March 2008	40 mins	Notes During
Juila Lawton	Author "The Dying Process"	Face-to-face interview	Jun 2006, April 2008	40mins, 40mins	Notes During
Penny Letts	Key architect/author of Mental Capacity Act (England &	Face-to-face interview	August 2007	1 hour 15mins	Digitally

	Wales) 2005				
Denzil Lush	Senior Judge (formerly Master) of the Court of Protection	Face-to-face meeting	June 2007	40 mins & contact over 2 days of shadowing at the Office of the Public Guardian	Notes After
Pauline Smith	Midlands End of Life Care Strategy Lead	Phone conversation x2	Sept 2007, Jun 2008	30mins, 30mins	Notes During
Beverley Taylor	Senior Lawyer at the Office of the Official Solicitor and Public Trustee	Phone conversation & face-to-face meeting	February, July 2007	15mins, 40mins	Notes after
Toby Williamson	Mental Capacity Act Lead at the Mental Health Foundation & Previously Co-Chair of the Making Decisions Alliance	Face-to-face interview	October 2007	1 hour	Digitally

PUBLIC EVENTS ATTENDED

NAME OF EVENT	WHEN	WHERE	SPEAKERS
Second Reading of Palliative Care Bill	February 2007	House of Lords	Bill introduced by Baroness Finlay.
Lent Lecture Series, Kings College: "Palliative Sedation or Euthanasia"; "End of life Decisions in U.K. Medical Practice"; "A Comparative Analysis of Regulating Active Voluntary Euthanasia"; and "Vegetative State: Legal & Ethics Dilemmas"	February 2007	Kings College, London	Dr Nigel Sykes, Medical Director, St Christopher's Hospice; Professor Clive Seale, Social of Social Science & Law, Brunel University; Samantha Halliday, Senior Lecturer in Law, Liverpool University; and Professor Keith Andrews, Director of the Institute of Neuropalliative Rehabilitation
"Physician assisted death — a good death?"	October 2007	Royal College of Physicians, Edinburgh	Professor Kenneth Boyd, Professor Kenyon Mason, Rev./Dr. Ewan Kelly, Sheila McLean, Dr. David Jeffrey, Professor Roger Higgs, Jeremy Purvis, Lord Phillips
Right-to-Die Europe Biennial Conference	12-14 th October 2007	Strasbourg, France	Numerous

Dignity in Dying's Annual General Meeting	October 2007, October 2008	London	DID board, members, Esther Rantzen
Ludwig Minelli Talk	December 2007	Conway Hall, London	Ludwig Minelli, Founder, <i>Dignitas</i>
"Human Dignity: What is it, and how should we respect it?"	January 2008	Scottish Council on Bio-Ethics, Edinburgh	Professor Kenneth Boyd, Professor Graeme Laurie, Dr Mary Ford, Professor Mona Siddiqui
Compassion in Dying's All Party Parliamentary Group	November 2007	House of Lords	Members of the all-party group
World Federation of Right-to-Die Societies Conference	31 st October – 2 nd November 2008	Paris, France	Numerous
NuTech Sub-Group Meeting	Nov 1 st 2008	Paris, France	Organised by Derek Humphry
UCL & Bindman Debate: "To be or not to be: a decision for the individual or the state?"	June 2009	University of Central London, London	Ken Macdonald, former Director of Public Prosecutions, Katherine Araniello, disability rights campaigner, Rob George, Evan Harris MP

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