

# **Who joins a UK right to die society and why?**

***A study of members of Friends at the End  
(FATE)***

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Thesis submitted to meet the requirements of the  
degree of Doctor of Philosophy

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## **Declaration**

I confirm that the work presented in this thesis is entirely my own.

Signed: \_\_\_\_\_

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My family and friends have experienced long periods of neglect. I thank them all for their forbearance, help and encouragement during the past five years.

Finally, I remember my father, Dr Robert Beattie (1908 -1982), to whom this thesis is dedicated.

# Abstract

The thesis presents quantitative and qualitative thematic analyses of a postal survey and interview study of members of Friends at the End (FATE), a Glasgow-based right to die society. This is one of the first UK studies aimed toward filling a gap in knowledge about who joins a UK right to die society, and their reasons for doing so. The thesis attributes responsibility for the right to die movement's continuing existence to contemporary socio-cultural norms of individualism and self-determination in promoting desire for autonomy and choice surrounding dying and death. It shows how and why a distinct group of predominantly older and higher social class individuals, 22% of whom have health and social care professional backgrounds, have decided to join FATE. The right to die movement is shown to be a new social movement concerned with health, ageing and death activism that challenges contemporary biomedical models of managing dying and death. The thesis shows how ageing, social class, religiosity, socio-medical constructs of dying, risk management and altruism toward others all contribute toward the ongoing existence of pro-right to die attitudes and beliefs. It also shows how personal fears about the manner of future dying, both physical and existential are frequently informed by personal experiences, identified as critical factors in decisions made to join the movement. FATE exists in a culture in which assessing risk has become very pervasive, and joining FATE is, for many members, a risk-avoidance strategy, given their concerns that future dying and death may be unpleasant. Conditional desire for hastened death is also shown to be informed by desire to avoid placing burden on others, a form of reciprocal altruism in which hastened death benefits both the dying person and family members as well as society as a whole.

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# Abbreviations and definitions

United Kingdom	UK
Friends at the End	FATE
Physician-assisted suicide	PAS
Do not resuscitate	DNR

Health and social care professionals      HSCPs: an umbrella definition for anyone who had worked professionally with patients in health or social care environments. The definition covers individuals with backgrounds in medicine, nursing, dentistry, veterinary surgery, pharmacy, physiotherapy, occupational therapy, speech & language therapy, psychology and psychotherapy and social work.

Scottish member of parliament	SMP
The Voluntary Euthanasia Society	VES
The Voluntary Euthanasia Society of Scotland	VESS

Euthanasia (euthanatos<sup>1</sup>)      Refers to the intentional killing (voluntary or involuntary), by act or omission, either as part of a person's end of life medical care or as a 'mercy killing' performed by a non-medical person

(Physician) Assisted suicide      Death by suicide with assistance from another person who may or may not be a physician

Hastened death      Death brought about through euthanasia or assisted suicide

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<sup>1</sup> From the Greek 'good death' (Kemp,2002).

# **Who joins a UK right to die society and why? A study of members of Friends at the End (FATE)**

## **Chapter 1: Introduction and background**

As a retired healthcare professional and now a research student in my 8<sup>th</sup> decade of life, I have held a long term interest in the right to die movement, primarily due to my own professional and personal experiences of dying patients, family members and friends, not all of whom were fortunate enough to avoid intense and prolonged suffering at the end of their lives. In the UK today, despite the undoubted excellence of palliative care services, and their phenomenal achievements in improving peoples' dying experiences, my own experiences have shown me that palliative care services cannot always prevent acute and prolonged suffering in their patients, nor can the principles of palliative care reliably reach out to all dying persons who would benefit from them in the UK. Also, systems failures can result in catastrophic experiences for patients receiving the best of end of life care and their family members, despite palliative care packages being in place. Palliative end of life care is neither currently universally available in the UK, nor is likely ever to become so due to resource limitations, although the Department of Health End of Life Care Strategy (2008) aims to make quality end of life care more widely available and work toward this aim is ongoing. Currently many people die of medical conditions not eligible for hospice care and although initiatives to train as many other health service staff as possible are in place, logistically this is unlikely to become a fail-safe system available to all dying persons who need it.

Although real risks of experiencing lengthy periods of suffering during prolonged dying do exist, and despite the right to die movement having been campaigning over several decades for legislation that offers the option of hastening death in specific circumstances, little empirical research has been focussed on the reasons why people join this movement. Therefore this thesis seeks to address this gap in knowledge by reporting on a study of members of Friends at the End (FATE), one of three main UK right to die societies that collectively, with other smaller groups, form a UK-based branch of the world wide right to die movement. The topic has been studied in order to address this relative absence of studies of UK right to die society membership and to determine what socio-cultural influences are driving the UK right to die movement, in

particular, FATE. The thesis offers an account proposing how contemporary culture, values and practices are implicated in the movement's continuing existence. The overriding aim of the study is to develop a sociological interpretation for this contemporary phenomenon and how it can be located within a framework that draws on the work of social theorists in order to expand current knowledge about who joins FATE, the underlying reasons people cite for joining, and how and why their pro-right to die views have been acquired. Apart from a small study conducted in the 1980s (Lam,1982), and more recently, an ethnographic study of older age right to die activism among members of FATE (accepted for publication) (Richards, 2011). Studying this topic is relevant as it proposes a rationale for how particular social conditions, values and practices are implicated in driving the right to die movement's continuing existence and expansion in the UK. Gaining a sociological understanding of the right to die phenomenon opens up a hitherto barely existent debate about how customs, beliefs, values and practices surrounding contemporary dying and death in the UK have the capacity to harm as well as benefit dying persons, their families and the wider society. A sociological understanding of why people join a right to die society, will, I hope, encourage greater attention to be paid to the question of how societies' values and customs might best evolve over time to modify those endemic beliefs and practices that inadvertently have potential to cause harm. To this end, the study draws on literature from philosophy, politics, economics and moral ethics to provide a broader palette from which the background to the sociological interpretation offered in this thesis is drawn.

In order to address this under-researched area, Friends at the End (FATE), a smaller right to die society with circa four hundred members and based in Glasgow, was approached and their agreement was gained to allow their members to be invited to participate in this study.

## **1. Aims and objectives of the study**

The study aims to develop a detailed understanding of the socio-demographic profile, beliefs and motives for joining one of the three oldest UK right-to-die societies, Friends at the End (FATE). It aims to develop a sociological interpretation of the findings through constructing an account of the complex social and other factors that have influenced the rise and continuing existence of the right to die movement. As the study is located in the medical sociology field, literature is drawn from sociology, medical

research, and other relevant disciplines in order to enhance present knowledge about why FATE, as one member of the world wide right to die movement, should exist in UK society today. The study's key objectives are:

- To gain a detailed understanding of individuals' motives for joining the right to die society FATE;
- To construct an account of the complex social and other factors influencing the rise of the right to die movement, and why individuals choose to join it;
- To add to existing knowledge and understanding about the right to die movement.

The study aims to add to existing knowledge and understanding about right to die society members' beliefs and values through addressing the following research questions:

1. Who joins FATE and why?
2. What influences are responsible for shaping people's personal beliefs and motives for joining?
3. To what extent might similarities and differences exist between FATE members and members of the US Hemlock Society?
4. Can right to die society membership be a product of reflexive formation of self-identity, characterised by risk profiling, risk avoidance and agency, that more generally typifies self identity in late modernity?
5. Is anticipated future suffering a significant influencing factor in decisions made to join FATE?
6. Is providing care for, or close association with, terminally ill individuals implicated in influencing pro-right to die attitudes?
7. Do parallels between terminally ill patients' reasons for anticipating a need for "requested death", or for requesting assistance to die and FATE members' reasons for joining exist?
8. Can religiosity co-exist with positive attitudes toward a legal right to die?
9. Is altruism implicated in decisions made to join FATE?
10. Might socio-economic matters such as costs/benefits be implicated in decisions to join FATE?

I hypothesise that:

1. Right to die societies and why people join them are products of the values and practices surrounding dying and death in those societies in which they exist.
2. Reflexive self-identity is implicated in pro-right to die attitudes
3. Individuals who join FATE are likely to have personal experiences of caring for terminally ill others
4. Religiosity can co-exist with commitment to right to die ideology
5. Altruism is implicated in decisions made to join a right to die society
6. Socio-economic factors are involved in decisions to join FATE

## **2. Background to the study**

The background to this study rests in how contemporary pro-right to die attitudes evolved as part of a spectrum of preceding attitudinal fluctuations toward suicide across diverse societies and many centuries; “historical strata laid down by culture[s] in motion “ (Williams,1990), from which the roots of the current UK right to die movement have been nurtured.

The “good death” (euthanasia<sup>2</sup>) has been a central concept in diverse societies; rituals of dying, causes of death, and duration of the dying process having changed over many centuries (Kellehear, 2007). Cultural values and practices associated with concepts of “good death” are dominated by the values of communities in which they occur and social acceptance of suicide as a good death has waxed and waned over centuries. Suicide was, for many people in the past, a means for achieving a good death that conformed with notions of idealised death (Emanuel, 1994). In ancient Greece and Rome, good death (euthanasia) was conceptualised as a gentle, happy, noble or heroic event; seen as a fitting end to lives (Van Hoof, 2004). Seneca stated a preference for suicide rather than a death characterised by prolonged suffering and Pythagoras, Plato and Aristotle all recorded approval of suicide in the face of incurable disease, but argued against its practice for other reasons (Kemp, 2002). Sanctity of human life was not always a moral consideration in times in which motives for suicide were not exclusively concerned with suffering caused by diseases (Dowbiggin, 2005).

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<sup>2</sup> Greek: ‘eu’ = good; ‘thanatos’ = death

Suicide is known to have been publicly acclaimed by certain factions such as the Stoics who widely endorsed suicide (Durkheim, 1897; Kemp, 2002), and some, but not all, philosophers and scholars of that period (Dowbiggin, 2005). Suicide was also socially constructed as good death in earlier western cultures outside of the graeco-roman world (Durkheim, 1897). But resistance toward pursuit of good death through suicide arose through the advent of the Hippocratic Oath which proscribed physician-administered euthanasia as the good death, although Dowbiggin (2005) avers that many physicians in ancient Greece and Rome ignored its injunctions.

When Christianity came into being, Kemp (2002) notes that Stoic philosophy of good death through suicide still persisted throughout the first two centuries of Christianity; Christian prohibition of suicide on the grounds of sanctity of life not becoming absolute until St Augustine, although Minois (1995) claims that absolute prohibition of suicide became established in the Roman Empire prior to Augustine. Historically, the good death in mediaeval times was defined by religious doctrine and concern for the soul. (Strange, 2009) with Christian moral values proscribing suicide as sinful and abhorrent (Woodman, 1998). Hastening death by suicide continued to be considered an unacceptable practice in the Christian west prior to the 1870s (Stolberg, 2007) although in 16<sup>th</sup> Century England, Sir Thomas More advanced a case for suicide in “pestilent and painful disease” in which life was “but a torment” (Kemp, 2002), portraying suicide as part of an idealised world in his ‘Utopia’ (Woodman, 1998). In 16<sup>th</sup> and 17<sup>th</sup> Century England, references to hastening death in the face of suffering started to appear in works by prominent intellectuals such as More, Bacon, Donne and Hume (Emmanuel, 1994). Leading thinkers in the 18<sup>th</sup> Century either justified suicide or “attacked the legal punishments for suicide as barbaric, unjust and useless” and over the 19<sup>th</sup> Century, suicide became widely accepted by Christians as sinful and the good death became, especially for the evangelical movement, one to be endured in the interests of repentance and salvation (Dowbiggin, 2005). At the same time, the 19<sup>th</sup> Century brought improved hygiene, advances in public health, housing and medicine (Kellehear, 2007) heralding changes in lifespan. Objections to Christian doctrine on euthanasia arose again in the 1870s, attributed by Kemp (2002) to having originated the modern euthanasia debate.

By the early part of the 20<sup>th</sup> Century not only had the German eugenics movement arisen but a renewed interest in euthanasia became evident in England, in part through

certain individuals' sympathies with the eugenics movement but predominantly due to concerns about 'slow and painful death' for which, through legalisation, euthanasia could be offered as "an act of mercy" (Kemp, 2002). The British right to die movement first came into being as an organisation with the foundation of the Voluntary Euthanasia Legalisation Society in 1935 (Kemp, 2002). This society continues to the present day, now under the name of Dignity in Dying and as the largest right to die society in the UK, campaigns for legalisation of assisted dying for terminally ill people. Since its inception two further British right-to-die societies were formed; Scottish EXIT<sup>3</sup>, founded in 1980 as a breakaway organisation from Dignity in Dying (then known as the Voluntary Euthanasia Society), and Friends at the End (FATE), founded in 2000. More recently (2009) a new right to die organisation, the Society for Old Age Rational Suicide (SOARS)<sup>4</sup>, was formed with the main objective "to begin a campaign to get the law eventually changed in the UK so that very elderly, mentally competent individuals, who are suffering unbearably from various health problems (although none of them is "terminal") are allowed to receive a doctor's assistance to die, if this is their persistent choice".

Over past centuries, duration of dying and manner of death varied between civilisations and societies. Stone Age people tended to die suddenly at an early age through violent attacks by animals and humans (Kellehear, 2007). Smallpox, typhoid, cholera, measles, whooping cough and diphtheria were major causes of death prior to the advances in science and medicine providing the ability to treat such diseases; changed patterns of mortality, dying and death have increased longevity during the twentieth and twenty first centuries, accompanied by longer dying trajectories (Seale, 2000). All these factors are likely to have modified older concepts of "good death", as degenerative diseases in older age have now replaced infections as the most common causes of death (Seale, 1998). Preferences for dying have changed in parallel; medieval persons fearing sudden death that prevented proper spiritual preparation while in modernity swift, pain-free deaths avoiding burden to others are more often preferred (O'Connor et al, 2010).

Today "good death" has become politicised (Kellehear, 2007) with changing attitudes and expectations for a good death now reflecting the need to negotiate extended dying processes. Desire for hastened death through suicide, latterly in the 20<sup>th</sup> and 21<sup>st</sup>

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<sup>3</sup> <http://www.euthanasia.cc/>

<sup>4</sup> [www.soars.org.uk](http://www.soars.org.uk)

centuries through voluntary euthanasia or physician assisted suicide, is a product of contemporary social environments (Durkheim, 1897; Walter, 2003). Increased life expectancy in the UK has had a positive effect on numbers of years with good health but also a negative effect on length of time people can expect with poor health and disability (Office for National Statistics, 2009). Negative consequences of increasing longevity accompanied by extended duration of chronic and terminal illnesses form a background to this study; fears about future poor quality of life, prolonged suffering and anticipation of opportunities for perceived adverse ways of dying are proposed to lie at the heart of right to die activism. The material realities of “the ageing, diseased and dying body exercise a determining influence on participation in culture” (Seale, 1998); voluntarily opting out of culture due to bodily disintegration in an ageing/dying paradigm is likely to inform pro-right to die beliefs. Death in the 21<sup>st</sup> Century has become “confessional” (Seale, 2004), institutionalised and managed (Kellehear, 2007); medically controlled within a dominating palliative care model (Howarth, 2007) and culturally orchestrated in ways that expect conformity with biomedical and ethical contemporary beliefs and values. Right to die society membership may constitute an act of opposition toward such cultural practices.

Media images of dying with life threatening illnesses portray dying as a heroic and personally transforming fight (Seale, 2004) that help influence cultural expectations surrounding dying and death. But contemporary dying and death have become hidden from public view with the real experience of death removed from everyday sight (Brown, 2008). The contemporary cult of bodily youthfulness is imbued with fear of bodily ageing, in association with the growth of anti-ageing consumerism in which “the human body is endlessly de-constructed and re-constructed in the interests of retail capital” (Gilleard and Higgs, 2000). In such a culture of commercialisation and perpetuation of youthfulness, ageing serves to focus attention on a diminishing future, and what it may hold before death occurs. Receding ability to engage in habitual functional and social life in older age can change older adults’ views about hastened death as physical, mental and social agency declines, leading to heightened levels of fear of the dying process (Cicirelli, 2002).

As consensus is lacking over “a strict biological definition of dying” (Kellehear, 2009), in order to acknowledge the potentially lengthy process of dying in modernity, dying is conceptualised throughout this study based on Brown’s (2008) biological model of



dying as a lengthy process of cumulative and irreversible bodily disintegration (at molecular, cell, organ and system levels) taking place over years; a “vast continuum of dying processes” (Hester, 2010) which, due to greatly increased life expectancy, more generally gathers momentum in older age. As Walters (2003) observes, a dying person may have to live with dying for decades, with physical patterns of dying fluctuating between cycles of (relative) wellness and decline (Kellehear, 2009).

Friends at the End (FATE)<sup>5</sup>, the subject of this study is a small Glasgow-based right to die society founded in the year 2000 as a result of a migration of members from another right to die society. FATE is a member of the worldwide Federation of Right to Die Societies; a global social movement uniting 44 right to die organisations across 24 countries. FATE is both a campaigning organisation and one which provides information and advice to members seeking a pragmatic solution to suffering in dying. FATE campaigns for a legal option to hasten death in Scotland through the media and through Scottish members of Parliament. Unlike Dignity in Dying, FATE campaigns for assisted dying for suffering older people with multiple pathologies in addition to persons with end stage terminal illnesses. Regular meetings are held for members with presentations on a variety of topics relevant to members’ interests. Advice is made available to members on living wills, Do Not Resuscitate (DNR) forms and information about NHS Trust Living Will and DNR policies. FATE also offers an advice and counselling service “for those suffering distress caring for the dying” and provides information and advice for individuals seeking the option of access to Dignitas, as a means of hastening death in the absence of a legal means of for hastening death in Scotland.

FATE’s stated aims<sup>6</sup> are to:

- Campaign for a change in the law relating to assisted suicide and euthanasia.
- Promote knowledge about end of life choices and dignified death.
- Support carers and those suffering in pain and distress, especially at the end of life.
- To advance the education of health professionals in the field.
- To support research in this sphere.

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<sup>5</sup> <http://www.friends-at-the-end.org.uk/>

<sup>6</sup> <http://www.friends-at-the-end.org.uk/about-friends-at-the-end.html>

This outline of the historical background to the right to die movement, and some of the concepts likely to be associated with right to die society membership forms the background to this study.

The contribution to knowledge offered by this thesis is made through presenting a new theory-based framework within which right to die society membership can be understood in the context of the societies in which they exist. The thesis builds on knowledge gained from previous right to die society studies, and shows how social, political and moral norms in contemporary western societies, and in particular, the UK, help to nurture the continuing existence of one specific, thriving, right to die society, FATE. This thesis has sought to explain how current social conditions create a climate in which, for persons of older age and higher social class, the right to die movement offers an opt-out route for individuals who do not wish to passively accept future adverse experiences in dying which they believe they could encounter under the care of UK health and social services. Rather, they wish to access means to achieve what they perceive to be an ideal mode of dying - a hastened death option in the face of an uncertain future in the hands of care services.

During the course of this study, I have learned a new vocabulary and expanded my knowledge and skills in research methodology and in understanding of the complex web of influences exerted by societies and cultures on human life experiences within the social world. Through seeking to construct a theory-based argument for the existence of right to die societies, I have also become very aware of the benefits of drawing on cross-disciplinary research such as medicine, psychology and economics, in order to enrich the construction of a comprehensive sociological understanding of the world according to FATE members.

## Chapter 2: Literature Review (Part A):

### Theories, Attitudes and Beliefs

The literature review presents a rationale for the continuing existence of the UK branch of the worldwide right to die movement, specifically one of its member organisations Friends at the End (FATE), why people choose to join FATE, and how this can be understood in the context of the characteristics and values of contemporary UK society and culture. Right to die society membership represents a fundamental question about the extent to which human ability, or desire, to adapt to and endure the complex end of life dying scenarios played out in an increasingly medicalised and extended version of ageing can be expected to continue unchallenged due to “disequilibrium between external discussions and controls and the internal definition-making power of medical practice” (Beck, 1992). It is not within the scope of this literature review to rehearse the arguments for and against legalisation of hastened death through such means as euthanasia or physician-assisted suicide, but primarily to focus on social and cultural factors implicated in creating a climate in which some individuals might perceive a need to join the right to die movement, in particular, FATE.

As a new social movement, the worldwide right to die movement campaigns for a legal right for self-determination on the manner and timing of death in specified circumstances for citizens of countries across the world. Forty four right to die organisations from 25 countries are members of The World Federation of Right to Die Societies, founded in 1980. This is an umbrella organisation that works to “secure or protect the rights of individuals to self-determination at the end of their lives”. Its stated mission is to:

- Disseminate current information and educational materials about voluntary euthanasia, physician-assisted dying, other right-to-die issues, and related matters of interest;
- Promote co-operation and liaison among our member societies;
- Facilitate international conferences on dying and death;

- Provide assistance, where requested, to groups and individuals interested in establishing similar societies in countries where such societies do not currently exist; and
- Respond to requests by interested groups, scholars, and individuals for information about right-to-die issues.

It is member societies of this organisation that collectively form a new social movement through seeking to challenge perceived oppressive sociopolitical and religious prohibition of choice in the timing and manner of death, under specified conditions, in those countries in which right to die societies exist. Thus, membership of FATE affiliates its members with the global movement. As a new social movement formed in the 20<sup>th</sup> Century, it is argued that social conditions implicated in informing individuals' reasons for joining the right to die movement include contemporary medical practices arising through medicine's relentless drive to develop and refine technologies to prolong human lives, a technological imperative that "shapes the goals-on-the-ground of medical practice and frames its gaze" (Kaufman, 2000). Other factors likely to play some part in influencing decisions to join the right to die movement include personal attributes of the reflexive self in modernity, individualism and expectations of choice and control. Suffering experienced during ageing, terminal illnesses, dying and death is proposed to be an important factor in anticipating future threats toward retaining the integrity of certain attributes of the self which are increasingly valued in late modern societies. Personal experiences of the suffering involved in extended periods of chronic illness and extended dying are likely, in some circumstances, to raise fears for the future. The review presents a case for the witnessing of suffering and its avoidance being an important reason for supporting the right-to die movement and, specifically, for joining FATE.

Other factors informing desire for hastened death in terminally ill, older and dying people in contemporary western cultures are considered in relation to right to die society membership. Fears associated with ageing and the dying process, religiosity, culturally mediated attitudes toward risk and vulnerability are discussed in the context of their influence on individuals' pro-right to die attitudes. Altruism is discussed in the context of concerns for others with desire to avoid burdening others through action to end life. Altruistic desire to benefit others as well as self, and socio-economic considerations are also discussed in the context of ageing and the dying process.

In this and the following Chapter, literature is reviewed under the following broad topic headings:

1. New social movement theory: ageing and dying, public opinion and risk
2. Professional opinion about assisted dying
3. Religion and membership of right to die societies
4. The self and individualism; threats to the self during ageing and terminal illnesses
5. Advances in biomedicine and contemporary dying
6. The burden represented by chronic illness and lengthy dying trajectories
7. Altruism as a motive for joining a right-to-die society
8. Association between socio-economic factors and desire for an assisted death

## **1. New social movement theory**

New social movement theory was selected as a relevant theoretical background to data interpretation at an early stage in the research. This was primarily due to campaigning activities being a fundamental part of right to die societies' pursuits, in their efforts to achieve legal options for hastening death. New social movements originally arose due to grievances and perceptions of injustice, linked with ideologies and economic-industrial systemic conflicts, transcending socio-economic class, gender, age and sexual orientation (Johnston, et al, 1994), and through dissatisfaction with current social conditions, and hopes for change (Blumer, 1994). Social movements act to bring to public attention life-political issues (Giddens, 1991). New social movements are characterised by desire to challenge contradictions between socio-cultural values and conventional social practices (McAdam, 1994). New social movements emerging now are "an expression of political individualism" (Beck, 2007). New social movements arise in order to campaign for more just and rational approaches to perceived social problems through political activism challenging inequalities between genders, social classes, ethnic groups, sexuality and (dis)abilities (Ali et al, 1998). Social movements in late modern Britain have widened their focus into fields concerned with more personal and intimate areas of human existence such as childbirth, sexual orientation, HIV/AIDS and breast cancer (McInerney, 2000). Such health-focused social movements have emerged due to increasingly powerful influence of science, technologies and medicine over social policy, social governance and socioeconomic systems (Brown and

Zavestoski,2004), not only compromising public participation in policy and decision-making but inappropriately framing political and moral issues. Brown and Zavestoski describe three categories of new health-focused social movements; either concerned with equitable access to health care; or health inequalities between race, ethnicity, gender, social class or sexuality; or morbidity-based movements that challenge the establishment over issues surrounding diagnosis, treatment and prevention.

New social movement theory is useful for understanding, and explaining the relative popularity of the right to die movement. as demonstrated by Fox et al, (1999) who see the US Hemlock Society itself as a new social movement. Thus the Hemlock Society campaigned for a right to die on the grounds of it being a human and a civil right, reflecting members' beliefs and their desire to be able to make such a personal choice for themselves in the future.

The global right to die movement can similarly be classed as a new social movement as it exhibits features common to other new social movements, namely as a political force challenging medical, religious, legal and governmental authorities (Brown and Zavetoski, 2004) because of its primary aim to achieve a change that allows terminally ill people legally sanctioned choice and control over the timing and manner of their deaths (Dignity in Dying, [www.dignityindying.org.uk](http://www.dignityindying.org.uk)), and in its members' campaigning against perceived oppression and injustice imposed by societies, religious authorities and governments who oppose legalisation of a right to hasten death under specific circumstances. The beliefs of members of the right to die movement resonate with new social movement theory due to the movement's aims representing a contradiction between socio-cultural values and conventional social practices (McAdam, 1994). As members of the worldwide right to die movement, campaigning by UK right to die societies, including FATE, is grounded in dissatisfaction as demonstrated by their involvement in power struggles with individuals and organisations who oppose legalisation of hastened death, and arising from their concerns about perceived issues surrounding contemporary dying and death that transcend social, materialistic and employment-related matters. The right to die movement proposes a new scheme or system of dying that allows terminally ill persons to die at a time of their choice (McInerney, 2000), in a social climate in which public discussion about legally ending lives is perpetuated through recurrent campaigning by people representing a wide spectrum of moral and ethical values and organisations. UK members of the right to

die movement, including FATE, desire a legal option to hasten death nuanced by perceptions of future risk of intolerable suffering under present medical management of dying and death. Their campaigning uses 'reality' stories about dying and death to promote their cause (Dignity in Dying, [www.dignityindying.org.uk](http://www.dignityindying.org.uk)).

Health social movements have arisen and proliferated to give a public voice to their members to challenge perceived systemic inequalities, omissions or shortfalls in healthcare. The UK right to die movement exhibits similarities with health-focused new social movements as its primary goals are to campaign for a change in current legislation due to members' concerns about suffering experienced during medically-orchestrated dying processes, evidenced through website accounts of suffering experienced by members' partners and relatives.

Since the birth of the first UK and US right-to-die societies in the 1930s (McInerney, 2000; Kemp, 2004), the right-to-die social movement has expanded to become globalised and inclusive of societies involved in right-to-die activism across diverse countries. Although the principle concern of the whole movement remains achievement of legalisation of voluntary euthanasia and/or physician assisted suicide in the respective countries where right to die societies exist, initially in the UK there was a strong eugenics strand to the movement's rhetoric, with arguments made for the conservation of scarce societal resources through the elimination of the old and infirm holding some sway. As McInerney suggests, the holocaust brought this aspect of the movement into disrepute. Today, the movement flourishes with its aims having adapted over time in response to changing socio-cultural norms, although legalisation remains its primary focus. McInerney (2006) has shown how rhetorical framing seeks to persuade and legitimise the existence and aims of new social movements. The UK right to die movement employs rhetorical framing in seeking change in current UK law through the use of the language of rights, autonomy and choice in promoting its cause (Dignity in Dying: <http://www.dignityindying.org.uk>). The UK right to die movement campaigns for what its spokespeople promote as a just and rational solution to a perceived social problem, intolerable suffering in dying, in the absence of a legal choice for terminally ill persons who wish to control the timing and manner of their death in the face of such suffering (Dignity in Dying, [www.dignityindying.org.uk](http://www.dignityindying.org.uk)) The right-to-die movement's agenda spans moral, ethical and legal aspects of end-of-life management, in a social climate where discussion about ending lives continues to excite public,

media, professional, religious and governmental interest (Commission on Assisted Dying, <http://commissiononassisteddying.co.uk>).

## 1.1 New social movements, ageing and dying

I hypothesised that right to die societies and why people join them are products of the values and practices surrounding dying and death in those societies in which they exist. Contemporary understanding of dying in western societies encompasses many positive and negative aspects of the dying experience (Kellehear, 2009c). UK right to die societies are arguably driven by cultural norms surrounding contemporary ageing and dying, with an emphasis on the more negative experiences that can occur, particularly in relation to fears about suffering during the dying process, in terminal illnesses and/or during extended longevity leading to a fourth age of disintegration and decline accompanied by multiple chronic morbidities, sometimes extending over lengthy periods before finally death occurs. As one right to die society member says:

*“I myself dread the long period of going downhill; my arthritis hurting more and more, being able to do less and less, being tired most of the time, no energy, no drive, not wanting to read or write, eat a meal, see my family or friends or gossip with my neighbours, having no role, unable to contribute in any way. Dying is a messy business; I dread becoming incontinent, being unable to get to the lavatory without help, needing someone to wipe my bottom. I dread pain, delirium, breathlessness, constipation, nausea; all the horrid things that happen at the end of life. I dread losing control of my life and of my body Before the time comes that life is a pain and not a pleasure, a burden and not a joy, I would like to be able to say: “Doctor dear, come on Tuesday with your little bag, give me an injection so that I can go to sleep and not wake up”.”*

(Friends at the End Newsletter, July 2010)

Social factors predicating the rise of the right-to-die movement include increasing longevity in western countries associated with advances in biomedical technologies and disease management. With increasing life expectancy, over 65s in the UK are projected to rise from 16% (2006) to 22%, with people 85 and over forming 4% of the population by 2031 (National Statistics online, 2008). At no previous time have so



many older people been ill and dependent for so long (Logue, 1993), and dying trajectories are likely to lengthen, creating major social issues (Spragins, 1999).

Public expectations of death-postponement have risen in parallel with heightened possibilities of extending life that inevitably raise cultural expectations of heroic death-delaying medical interventions, encouraging the search for ever more effective life-extending regimes and agents in the bio-medical and pharmacological sciences . Bauman (1998) describes this as a medical paradox in which, having defeated one form of death after another, medicine discovers even more conditions to be defeated, thus distancing itself from the inevitability of death whatever the cause. Death has become an enemy to be defeated, not welcomed (Illich, 1976) and public expectations of life-prolongation, informed by advances in medical science and technologies, often exceed reality (Ashby, 2009). Some patients dying in hospital are known to receive unwanted interventions (Cartwright, 2000) and other commentators argue contentiously that pneumonia, the “old man’s friend”, is persistently thwarted through the use of antibiotics (Syme, 2008).

Previous research on right to die society membership showed that right to die society members were predominantly white, female, over 65 years of age and of higher social class. In considering age as a factor implicated in right-to-die society membership, examination of studies investigating end of life issues amongst older people show variance in the acceptability of euthanasia and physician assisted suicide (Kelner, 1995, Catt et al, 2005). Physician-assisted suicide or euthanasia is acceptable to some older people (Frileux et al, 2002) but lack of desire to either control or choose the timing and manner of death amongst older people with heart failure was found by Gott et al, (2008). Kelner’s (1995) study shows a clear division in attitudes, mediated by social class and level of educational attainment, toward desire for power to control decision-making around dying amongst elderly patients.

Elias(1982) contends that old age is treated as a deviation from normality and it is argued that geriatric medicine has created a ‘burden of ageing’ paradigm through discourses “emphasising dependency, alienation and marginalisation” into medicine’s other expert discourses (Pickard,2010). Erosion of traditional family structures suggests older, ill and dying persons are more likely to become confined in institutions

over the latter months or years of their lives (Warnock and Macdonald, 2008). Sequestration of elderly and dying people in institutions (Lawton, 1998) serves to disempower individuals in a social climate in which autonomy, personal control and self-management are valued collectively and individually (Kellehear, 2007). As Gilleard and Higgs (2000) observe, very old people tend to “survive only within the interpretive structures of others - increasingly caught in the webs of significance spun by the functionaries of health and welfare systems”. This systemic trend serves to institutionalise disempowerment and loss of autonomy for those older people who have become captives of care systems. Evidence for suffering and disenfranchisement in older people’s dying offers a representation of dying at odds with the view that dying ought to involve actions taken by people exercising some control over their experiences (Kellehear, 2009b).

### 1.1.1 Ageing and fourth age: fears associated with the dying process

“The world wants longevity but it does not want old age. Dying is bad, to be avoided at all costs, but so is decrepitude”.

(Appleyard, 2009)

“...the greatest impoverishment of all - exclusion from the processes that establish and give meaning to everyday life”.

(Gilleard and Higgs, 2000)

New social movements concerned with social issues in ageing and dying in the UK, (represented by organisation such as Age England (formerly Age Concern<sup>7</sup>) and the Alzheimers Society), have helped turn public attention toward both positive and negative aspects of ageing and dying in the UK today; this in a climate in which prevailing cultural discourses surrounding ageing are primarily concerned with resistance to ageing (Gilleard and Higgs, 2000). In such a cultural climate, the importance of retaining youthfulness tends to be associated with institutional practices that emphasise a pervasive societal antipathy toward old age (Higgs and Rees Jones, 2009). Societal antipathy toward old age can be seen to manifest itself through the plight of many older people with physical and mental impairments, subjected to social isolation, and discriminatory practices endemic in health and social care services, with

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<sup>7</sup> End of Life Issues; a Policy Position Paper. Age Concern, 2002

the quality of their care being compromised by systemic and organisational factors (Seymour, 2012).

Despite medical advances having increased longevity in western societies, and despite development of palliative care services for dying people since right to die societies were originally formed, negative healthcare-related experiences associated with ageing and dying continue to provide a focus for movements concerned with social issues surrounding older age. The right to die movement, of which FATE is a member, clearly falls into this category of social movement due to its campaigning activities. Increasing longevity due to medicine's successes in prolonging lives of very poor quality during extended dying processes is implicated. Higgs and Rees Jones (2009) cite dread of longevity and older age being informed by bodily failures such as incontinence, dementia, inability to maintain coping strategies and loss of accustomed roles and social connections. Seale (2000) cites fears associated with ageing relating to lengthy illnesses involving suffering and dependency. In this context Brown (2008) also cites anticipation of prolonged physical and mental decline associated with decreasing quality of life.

Due to the ongoing increase in longevity, older age in western societies in the 21<sup>st</sup> Century can now be divided into two distinct phases; a third and a fourth age (Gilleard and Higgs, 2000); the third age being characterized by an emphasis on positive lifestyles in which power, agency, citizenship and material consumption are features of social identity post-retirement. In contrast, the fourth age refers deeper old age in which dependency, infirmity and ultimately death define a later-life identity radically changed from that of the third age. In the fourth age, compromise of bodily appearance, physical and mental functioning and bodily control pose potential threats toward retaining agency and identity (Higgs and Rees Jones, 2009). The incidence of loss of mental capacity (dementias) is likely to increase in the fourth age, leading to a perception of 'betrayal' by the ageing body and brain, with a high percentage of people being likely to pass their final years with an 'uncivilized' body and losses of mental and physical capacities (Higgs and Rees Jones (2009). The prevalence of dementias in Western Europe rises steeply to almost 25% in persons aged 85 and over (Alzheimer Disease International factsheet, 2008). In the UK, for women aged over 80 years, dementia is one of the leading causes of death (Office for National Statistics, 2011). In 2009, in England and Wales in total there were 16,424 deaths in which dementia was

named as one of the causes with a further 6,194 death from Alzheimers (Office for National Statistics, 2011). In view of such threats to intellectual integrity in older age, it is reasonable to suppose that certain individuals may wish, or choose to forego such mental and physical deprivations through joining a right to die campaigning group, as consideration of such factors can induce serious concerns about future suffering and “bad death” amongst healthy individuals (Vandrevala et al, 2006). Fear of the fourth age is evident through formation of the newer UK right to die Society for Old Age Rational Suicide<sup>8</sup> referred to in the previous chapter. Thus, culturally defined norms of managing ageing in contemporary western societies, featuring social exclusion, physical and mental decline, institutionalisation, dependence and diminishment of quality of life are implicated in decisions taken to join the right to die movement. Inferences can also be drawn that right to die societies would be more likely to be populated predominantly by older people. Although the present demographic profile of the membership of UK right -to-die societies has not been re-examined since an earlier study in which two thirds of the membership of Exit (now Dignity in Dying) were found to be women aged over 60 years (Lam,1982), older age is a notable feature of US and Australian right to die society membership. Magnusson (2002) comments on the mostly older volunteer members of Australian right to die societies, and most US Hemlock society members have been identified as older, white, better educated, of higher social class and female>male (Wilson et al, 1998). Kelner (1995) associates higher social class and level of educational attainment in older patients with positive attitudes toward desire for power to control decision-making around dying.

### 1.1.2 Choice in contemporary society

As Popper and Eccles (1997) observe, a (human) animal’s problem situation depends, among other factors, on its preferences and choices. But despite freedom in ability to make choices having the capacity to beget problems, choice has become an idealised concept in contemporary western societies, embodying values associated with individualism, autonomy, freedom and emancipation in the late modern self (Rose,1996; Giddens, 1991; Strathern 1991). Values placed on choice in modernity are discussed in more detail in Chapter 3, Section 1.

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<sup>8</sup> SOARS: [www.soars.org.uk](http://www.soars.org.uk)

Choices in dying as a right is a key principle adopted by the right to die movement. As Dignity in Dying<sup>9</sup> states: “We believe that everyone has the right to a dignified death.

This means:

- Choice over where we die, who is present and our treatment options.
- Access to expert information on our options, good quality end-of-life care, and support for loved ones and carers.
- Control over how we die, our symptoms and pain relief, and planning our own death”.

## 1.2 Public opinion about hastened death

Contemporary attitudes about hastened death are a product of historical strata laid down by cultures in motion (Williams, 1990). Studies of members of the public, professionals and patients show wide variation in people’s opinions about hastened death. Since the mid-1970s public support for euthanasia “has hovered between 60 - 80% on both sides of the Atlantic” (Seymour et al, 2010) and this can be seen as a driver of the right to die movement. Levels of European public acceptance of euthanasia differ widely between countries according to social class, educational level, age, and religious belief (Cohen et al, 2006). Great Britain is one of the relatively accepting countries together with Holland, France, Belgium, Denmark, Sweden and others. Members of the public in France, the Netherlands and the UK are less opposed to euthanasia and physician-assisted suicide in terminal illness than healthcare professionals (Teisseyre et al, 2005; Rietjens et al, 2005). Emanuel et al (1996) report 65.6% US public support for euthanasia and 66.5% public support for physician assisted suicide for unremitting pain. A 2007 Gallup Poll indicated higher levels of support for euthanasia than for physician assisted suicide (PAS) amongst the US general public with 71% in agreement with the moral acceptability of euthanasia in incurable diseases. Carroll’s (2007) study showed slightly higher levels (49%) of agreement with physician-assisted suicide in incurable disease characterised by severe pain. In Holland, 85% of the public support active assistance to die, notably in response to specific requests from patients suffering with incurable cancer; lesser acceptance being evident in other circumstances (Rietjens et al, 2005).

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<sup>9</sup> [www.dignityindying.org.uk](http://www.dignityindying.org.uk)

Many people consider the slow dying from dementias to be a degrading and undignified way of dying in which social death and death of self precede biological bodily death (Howarth, 2009). In the Netherlands and Finland, public support for actively ending lives of patients with dementia is greater than among professionals (Rietjens et al, 2005; Rynänen et al, 2002) although Finnish doctors express high levels of agreement with passive euthanasia in severe dementia independently of their religious belief. A majority of the British public favours hastened death in dementia although ethnicity influences attitudes and white British respondents are more likely to agree with euthanasia for themselves than individuals from other ethnic groups (Williams et al, 2007).

UK opinion poll evidence suggests a majority of the British public support a legal right to hastened death for terminally ill persons. Seale (2000) observes that rising levels of support for hastened death to relieve suffering result from cultural forces exerted through changes in the nature of healthcare and care of dying patients. British Social Attitude (BSA) Surveys conducted over 11 years pre-1995 (O'Neill et al, 2003) show high levels of public support for physician assisted suicide; this rose from 75% - 84% during this period. The 2007 BSA survey (Clery et al, 2007) indicates a slight fall (80%) in favour of active voluntary euthanasia for persons with an incurable and painful illness with fewer (60%) in agreement with physician assisted suicide. The 2010 BSA survey (Park et al, 2010) reports 82% "probable" or "definite" support for doctors to be allowed to end the lives of patients with painful incurable diseases at a patient's behest.

The media exerts considerable influence over attitudes and opinions (Howarth and Jefferies, 1996). While public opinion has remained broadly consistent over time, it is suggested that the media has raised levels of public understanding about medical technologies but at the same time levels of trust in doctors may have diminished following events such as the Shipman murders (Bowker, 2009). Seale (1998) suggests trust in medical expertise is dependent on leaps of faith as emotional disclosure between patient and doctor is unequal with patients being encouraged to trust their doctors despite trust not being mutually equivalent in this relationship as doctors are taught to question patient beliefs and motives. Nevertheless, Hall et al, (2005) quote one small study (Graber et al, 1996) in which a majority of primary care patients said they would continue to trust their doctors even though they assisted with suicide or

performed euthanasia, and in their own larger study of 956 US individuals, 58% indicated that legalising euthanasia would not cause their trust in doctors to be diminished. As members of the public, patient opinions about the acceptability of hastened death vary widely between studies they have participated in either as patients or as members of the public.

It is clear that the significant relationship between opinion poll evidence and the right to die social movement is a key factor in nourishing right to die philosophy and the right to die movement, although, as we have seen, public opinion polls are considered by some to be unreliable sources of informed opinion. The movement does, however, use public opinion poll evidence to promote its cause:

*“British Social Attitude (BSA) survey 2007: 80% agreed that a person with a terminal and painful illness from which they will die should be allowed an assisted death (2)”.*

(Dignity in Dying, 2011<sup>10</sup>)

The formation of public opinion in society operates through the interaction of social movements such as campaigning groups, whose success is dependent upon public opinion support (Blumer, 1948). In the UK, general public opinions about legalisation of euthanasia and physician assisted suicide have consistently been in their favour, but public attitude research findings cannot be taken at face value as “...public opinion polls are probably confounded because the public may not adequately understand either the efficacy of palliative care or their right to refuse unwanted treatment...In our view, public opinion alone is not a rational basis for the legalization of physician assisted suicide” (Quill et al,1998). It has similarly been argued that despite continuing public debate in the UK, the public “remains relatively uninformed about the subject” (Clery et al, 2007) and Blumer (1948) concurs with this view. At the same time, media reporting of these matters is likely to be biased and inaccurate (Seale, 2010). Although many citizens in democratic societies feel their views and opinions should influence legislation, private individuals are unlikely to have a direct influence on political decisions, and public opinion polls are more likely to be “commissioned by those with a vested interest in a particular outcome” (Badcott, 2010). In public opinion research, those with religious beliefs repeatedly demonstrate a vested interest in influencing attitudes toward euthanasia/PAS (Cohen et al, 2006). Badcott additionally observes

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<sup>10</sup> [www.dignityindying.org.uk](http://www.dignityindying.org.uk)

that elected members of Parliament “are not obliged to seek or be guided by the opinions of their constituents” as the diversity of opinions would make this impossible.

### 1.3 Risk and assisted dying

New social movements arise in part due to the changing risks facing societies in modernity (Giddens, 2006). Risks in this globalised world, according to Beck (2009), have generated new kinds of risk communities signalling the normativity of risk in contemporary lives. Contemporary UK right to die societies exist in a social climate in which risk, global, national, local and individual, permeates the social fabric and daily existence of the population (Howarth, 2007). The pervasive contemporary UK culture of risk aversion is exemplified by bodies such as the Health & Safety Executive<sup>11</sup> and the insurance industry (Zelizer, 1978) among others. Extensive grey areas of socially manufactured existential insecurity and uncertainty exist (Beck and Beck-Gernsheim, 2001), placing contemporary western societies within an ontological framework where risk and fear are reflexively created, endemic, generated by wealth and market economies, and affecting all levels of social hierarchies and individuals in their everyday lives (Beck, 1992; Furedi, 1997). Beck (1992) describes this phenomenon as a process in which new socially produced risks arise in parallel with new interests in concealment of risk from public agendas due to perceptions of the public as “ignorant if well-intentioned”. Beck credits science and medicine with authoritarianism and with responsibility for creating and continuing to create many of the risks and hazards arising in society today, including increasing world population growth and longevity, fuelling risk culture in modernity. Medicine and spreading medicalisation of increasing numbers of medically created risks are implicated by Beck in changing the world’s and individual’s relationship to illness, health, and by default, to dying and death. Heightened fears about health risk, and public concern about health (Furedi, 1997) has become a more prominent feature in modernity, fed by “scientific and medical representations” of the risk of death” (Seale, 1998). Many problems related to risk are said to involve “people being made vulnerable to experiences of suffering (Wilkinson, 2006). While risks of suffering in dying have always existed, the nature of these risks have changed over time due in part to both increasing longevity, and medicine’s ability to sustain life in circumstances where prolonging lives would have been impossible in the past. Therefore, risks associated with ageing and particularly surrounding the fourth age resonate with Wilkinson’s contention. In a

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<sup>11</sup> [www.hse.gov.uk](http://www.hse.gov.uk)



cultural environment in which risk plays a prominent part in political, organisational and social life of the nation, risk is arguably an important factor in fostering new social movements, and in particular, the right to die social movement.

The meanings of risk in modernity relate to ideas about probability of events that may be either good or bad, although now risk tends to refer mainly to negative potential outcomes, predominantly environmental, lifestyle, medical, economic and criminal risks (Lupton, 1999). Risk was on the public's agenda, evidenced by the existence of the insurance industry, before the UK right to die movement became organised in the 1930s.

Global risk represents "the anticipation of a catastrophe" (Beck (2007); Beck claims risk societies are potentially revolutionary. Furedi (1997) describes societal preoccupation with risk, an explosion of new risks, heightened public concerns about risks, inflation of systematic risk assessment and heightened anxieties about health-related risks. Furedi (2007) maintains risk is the product of a 'culture of fear', shaped by cultural and historical factors; creating a contemporary fear culture feeding an obsession with risk in contemporary UK society. Furedi (2008) proposes links between the omnipresent culture of insecurity and risk with culturally perceived vulnerability which, in his view, has overwhelmed the view of the public as resilient with one in which people are seen as victims, and as such, collective vulnerability has become a dominant idiom.

It can be argued that, at micro level, Beck's concept of global risk echoes the risk to individuals and society at large of potentially catastrophic effects of human morbidities, informing numerous new 'revolutionary' health social movement agendas. Dying in a contemporary "risk society" (Beck, 1992) where personal responsibility for health and avoidance of health risks are prominent on public health agendas (Howarth, 2007), means some individuals' personal perceptions of risks associated with dying and death are likely to influence action to avert such risks. Lupton's (1999) concept of negative risk associated with individually perceived medical risks, lifestyle risks, interpersonal risks and economic risks associated with ageing, dying and death resonates with the right to die movement's aims and beliefs. Medical and healthcare-related risks associated with dying (Nuland, 1993); risks of threats of bodily defilement through uncleanliness and unboundedness (Douglas, 1966), risks toward the self and

significant others (Hudson et al, 2006) and economic risk (Chapple et al, 2006) all offer possibilities for the basis of risk-based decisions made to join a right to die society.

With risk having become “a defining feature of later modernity”, Hallowell (2006) argues that risk equates with real dangers and the reality of peoples’ lived experiences of risk has been absent from the sociological literature. Hallowell’s study of women living with risk of ovarian cancer illustrates how witnessing painful and distressing deaths of family members can heighten risk awareness about unpleasant future possibilities for dying, inducing desire to avoid similar ways of dying. Life insurance provides another example of how risk of death is acknowledged with a monetary value placed on lives (Zelizer, 1978); planning for death through taking out life insurance being a “positive act of control” (Seale, 1998) and the action of a responsible citizen (Petersen, 1997). The normative practice of taking out insurance against illnesses and death in western societies manifests a need to control life events, and, as Seale (2000) suggests, increasingly a desire to control death. Thus joining a right to die society can be compared to taking out an insurance against future death-related events.

## **2. Professional opinion**

Doctors and nurses share many beliefs about voluntary euthanasia, informing both negative and positive attitudes toward it (White et al, 2008). Attitudes of healthcare professionals toward euthanasia and physician assisted suicide tend to be less favourably disposed toward their legalisation than the general public (Emanuel et al, 1996; Reijtens et al, 2005; Seale, 2009). Professional opinion mediated by religiosity and speciality is influential in determining the end of life care people can expect to receive in different care settings (Seale, 2010). Awareness of diversity in professional attitudes and opinions arguably has a potential to influence decisions made to join a right to die society.

### **2.1 Doctors’ attitudes**

Doctors attitudes toward euthanasia, physician assisted suicide, their legalisation and how legalisation might influence their own practices vary between studies, between country where practicing, speciality, age, religiosity and whether or not doctors practice

in jurisdictions where hastening death is legally sanctioned (Seale, 2009). Also, differences in sampling and question phrasing compromise the ability to fully compare results across studies.

Attitudes of French physicians toward legalisation of euthanasia are mediated by religiosity and clinical speciality; physicians trained in palliative care being less likely to support legalisation in France (Peretti-Wattel et al, 2005). Between 2001 - 2009, Austrian medical students' attitudes have become increasingly positive in principle toward the acceptability of euthanasia and readiness to practice it. This trend is suggested to be driven by increased value being placed on patient autonomy over time (Stronegger et al, 2010).

It is evident that in jurisdictions in which hastening death is legally sanctioned, attitude studies of professionals indicate higher levels of support for the practice of euthanasia and/or physician assisted suicide than in other jurisdictions. Amongst Dutch physicians, 56% support peoples' right to decide about their own life and death (Onwuteaka-Philipsen et al, 2003); 64% consider active ending of life acceptable in terminally ill adults experiencing pain (Rietjens et al,2005). In Switzerland where legislation permits assisted suicide, Hurst and Mauron (2003) report Swiss oncologists and palliative care specialists as more likely to favour physician assisted suicide than euthanasia which remains illegal. In a separate study of medical students, oncologists and palliative care specialists, palliative care specialists are less favourably disposed toward legalisation than oncologists; both groups favour physician assisted suicide more highly for themselves than for their patients (Marini et al, 2006). Familiarity with death and dying (oncologists) and familiarity with methods for alleviating suffering in palliative care are proposed by Marini et al (2006) to account for the differences in attitude between these two specialities.

In the US, a review of thirty nine studies of physicians' attitudes toward physician assisted suicide and active voluntary euthanasia suggests physician assisted suicide is more acceptable to doctors than euthanasia; this review shows a majority of doctors being in favour of legalisation of physician assisted suicide (Dickinson et al, 2005).

A 2005 survey of European and Australian doctors reports higher levels of support for patients' rights to decide on hastening death amongst non-religious doctors with the greatest levels of support among doctors from countries where physician-assisted suicide and euthanasia are already legalised (Holland, Belgium and Switzerland) or had been briefly legalised (Australia) (Miccinesi et al, 2005). In a study of Australian medical practitioners, 57% of the 1000 participants thought legalisation was desirable and 44% thought that patient requests to hasten death were sometimes rational (Baume, 1998). In contrast, a small later study of the attitudes of 24 Australian doctors toward euthanasia found most being generally opposed (Kelly et al, 2003) but subsequent studies indicate less negative attitudes toward legalisation of hastened death. Three longitudinal studies of doctors in Victoria, Australia, showed 53-60% of doctors supportive of legalisation of voluntary euthanasia, and 46% (in 1 study only) supportive of legalisation of physician assisted suicide (Neil et al, 2007).

In the UK, indeterminate numbers of doctors oppose legalisation of physician assisted suicide and voluntary euthanasia as members of organisations including the Association of Palliative Medicine of Great Britain & Ireland, the Christian Medical Fellowship and the Medical Ethics Alliance, collectively part of the Care Not Killing Alliance<sup>12</sup>. Levels of opposition and support vary between successive attitude studies of UK doctors but the official stance taken by the BMA reflects opposition of its members toward legalising euthanasia and physician assisted suicide:

*"The BMA:*

- *believes that the ongoing improvement in palliative care allows patients to die with dignity*
- *insists that physician-assisted suicide should not be made legal in the UK*
- *insists that voluntary euthanasia should not be made legal in the UK*
- *insists that non-voluntary euthanasia should not be made legal in the UK"*<sup>13</sup>

A literature review of fifteen studies of UK doctors' attitudes toward euthanasia and physician assisted suicide reveals majority opposition to both active voluntary euthanasia and physician assisted suicide, suggesting that a majority of UK doctors oppose their legalisation (McCormack et al, 2011). In the absence of legalisation of

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<sup>12</sup> <http://www.carenotkilling.org.uk/>

<sup>13</sup> [http://www.bma.org.uk/images/endlifedecisionsaug2009\\_tcm41-190116.pdf](http://www.bma.org.uk/images/endlifedecisionsaug2009_tcm41-190116.pdf)

euthanasia or physician assisted suicide in the UK, this finding conforms with the trend for legalisation to be associated with less professional opposition, as seen in the Netherlands, Belgium, Switzerland and the USA .

## **2.2 Nurses' attitudes**

Studies of nurses' attitudes towards euthanasia and physician-assisted suicide in countries other than the UK show their views tend to be complex, reflecting a wide range of opinions that, similarly to doctors, differ between age groups, specialty and country of origin (Kitchener, 1998; Berghs et al, 2005). Literature reviews of empirical studies (Verpoort et al, 2004; Berghs et al, 2005) identify complexity and wide variation in nurses' attitudes toward the legalisation and practice of euthanasia and whether or not they would be willing to care for patients who requested euthanasia. Religious and moral values exert a significant influence on attitudes. Exposure to patient suffering also exerts influence on nurses' views either for or against euthanasia; acceptance of euthanasia being dependent on patients' individual situation, patient quality of life and respect for patient autonomy (Verpoort et al, 2004).

As with doctors, religiosity plays a role in shaping nurses attitudes toward hastened death. Australian nurses least in favour of active voluntary euthanasia tend to be older, Catholic and working with terminally ill patients; critical care and mental health nurses being the most supportive (Kitchener, 1998). In jurisdictions in which hastening death is legalised, as with doctors, Oregon hospice nurses (and social workers) are highly supportive of the Oregon Death with Dignity Act although nurses are less supportive of provision of lethal prescriptions to patients than social workers (Miller et al, 2004). A majority of Belgian nurses agree with euthanasia (92%) although religious nurses are less accepting than others (Inghelbrecht et al, 2009). Similarly, studies of Finnish nurses show non-religious Finnish nurses to be less opposed to euthanasia than religious nurses (Kuuppelomäki, 2000; Ryyänen et al, 2002).

In contrast to the Netherlands and Belgium, evidence about attitudes of UK nurses toward legalisation of euthanasia and/or physician assisted suicide is limited (Holt, 2008). In submitting evidence to the House of Lords on the Assisted Dying Bill, the Royal College of Nursing (RCN) considered euthanasia to be "contrary to the public

interest, medical ethics and patients' civil rights" (Holt,2008). But apart from one small published study, Holt also cites instances where opposing views have been publicly stated by UK nurses, suggesting support for the RCN's official statement is unlikely to be unanimous within the profession. This contention is supported by Sanders (2004) in her submission of evidence to the House of Lords on the Assisted Dying Bill, who stated that responses from members of the profession to the RCN's formal consultation were "overwhelmingly in favour of changing the law". A small survey of clinicians including 36 UK nurse keyworkers with a special interest in palliative care indicated nurses were either more in agreement or neutral than consultants on whether physician assisted suicide should be allowed (Pugh et al, 2009). Currently, there is insufficient evidence available to show with any degree of certainty what attitudes toward euthanasia and physician-assisted suicide members of the UK nursing profession might collectively hold.

### **3. Religion and attitudes toward hastening death**

Traditional Christian views prohibit euthanasia and physician assisted suicide. Engelhard and Iltis (2005) go even further by suggesting a possible Christian duty to prolong life through the use of technologies in order to "gain a last opportunity for repentance". With attitudes toward suffering central to the Christian debate, given that all suffering is ultimately relieved through death, Badham (2009) argues a Christian case for legalisation of assisted dying, contending that Christians have either a choice of belief in suffering as an opportunity for spiritual growth that proscribes assisted death or conversely, in suffering requiring a compassionate and humane response where, in some cases, assistance to die could be considered morally right.

The Catholic Church wields authority over end of life issues, based on long-established doctrines and more recently through Pope John Paul II's Declaration on Euthanasia, in which suffering in dying is sanctified through being linked with the passion of Christ (Badham, 2009). Larue (1985) contends that no other religious organisation has "been responsible for more literature about euthanasia and the right to die". Catholicism views people as stewards of their bodies; bodily life being seen as sacred and therefore not to be deliberately ended (Markwell, 2005).

The Church of England also holds fast to traditional principles of proscribing hastening of death (Williams, 1996), although the religious conformity of earlier times (Kellehear, 2007) has given way to questioning of church doctrine (Badham, 2009). Individualism and reflexivity of self in modernity (Giddens, 1991) is likely to encourage such questioning of previously unquestioned precepts held by the Church. As Tullett (2006) observes:

*"I am a priest in the Church of England, I know of others among the clergy and many among the laity who support a change in the law. A recent poll shows that 84 per cent of Christians across all denominations who worship at least monthly would like to see assisted dying legalised when people are confronted with the unbearable and unrelievable suffering; and 66 per cent of churchgoing Anglicans support the legislation.....How can subjecting someone to suffering be classed as loving?"*

In Judaism as in Christianity, people do not have a right to commit suicide (Dorff, 2005) and any form of active euthanasia is strictly prohibited, although some individuals interpret Jewish Law more liberally (Larue, 1985). Jewish teachings support the sanctity of human life without regard to its length and quality (Katz, 2000), and oppose "any measures which could be interpreted as hastening death". These include acts involving the body. Strict laws apply to the conduct of dying and death and subsequent mourning period within this Faith. However, the traditional view is not necessarily held by all members of the Jewish faith. More liberal approaches diverging from Orthodox Judaism have been expressed, and not all adherents of the faith cleave to orthodoxy in this respect (Rich, 2011).

Islamic teachings also view life as sacred with obligations placed on health care providers to save and prolong life. Euthanasia and assisted suicide are considered to be acts of disobedience against God (Sachedina, 2005). This being the case, similarly to Catholicism and Judaism, Islamic law does not support individuals' right to die and lives may not be terminated by human intervention.

The situation is less clear in multitheistic religions such as Hinduism and Buddhism. Acceptance or proscription of euthanasia and/or physician assisted suicide appear to be ambiguous in Hinduism, dependent on differing interpretations by authority figures,

some of whom proscribe hastened death, others condoning it in particular circumstances. Firth (2005) contends generalisation about end of life matters for Hindus is not possible because beliefs and attitudes will vary according to social class, educational status and religious tradition; some authorities would allow suicide in certain circumstances. Based on the views of one authority, Larue (1985) suggests that individuals are free to make their own decisions, subject to the laws of the country.

The Buddha forbade the taking of life though conflict can arise between this and the Buddhist precept of duty to relieve suffering and compassion for suffering (Keown, 2005). But depending on the interpretive framework employed, a minority of Buddhists would support hastening death on compassionate grounds.

Being religious is “strongly and independently associated” with public attitudes towards hastening death (Emanuel et al, 1996) and “strength of religious affiliation...a significant determinant of opposition” to its legalisation (O’Neill et al, 2003). However, despite the proscriptive stance of the major religions, correlation between religiosity and opposition to euthanasia and/or physician assisted suicide is not absolute and the views of some adherents may not all conform to those of their spiritual leaders. The 2010 BSA survey (Park et al, 2010) identified permissive attitudes toward death hastened by doctors in respondents who said they were either religious or “fuzzy faithful”. Original founders of the Voluntary Euthanasia (Legalisation) Society in 1935 included three clergymen (Kemp, 2002). Gill (1998) notes claims for increasing Christian support for legalisation of euthanasia or assisted suicide, including both clergy (Tullett, 2006) and regular churchgoers (Badham, 2009). Modernisation may be loosening the links between religiosity and assisted dying; joining the right to die movement may be symptomatic of a backlash against the orthodoxies of the medical profession and the major religions (Howarth and Jeffreys, 1996). The acceleration of medicine’s technical aspirations associated with peoples’ increasing dependence on medicine has caused moral and spiritual preparedness for death to become less relevant (Williams, 1990). Secularisation in western societies, part of the process of modernisation (Brown and Snape, 2010), manifests in areas of life such as the insurance industry in which lives and death have become commodified as artefacts with material and monetary value; antithetic to traditional religious concepts of lives as sacred (Zelizer, 1978).



Although contemporary secularisation of diverse societies has been charged with responsibility for support for euthanasia and physician assisted suicide, (Peretti-Wattel et al, (2005); Cohen et al, 2006), this is not necessarily the case as Badham (2009) shows that support does exist for hastened death from within the Christian community and that religious principles can be recruited to support assisted dying. Patient attitudes toward legalisation of euthanasia and physician assisted suicide vary independently of their religious beliefs as shown in one patient study (Wilson et al (2000), in which 64% of Roman Catholic and Protestant patients were in favour of legalisation.

Agencies contributing toward determination of policy and practices relating to the ongoing UK assisted dying debate include senior representatives of three major religions<sup>14</sup>, who are unanimous in their opposition<sup>14</sup> to the legalisation of assisted dying (Howarth and Jefferys, 1996; House of Lords,2005). The three great monotheistic religions (Christianity, Judaism and Islam) forbid hastened death through euthanasia and physician assisted suicide (Dorff, 2005; Sachedina, 2005). However, Howarth and Jefferys (1996) claim that religious authorities are losing previously held power over today's debates surrounding legalisation of assisted dying

In the healthcare professions engaged in end-of life care, religious belief, ethnicity and speciality influences professional attitudes toward legalisation of assisted dying, the use of continuous deep sedation, and intent to shorten life (Waddell et al, 1996; Cohen et al, 2006; Gielen et al, 2009; Pugh et al, 2009; Seale, 2010). Stronger religious faith in nurses is associated with greater opposition toward legalisation of euthanasia (Verpoort et al, 2004). Seale's findings also show religious belief influences clinical decision-making. The care patients can expect to receive at the end of life may therefore vary dependent on the relative religiosity of the professionals involved.

In considering the relationship between religiosity and membership of a right to die organisation, studies of the US Hemlock Society membership show religious affiliation to be rising over time; from 49% in 1983 to 59.5% in 1995 and 64.5% in 1995 (Cossman et al,2002), demonstrating that religious belief does not necessarily preclude membership of a right to die society nor does personal religiosity necessarily

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<sup>14</sup> Christianity, Judaism, and Islam

prevent support for legalisation of physician assisted dying or euthanasia in terminal illnesses. In the later study by Blevin et al (2005), among participants who believed in an afterlife or were “not sure”, none indicated their religious beliefs conflicted with assisted death.

The extent to which religiosity is reconciled with, or even used to justify support for hastened death amongst members of UK right to die societies remains unknown, although some professed UK Christians have indicated their support for legalisation of euthanasia and/or assisted dying (Howdle, 1998, Badham, 2009). Also, little is known about how religious individuals, in particular right to die society members, might personally reconcile their religious beliefs with pro-right to die attitudes although in one small sample of US right to die society members who were religious or believed in an afterlife, none believed that assisted death at the end of life was punishable and most saw no spiritual value in suffering (Blevins et al, 2005). Seale (1998, P187) suggests that religious and cultural influences “fade into insignificance in the face of the overwhelming physical and emotional experience of suffering”.

It is clear that, despite prohibition of euthanasia and physician assisted suicide by many of those in positions of religious authority, religiosity does not always preclude support for legalisation of hastened death or for membership of right to die societies. In those jurisdictions where hastening of death (by euthanasia or physician assisted suicide) is legalised (The Netherlands, Belgium, Switzerland, and the US State of Oregon) levels of religiosity tends to be high amongst the general populations. The 2000 Swiss census, for example, showed over 78% of the population were religiously affiliated

(<http://www.bfs.admin.ch/bfs/portal/fr/index/themen/01/22/publ.html?publicationID=1615>), and in the Netherlands circa 60% are religiously affiliated

(<http://www.nationmaster.com/red/country/nl-netherlands/rel-religion&all=1>). It is therefore not unreasonable to suggest that an unknown number of UK right to die society members are likely to be religious, and able to justify their beliefs on religious grounds. In the absence of other studies showing the extent to which UK right to die society members might also be religious, this study reports on the religiosity of members of FATE, and how members reconcile their religious beliefs with their support for this right to die society.

## 4. Discussion

This review offers a theoretical framework for understanding why some people desire a legal option to choose a hastened death and so join a right to die society in the UK today. It proposes that social factors including ageing, existing terminal illnesses, religiosity, self-attributes, experiences of suffering, altruism, risk, vulnerability and economic cost/benefit considerations are likely to be collectively responsible for their joining FATE.

So who joins FATE and why might people join this right to die society? Development of this review is informed by the research questions as detailed in Chapter 1:

1. Who joins FATE and why?
2. What influences are responsible for shaping peoples' personal beliefs and motives for joining?
3. To what extent might similarities and differences exist between FATE members and members of the US Hemlock Society?
4. Can right to die society membership be a product of reflexive formation of self-identity, characterised by risk profiling, risk avoidance and agency, that more generally typifies self identity in late modernity?
5. Is providing care for, or close association with, terminally ill individuals implicated in influencing pro-right to die attitudes?
6. Do parallels between terminally ill patients' reasons for anticipating a need for "requested death", or for requesting assistance to die and FATE members' reasons for joining exist?
7. Can religiosity co-exist with pro-right to die beliefs?
8. Is altruism implicated in decisions made to join FATE?
9. Might socio-economic matters such as costs/benefits be implicated in decisions to join FATE?

The right to die movement as a new social movement reflects an ongoing conflict between the establishment and individual members of the public. Little empirical evidence is available to show who joins a right to die society in the UK today and the reasons why people do so.

As campaigning societies, members of the worldwide right to die movement collectively conform to criteria for a new social movement and to health social movements in particular due to the movement's activities that challenge society's established cultural values in the health, legal and moral establishments. As part of this new global social movement, desire for choice and control over managing dying and death drives right to die activism in UK member societies, including FATE. Views differ as to why this phenomenon has arisen and continues to exist in the 21<sup>st</sup> Century, although it is clearly a product of societal values and practices. I hypothesised that people will join a right to die society because the societies in which they exist are characterised by cultures, values and practices that cause some individuals to consider hastened death to be a desirable and/or a necessary option. Current values and practices relating to medicine, law and the religious establishment in contemporary UK society suggest this hypothesis is supported.

Some authorities suggest secularisation of society might be in part responsible for the rise of the right to die movement but this is not definitive as evidence exists for religiosity co-existing with positive attitudes toward a right to die. Others suggest bio-medical advancement having fundamentally changed the way people die, and the length of time they take to do it, has imposed unpleasant ways of dying on unknown numbers of people, that could be implicated in decisions to join the right to die movement. I argue that another cultural factor implicated in right to die society membership, specifically FATE, is the risk culture existing in contemporary western societies including the UK. Risk and risk prevention currently pervades the fabric of UK society at all levels and within this risk and vulnerability to risk culture, I propose that heightened awareness of the risk of bad experiences during dying and death are likely to inform some peoples' sympathies toward a legal right to die being made available.

The review presents evidence for a marked contrast between levels of UK public support for legalisation of hastened death (although whether the general public fully understands the implications of legalising hastened death is open to question) and the views of UK doctors and nurses in whom high levels of opposition are evident. These contrast markedly with professional opinions in some of the jurisdictions where hastened death is legally permitted, but it remains questionable whether professionals' views might be open to modification or whether their personal views may differ from

their professional views, and if so, for what reasons. I suggest that ageing is one of the most likely factors to be implicated in modifying previously held views on hastened death. Politically, despite the consistency of public opinion, representatives in the UK parliament are not required to support the views of their constituents in debates such as the right to die debate. With the right to a 'free' or 'conscience' vote being enshrined in parliamentary procedures<sup>15</sup>, this could potentially be another factor informing peoples' reasons for joining the movement, reflecting individuals' relative powerlessness within the socio-political system.

The literature review also shows how specific characteristics of contemporary UK society, and its value systems, are likely to be implicated in supporting right to die society membership within a discrete section of the population. Data from studies of the Hemlock society indicate older age, more females than males, and higher social class are a consistent feature of right to die society membership. Higher social class relates to specific attributes of self efficacy. The emancipated reflexive self in an individualistic society therefore offers one potential factor implicated in influencing decisions to join the right to die movement. In a society that values self-efficacy, positive attributes of self including effective self-management, of increasing importance in higher -level occupations, these personal attributes are likely to be factors responsible for desires for choice and control, core features of right to die society rhetoric, over the manner dying and death. Threats toward the self such as dignity compromising bodily unboundedness are shown to induce disgust in self and others. It is shown how upholding the accustomed self can be challenged by bodily disintegration, resulting in humiliation and loss of dignity. Loss of mental capacity is also a significant threat to self, fear of loss of mental capacity being a repeated concern noted in studies of patients.

The argument that the ability of medicine to prolong poor quality lives might influence people to join a right to die society is supported by data drawn from studies that show how a potential exists for dying being extended over long periods accompanied by increasingly adverse quality of life and opportunities arising through medical interventions and care regimes for imposing prolonged suffering. As this particular argument is aimed toward providing an answer to the overarching research question of

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<sup>15</sup> <http://www.parliament.uk/site-information/glossary/free-vote/>

why people might join a right to die society, and a body of evidence for the existence of such negative possibilities exists, at the same time it is important to acknowledge that medicine's capacity to extend lives also confers immense benefits on peoples' health and the quality of their lives as they age and during the course of terminal illnesses.

With reference to Brown's (2008) model of ageing, in this review I have treated ageing as commensurate with lengthy dying, subject to possibilities for prolonged suffering. This is particularly relevant for people entering the fourth age, in which physical and mental incapacities are likely to accelerate. Although the acceptability of hastening death is shown to vary in studies of older people, the review presents evidence supporting the view that ageing is likely to be an important driver of right to die society membership through showing how longer life expectancy can extend the duration of dying in a culture where disempowerment, stigmatisation, marginalisation and institutionalisation of older people have been shown to exist. The negative impact upon body and mind characteristic of the fourth age (Gilleard and Higgs, poses many threats toward individual wellbeing. Potential losses of physical capacity, social agency and mental capacity and the threat of institutionalisation; losses of dignity, agency and quality of life are all likely to generate fear of the fourth age. Loss of control over body boundedness serves to compromise accustomed and acceptable standards of behaviour in society. I suggest that the risk of inability to comply with and maintain social norms relating to personal standards of bodily control and bodily hygiene in older age is likely to be an important element informing desire to have the option available for hastened death in the future.

With the incidence of dementias increasing with age, it is understandable that some individuals might wish to forego the fourth age altogether, and of these, some could take action in the hope that they could do so through joining a right to die society. It may well be that it is the fourth age that provides the biggest threat of all toward the wellbeing of individuals and society as a whole, due to its increasing demands upon personal and national resources, and for individuals, potentially, accumulating forms of suffering and loss.

The lived experience of advancing age associated with multiple threats to future wellbeing and uncertain levels of risk associated with engagement with the healthcare

system posed by the medicalised versions of ageing, plus threats of loss of mental capacity, resource limits for care and threats of sequestration from society and chosen lifestyle offer fertile soil in which right to die societies could possibly flourish. A case is offered for peoples' personal values relating to the management of their bodies in ageing and dying to bear some responsibility for decisions to join the right to die movement. Kellehear (2007) observes that modernity has become associated with "the shameful death" despite the advances in medical technologies and skills; deaths deemed shameful because of the labelling and stigmatisation of older people, stigmatisation of infectious diseases such as AIDS, and removal of older people from their communities into nursing or other residential homes. I contend that it is likely that perceptions and fears about the potential for future threats to self and wellbeing might serve to perpetuate right to die society membership.

I hypothesised that individuals who join FATE are likely to have had personal experiences of caring for terminally ill others and as a result, anticipation of similar forms of future suffering would be a factor informing decisions to join FATE. Suffering, dimensions of suffering and risk of suffering over a continuing dying trajectory is shown to be associated with desire for hastened death in terminally ill patients. Personal experiences of suffering are reported on the Dignity in Dying website<sup>16</sup> by its members; it is likely that some FATE members will have joined the movement because of experiences involving suffering.

I hypothesised that religiosity can co-exist with commitment toward legalising hastened death. Evidence cited shows that although the major religions proscribe hastening death, the opinions of some authorities, and evidence from the Hemlock Society studies, indicates that the official stance taken by the main religions on physician assisted suicide/euthanasia is not necessarily concordant with the views of all their adherents. This lack of consensus between religious laity and religious leaders toward hastening death suggests some members of FATE are likely to be religious, although as evidenced in the Hemlock studies, they may be in a minority and are likely to exclude people from specific religious backgrounds and ethnic groups, notably persons from African-Caribbean backgrounds and adherents of Catholicism and Islam.

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<sup>16</sup> [www.dignityindying.org.uk](http://www.dignityindying.org.uk)

# Chapter 3: Literature Review (Part B)

## The Self, Biomedicine and Contemporary Dying

### 1. Theories of self and individualism

Theoretical concepts of self, individualism and agency offer a framework within which decisions made to join a right to die society and the reasons underlying those decisions, may be understood, pointing to the importance of a particular approach to the self that is characteristic of late modernity, and I hypothesise that reflexive self-identity is implicated in pro-right to die attitudes. This section aims to show how theory-based attributes of self in modernity are likely to mirror particular characteristics of persons motivated to join a right to die society, based on the premise that such individuals will embody self-characteristics of individualism and agency, with widened expectations of choice. Walters (2003) asserts English individualism stretches back at least to the 12<sup>th</sup> Century, profoundly influencing English cultural approaches toward death and “the good death” as an ideal, which is retained in the UK’s contemporary multicultural society. Kellehear (2007) associates individualism and urbanisation with heightened anxieties about death, this being explained by the gradual waning of past ritualised “cultural prescriptions” surrounding dying and death. Now, individualistic cultures embody expectations of freedom, autonomy and emancipation of the self with choice an idealised concept in the late modern self (Strathern, 1991).

Contemporary UK politics operate within a nexus of mechanisms that seek to fulfil political, social and economic goals through making choices available to individuals (Giddens, 1998). With choice a fundamental component of daily life associated with lifestyle choices and life politics, lifestyle has become a material representation of personal narratives of self-identity (Giddens, 1991). However, choices made available through these systems of authority can also operate as a tyranny of subjectification (Giddens, 1998), imposing unwanted choices, insufficient choices, or choice options actively preventing individuals from access to autonomous freedom of choice within a given domain. One contemporary example of this is demonstrated by the current NHS choice agenda in which the choice agenda for patients operates within narrowly



defined limits<sup>17</sup>. In practices surrounding 'choice' in healthcare, according to Rose (2007), management and communications of these practices involve coercion through seeking to manipulate the self into new reflexive pathways that can alter healthcare decisions in ways that achieve results desired by healthcare professionals, healthcare managers, or ultimately, healthcare policy makers, constituting a form of dominance through offering desired options under the guise of choice. Rose (2007) also maintains that although choice has become adopted as an ethical principle by agents exerting a pervasive biomedical control throughout society, coercion and consent are woven into a complexity of social entanglements that serve to compromise freedom of choice. Choice as a quasi freedom may therefore constitute a harm rather than a benefit as it can deny people their preferred choices. Another example of choice as a form of control occurs through risks and potentially negative consequences associated with those choices on offer. Excessive possibilities attendant on the consequences of having choice may breed anxiety about making the right choice (Salecl, 2010).

Multiple choices may be seen as oppressive by older persons whose preferences can be for fewer choices (Reed and Mikels, 2008) and multiple "choice overload" can result in adverse experiences (Reed et al, 2011). Autonomy itself can operate as a form of oppression according to Foster (2009) in respect of its attempts to transcend established ethical principles such as the sanctity of life, beneficence and non-maleficence, in particular with reference to doctors being expected to respect patient autonomy while at the same time, being expected by autonomous patients to act in ways that could conflict with the ethical principles required of practicing doctors. Foster sees autonomy operating as a hegemony in contemporary society, that does not necessarily act for the ultimate benefit of patients. This view raises a question about whether medicine also acts as a hegemony that similarly may not always operate for the ultimate benefit of patients regardless of the ethical principles underlying medical practice.

For members of right to die societies, it is likely that "deathstyle" choices might represent, in principle, an extension of Giddens's concepts of lifestyle choice as a

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[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_103479](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_103479)

reflection of self-identity in a modernity in which individualism and self-efficacy are closely linked with the plurality of choices available.

The right to-die movement already existed when new theoretical concepts about the nature of the individual self were appearing in the 1970s. Michel Foucault (Clark and James, 2003), Anthony Giddens (1991) and Nikolas Rose (1996) conceptualise the late modern self as a self-regulated phenomenon or paradigm, its individual characteristics reflexively mediated by life experiences, social status and relative affluence; the process of reflexive self-adjustments involving interplay between external factors and internal self-governing mechanisms. Self-identity, self-control and self governance tend to be concentrated in more highly educated groups, with planning for and controlling major life events a significant aspect of self-identity (Seale, 2000). Reflexive construction of self is also likely to be influenced by personal values and concepts of an ideal self. The birth of psychology as an academic and clinical discipline adds a further dimension to conceptualisation of self through behaviour-based theories of self-efficacy, perceived behavioural control or locus of control theory (Ajzen, 2002). Self identity is created, as an individually designed construct composed of personality traits chosen and assumed in the interests of the individual concerned in order to relate to the world in ways that individual deems desirable, through assemblage of “technologies that create individual agency and freedoms”, collated to enable individuals to choose the persona they present to the world (Rose, 1996). Not only does psychology explain features of self but it is in itself an externally applied mechanism governing self and its freedom, with the modern self “intrinsically bound to a regime of subjectification” that obliges the modern individual to act as if free (Rose, 1996). Goffman’s (1959) theories of self suggest the reality of the self is not necessarily exposed because the public face of self is presented via a performance through which individuals present their version of an optimally idealised image to the world; self-presentation therefore being a matter for choice. This being so, anticipation of being unable, through terminal illness, to choose or ‘perform self’ may pose a threat to personally idealised forms of self-presentation, representing a loss of self. Individuals’ identities and how they present themselves to the world in modernity depend on reflexive, intentional self-construction with disjunction occurring between the ideal self and threats posed to that self by suffering during extended dying trajectories; suffering being orchestrated by cultural, medical and religious norms within contemporary western societies (Kaufman, 2000).

Rationality and pragmatism as qualities of the ideal self are implicit in right to die movement rhetoric through promoting the need for legalisation of hastened death as providing a rational choice for a guaranteed good death in the face of intolerable suffering. Opinions vary as to whether suicide, and by inference assisted suicide, could be a rational choice for achieving a good death. On one hand, desire to hasten death is considered irrational due to the presence of depressive illness (Emmanuel et al, 1996; Emanuel et al, 2000; Lavery et al, 2001; Kelly et al,2002; Johansen et al,2005; Pearlman et al, 2005; Chapple et al 2006; Chochinov et al,2002), although distinguishing between depressive illness and intense normal sadness may be problematic (Wakefield et al,2010). In contrast, Lester (2006) maintains choosing suicide should not necessarily be assumed to be illogical, irrational or the product of a psychiatric condition. Prado (1998) argues that suicide in older age, although generally categorised as pathological in origin might also be sacrificial for the sake of others, or even a sensible solution to pre-empt older age or terminal illness-related deterioration but suggests such views tend to be culturally dismissed.

With perceived right to freedom and choice in dying framing the rhetoric of UK right-to-die societies, the idea of an emancipated, reflexive self, examining and re-shaping itself in response to life experiences, fulfilling expectations of choice, autonomy and control resonates with the ethos of the right -to-die movement, given that people are likely to act in ways that protect the attributes of self they most value. Contemplating a future in which valued autonomy and self-efficacy might become threatened through the self-diminishment imposed by patienthood (Daneault et al, 2006), acquired morbidities in advancing age or terminal illnesses might therefore attract opposition toward perceived threats to selfhood implied by joining a right-to-die society. I suggest that individuals joining a right to die society will be more likely to be predominantly those whose selves are individualistic and emancipated.

But some questions remain unanswered with regard to an association between emancipated reflexive selfhood with right to die society membership. Data from the US indicates older and female members predominate; why this may be, how might the relative absence from US right to die societies of less educated persons and persons from cultures other than white be explained, how might culture, custom, and religion influence membership, and to what extent might these factors be replicated in the UK

right to die community cannot as yet be fully explained. Fox et al (1999) suggest the predominance of female members of the Hemlock Society might be due to women being more likely to take a proactive approach to future risk associated with dying due to increasing longevity and the likelihood of outliving their partners. Also, the predominance of older age is suggested by Fox et al (1999) to be associated with the increasing salience of death and dying issues as age advances, but the authors note that because Hemlock Society members are culturally different from the general US population, this does not provide a definitive explanation. Based on the US studies, cultural and social class barriers toward right to die membership appear to be mediated to a degree by religious belief, ethnicity and educational level.

### **1.1 Threats to self: longevity, prolonged dying and diminished quality of life**

For individuals who choose to join the right to die movement, anticipating threats toward accustomed self-efficacy and self-agency imposed by longevity, bodily malfunctioning, diminishing quality of life and contact with the healthcare system (Öhman et al, 2003) is likely to provide impetus toward seeking to retain control of their future dying and death. Anticipation of extended dying might also encourage people to join the right to die movement. Munday et al (2007) quote three categories of dying trajectory: long periods of chronic illness with short period of terminal decline, gradual functional deterioration punctuated by episodes of serious acute illness and 'prolonged dwindling' of the very elderly. Each of these categories describes a lengthy dying process. Terminal illnesses in some instances extend over periods as long as 15 years (Wilson, 2000). Suffering experienced during slow dying in older age of long-term chronic diseases can lead people who "prefer assisted sudden death to assisted slow dying" to seek an earlier death (Kellehear, 2007). Kellehear (2009b) observes that dying by suicide in old age "is the largest age-related suicide rate". However, living with severe, enduring and progressive chronic illnesses in older age, by definition part of the dying process (Brown, 2008), in association with multiple forms of physical and emotional suffering, are accompanied by human qualities of ability to adapt, endure, and to derive some measure of well-being and happiness from their situation (Öhman et al, 2003).

The ability to enhance and maintain health and well-being in an extended older age is one of the most significant positive achievements of medicine over the past Century. But at the same time, medicine's devotion to saving life, while lacking the ability to halt ageing, can prolong dying, sometimes over the course of many years (Brown, 2008; Heath, 2010). For many people, dying is longer "than ever previously in human history" (Ashby, 2009); individuals are likely to have unique fears and concerns about their own dying process (Buckman, 2000) and dying can be feared more than death itself (Carmel and Mutran, 1997). Brown (2008) contends that people face "real horrors" at the end of life because society has not addressed the issue of how people should exit life and suggests that a socially determined solution is required to address this socially created crisis. Kellehear (2007 pp.236) notes issues surrounding the timing of death that include obsessive prevention of dying through technological "over-servicing", suggesting a tendency to prevent people from dying "in their own time". Daily symptom burden in chronic diseases can be high (Janssen et al, 2008) life-extension may not necessarily improve or maintain an acceptable quality of life, nor avoid imposing additional suffering. Chronic illness has a significant impact on individuals in terms of physical symptoms, care needs and perceived meaning of self and identity (Harman and Clare, 2006). Potential for threats toward the self in situations such as these, arising from extended longevity, is demonstrated by the numbers of years people spend in poor health and with disabilities later in life (Office for National Statistics; Social Trends 39,2009) and the exponential increase in incidence of dementias accompanying increasing age (Alzheimer's Society, 2010).

Extended longevity associated with vulnerability threatens the self, through 'vulnerability' having become an externally assigned characteristic of self; a descriptor of intrinsic identity rather than a circumstantial state, evidenced by "the newly emerging term, 'the vulnerable'", suggesting powerlessness and fragility of self (Furedi, 2007). Vulnerability can be created and enhanced through systems providing care; patients are made vulnerable when "naked, prone, weak, (and) subject to the surveillance and control of stronger clothed staff" (Twigg et al, 2011). The palliative care ethos tends to reinforce ideas about dying person's vulnerability, loneliness and helplessness through their concern with avoidance of dying alone, even though this may be preferred by some, symbolic of personal agency (Kellehear, 2009a).

The meaning of quality of life, like suffering, is a complex personal construct (Finlay, 2005) and individually unique (Kaasa and Loge, 2003). Better health status and longer life are not the only factors influencing quality of life in older age (Lloyd-Sherlock, 2000) as social, economic and political change have had both positive and negative consequences for older people. Desire to have lives prolonged through the use of life-extending technologies is not always welcomed by older people, depending on quality of life post-intervention (Underwood et al, 2009). Challenges to quality of life issues in extended longevity are likely to contribute toward disempowerment of the self. Towards the end of life, quality of life may be, in part, determined by the quality of care received. Quality of life is a central concept in palliative care (Kaasa and Loge, 2003) and an important factor in maintaining the palliative care movements' stated aim for "achievement of the best quality of life for patients and their families" (The National Council for Palliative Care). Poor quality of life in dying patients is associated with desire for hastened death (Arnold et al,2004) and older people dying in settings other than palliative care settings may be denied the care regarded as "best practice" in palliative care (Holloway,2007). Important domains in delivering quality end-of-life care for cancer patients include not being kept alive (on life support) when there is little hope of meaningful recovery, being able to trust doctors involved in care and honest communication of information, at the same time acknowledging these may change as death advances (Heyland et al,2006).

Given the resonance between social and psychological theories of self (Ajzen,2002; Rose (1996), as a framework for care of dying hospice patients, Maslow's Hierarchy of Needs (Zalenski and Raspa, 2006), embodies determinants of self-conserving quality life for dying patients (Herbst, 2006). (Dis)Empowerment of the self can be considered in the context of Maslow's hierarchy of human needs that enable individuals to attain self-actualisation or personal potential and growth. Basic physiological needs (food, drink, warmth, sleep, air, sex), safety needs (security, stability), the need to belong (relationships, family, social contact) and needs for self-esteem and prestige all contribute toward the goal of self-actualisation. According to Clarke et al (2006) "Maslow's theory of human need and motivation is suited to underpin a measure of well-being, as it provides an explanation of what is required to improve life outcomes". How well a person's needs are being met throughout all stages of the dying process will affect the dying person's sense of self. Recent studies cited by Clarke are said to have widened the use of Maslow's theory "to consider development and well-being issues as strong links exist between understanding human motivation and defining

well-being.” A consequence of sequestration is to compromise need fulfilment and so, by implication, the sense of self. It is striking to observe how many of these needs will erode and be lost in the dying individual sequestered from their accustomed homes and communities. “Unsatisfied basic needs cause feelings of physical pain, illness and discomfort” (Clarke et al, 2006). As needs increasingly cease to be fulfilled as death approaches, it follows that the experience of loss and erosion of sense of self will accelerate.

## 1.2 Threats to self: suffering

*“The suffering that dying (and other) patients may endure is far broader than the experience of pain: suffering also involves the humiliation of physical dependence, loss of continence, and the distress of ceasing to be able to engage in meaningful relationships with others”.*

(Lawton, 2000, pp.178)

Kellehear (2009b) observes that “studies of dying have...largely ignored the growing literature on human suffering” and in his review of the literature on suffering notes that suffering is not a single concept, but “ a set of explanations about distress”, combining physical, perceptual and political components all subject to differing opinions about how these may be defined. Human suffering poses a major threat to maintaining integrity of the self (Lawton, 2000), and it has been argued that suffering is a response to dissolution of identity (Kellehear, 2009b). Health care services potentially contribute toward increasing levels of suffering, self-loss and adding to burden of illness through objectifying patients into “manageable units of pathology, affected organs and side effects of treatment”, so negating their personhood (Daneault et al,2006). Bodily suffering in terminally ill patients is understood to undermine persons’ will to live and influences desire for hastened death (Rasmussen et al, 2010) and is one of the most likely reasons for inducing patient desire to die earlier (Seale and Addington-Hall, 1994). However, heightened levels of suffering can be reduced through a range of self-conserving palliative care and other services’ interventions, and also by carers and by patients themselves through reflexive adaptation to progressive changes over the course of their diseases (Öhman et al, 2003), thus reducing negative effects of suffering upon the self.

Dame Cicely Saunders described suffering in terminal illnesses as “total pain” (Kellehear, 2009b). Medical assumptions about suffering tend to focus on pain (Cartwright, 2000; Seale, 1998) and before the 1990s pain was seen as a primary reason for requests for hastened death although it is latterly recognised that this is not necessarily the case (Boisvert, 2009; Monforte-Royo et al, 2010). Suffering is an individualised phenomenon (Verpoort et al, 2004) and partially subjective in nature; a “property of the whole person” (Sensky, 2010) and difficult to define (Rietjens et al, 2006). Seale (1998) quotes Illich (1976) to argue that medicine has lost the capability to conceptualise suffering “as a meaningful component of human existence”. This contention is reflected in every-day medical discourse in which ‘pain’ or ‘symptoms’ commonly refer to obvious patient suffering (Terry and Olson, 2004) and ‘suffering’ commonly refers to ‘diagnosis’ (as in patients suffering from anything between terminal illnesses and a hangover) (Sensky, 2010) rather than referring to the negative impact of a diagnosed condition on individuals’ bodies, minds and quality of life (Rodgers and Cowles, 1997). Rasmussen et al, (2010) argue that a “logical scientific approach” cannot provide an appropriate means of obtaining in-depth understanding of terminally ill patients’ suffering and Lawton (2000) believes professional talk about intolerable or unbearable suffering in dying to be more often confined to “pain” in order to avoid articulating less palatable or more elusive and subjective aspects of suffering, although existential and psychological factors are major factors in patient suffering (Syme, 2008). Terry and Olson (2004) found evidence for a significant percentage (28%) of suffering in hospice patients being entirely non-physical in origin. In light of these findings, “total suffering” as opposed to “total pain” could perhaps better describe the phenomenon of human suffering more aptly, due to conceptualising and measuring by an outsider of the sum of the constituent parts of any individuals suffering by its nature, intensity, subjectivity and variability between individuals, renders it unlikely to be fully amenable to objective measurement.

So, conceptually, the nature of individual suffering is elusive. Frank (2001) argues that the reality of patient suffering, apart from physical aspects, cannot be fully accessible to others as it resists articulation although Alaszewski (2006) argues that lived experiences of suffering can be understood through diaries and other personal documents, although in the case of terminally ill persons these may not be accessible to professionals providing care, nor to others until after death has occurred.. Unbearable suffering has been defined as “a subjective experience of suffering that is



so serious and uncontrollable that it exceeds peoples' capacity to bear (Ruijs et al, 2009). Carnevale (2009) investigates suffering as an emotion; while acknowledging Hacker's (2004) conceptual model of suffering corresponding best with "clinical suffering", his contention is that suffering is also an emotion that cannot be measured objectively due to its subjective nature. Suffering is complex, entailing "the assignment of meaning to a situation... and this meaning is intensely negative in nature...related to humanness and dignity" (Rodgers and Cowles, 1997). Also, non-physical suffering has a "profoundly moral status"; stories told about suffering form "moral parables of right and wrong, of moral virtue and moral flaw, of reason and rationalisation" (Charmaz, 1999).

Judgments about severity of patient suffering are inconsistent between medical professionals and specialties (Rietjens et al, 2009). Due to subjective elements in lived experiences of suffering, patients who perceive their own suffering to be unbearable may encounter professional disbelief, as suffering deemed unbearable by patients "must at least be recognisably unbearable for the physician" (Pasman et al, 2009). This may pose another challenge to patient self-efficacy as Pasman et al. suggest that physicians view physical components of suffering (symptoms) as more likely to be unbearable than the more subjective existential and psychological aspects of suffering (Pasman et al, 2009). Heightened suffering as a lived experience is difficult for professional observers to assess, measure and reach consensual accord between themselves and their patients as to the degree of intolerability being experienced by those patients (Reitjens et al, 2009); and especially in seeking to develop a holistic measure of an idiosyncratic, physical and existential, subjective state. Frank (2001) contends disjunction exists between doctors' assessment and interpretation of patient suffering and patients' actual lived experience of that suffering; further contending that persons are transformed into patients "when a diagnostic category is appended to his or her name" implying individual selfhood may be compromised through becoming subject to the professional gaze.

Rydal-Hansen's (2005) study of patients with incurable cancer proposes a model of existential suffering centering on increasing powerlessness, increasing loneliness and isolation and existing in a persistent and at times unconquerable struggle to maintain and regain control; these three key features mediated by patients at the mercy of their bodies, the illness, the treatment, the death, the professionals, their articulateness, and

the past, present and future. More recently a measuring device (SOS-V) claiming to be the first measuring device to assist in determining the degree of severity of patient suffering (Ruis et al, 2009) has been developed with end-stage cancer patients. Nevertheless, Frank (2001) asserts the lived experience of suffering, based on his own experience, remains:

*“concealed, impossible to reveal; it remains in darkness, eluding illumination; it is dread, beyond what is tangible even if hurtful. Suffering is loss, present or anticipated... We suffer the absence of what was missed and now is no longer recoverable and the absence of what we fear will never be. At the core of suffering is the sense that something is irreparably wrong with our lives, and wrong is the negation of what could have been right. Suffering resists definition because it is the reality of what is not.”*

Suffering is an under-researched and uniquely individual construct of physical and psychological factors (Rydal-Hansen, 2005). Frank (2001) questions the ability of qualitative research to enhance recognition of suffering and asks whether research merely becomes “an organizing practice through which medicine and society can avoid recognizing suffering.

### 1.2.1 Desire for hastened death: suffering experienced

Bodily distress can serve to separate the body from the self and lead to desire to end ones' life (Rasmussen et al, 2010). Desire for hastened death is increasingly debated in palliative care literature (Finlay and George, 2011). Terminally ill patients' desires for hastened death, and the complex reasons for such desires, are described in numerous studies (Kelly et al, 2002; Chochinov et al, 2002; Georges et al, 2006; Hudson et al, 2006). Constructs of suffering, distress and dependency differ between diseases and attitudes toward desire for hastened death and euthanasia (Seale and Addington-Hall, 1994). Despite receiving end-of-life palliative care, some terminally ill patients still express desire for hastened death (Kelly et al, 2003; Ganzini and Back, 2003; Jansen-van der Weide et al, 2006; Terry et al, 2006; Gill, 2009). Arnold et al, (2004) assert desire for hastened death at the end of life is not uncommon and cite studies attributing this desire to multiple quality of life issues and concerns about suffering. Concerns

about end of life care, quality of care and economic burden are also implicated in attitudes toward hastening death (Givens and Mitchell, 2009).

An analysis by Nissim et al (2009) of the multidimensional nature of desire for hastened death in advanced cancer patients subsumed findings under three main headings; as a persistent hypothetical exit plan, as a transient phenomenon expressive of despair or as a manifestation of 'letting go' arising in the last weeks of life when death is welcomed, feelings of despair being most pronounced during episodes of severe pain. The results of this study suggest desire for hastened death "is not necessarily pathological" and this may explain the small but relatively high number of requests for hastened death reportedly found in patients under the care of palliative care services. A higher incidence of suicide is found amongst patients with cancer and chronic illnesses than in the general population (Hudson et al, 2006; Nissim et al, 2009), suffering most likely being implicated. Some dying cancer patients who believe their suffering justifies euthanasia do so on the basis that (a) if life was perceived to be meaningless there would be no point in suffering further, (b) anticipatory fears about losses and future suffering and (c) mistrust about possibilities for receiving help if suffering was related to poor symptom control, nursing care and communication (Karlsson et al, 2011).

Common factors in studies examining patient motives for requests for euthanasia or physician-assisted suicide in diverse terminally ill patient groups associate desire for early death with pain, depression, hopelessness, poor quality of life, and loss of dignity (Emmanuel et al, 1996; Emanuel et al, 2000; Lavery et al, 2001; Kelly et al, 2002; Johansen et al, 2005; Pearlman et al, 2005; Chapple et al, 2006; Chochinov et al, 2002 and others). In these and similar studies, depression appears to be treated as an end rather than a means. Emanuel et al, (2000) report 60% of terminally ill patients support euthanasia or PAS in principle, but far fewer actually consider it for themselves. A study of 70 terminally ill patients by Wilson et al (2000) reports 64% supporting euthanasia and physician assisted suicide as legal options; those against legalisation citing religious beliefs and moral values, potential for abuse, an inappropriate role for physicians and other concerns as reasons for their stance. The most common reasons cited by near to death cancer patients' requesting euthanasia are general weakness, hopeless suffering, loss of dignity, meaningless suffering, physical symptoms and loss of control (Georges, et al, 2006). In a systematic review of 35 research papers (Hudson et al, 2006), the most common themes associated with requests for an earlier death in

terminally illness are pain, burden to others, loss of autonomy and control, physical symptoms and existential suffering. Other researchers report anticipated fears; “fear of losing independence”, “fear of poor quality of life”, “fear of worsening pain”, “fear of losing dignity” and “readiness for death” (Ganzini et al, 2002); and desire for choice over the timing of death and fear of loss of mental capacity (Chapple et al, 2006). In a study of hospice social worker’s perceptions of cases where patients or family members expressed a desire to hasten the patient’s death, reasons cited most frequently were decreased ability to participate in activities that make life enjoyable, poor perceived quality of life, loss of autonomy, depression, fear of being a burden to others, physical symptoms excluding pain, and loss of control over bodily functions with uncontrolled pain not being of major concern (Arnold et al, 2004). Amongst a sample of Oregonians strongly interested in physician assisted suicide (Ganzini et al,2009), the most significant reasons found for their interest were in order to retain control of circumstances of death, and, in anticipation of future suffering perceived as intolerable, poor quality of life, pain and inability to care for themselves. Physician assisted suicide appears to be seen by this sample of patients as “a protection against the risk of future experiences they do not believe they can endure”. Uncertainties about future dying clearly fuel interest in access to hastened death conditional on suffering becoming intolerable.

As in many studies of patients (Johansen et al, 2005; Ruijs et al.,2009 and others), desire for hastened death because of prospective concerns about ‘intolerable’, or ‘unbearable’ suffering in dying permeate right to die movement discourse (Dignity in Dying<sup>18</sup> ). Desire for a legal option to avoid intolerable or unbearable suffering fuels the movement’s raison d’être. Blevins et al’s (2005) study of US right to die society member’s prospectively held reasons for hastening death associated with their end of life beliefs found a majority belief in considering hastened death when terminally ill, with the anticipated future conditions informing desire for hastened death most feared being severe pain, severe breathlessness, impending losses of physical function and autonomy, burden on others, overwhelming fatigue, “time to die” and financial cost (of care). They further suggest that such pro-right to die attitudes are likely to be based on long standing value systems. Five years after enactment of Oregon’s Death with Dignity Act, Ganzini and Back (2003) report a revision of their original theories as to why patients requested assisted suicide. Physical symptoms were less likely to be the basis for requests although fear of worsening symptoms was implicated. Patients

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<sup>18</sup> [www.dignityindying.org.uk](http://www.dignityindying.org.uk)

requesting assisted suicide were of higher socio-economic status than the Oregonian population; requests were made despite palliative care services being received; patients were less likely to be depressed; many individuals who place great value on controlling their lives learned from adults in childhood to view receiving care from others as humiliating; and dependency was dreaded.

Desire expressed by terminally ill patients for hastened death, regardless of its origin, does not necessarily lead to action. In Oregon, between 1998-2010 the number of suicides by terminally ill persons is consistently far fewer than the number of lethal prescriptions issued to them (Death with Dignity Act Annual report, 2010). Australian Palliative Care service patients within 5 - 21 days of death who expressed positive ideas about suicide cited “ uncertainty about their ability to end their life without increased suffering or without implicating others in illegalities” or concerns about “the reactions of others to their act”; they were not concerned about the act of suicide being unjustified (Terry et al (2006).

Quill (1998) suggests that: “...the desires of healthy persons for control over the circumstances of their deaths may bear little relation to the desires and needs of terminally ill patients”. Reasons underlying desire for hastened death in a hypothetical future implied by membership of right-to-die societies are as yet not fully understood and it is not clear whether factors driving individuals to join a right-to-die society might be similar to factors driving requests for assistance to die amongst terminally ill patients. Prospective fears about status change from functional adult to patient (Lupton 2003), contemplating a future decaying and dying body (Lawton, 1998), anticipation of invasion of privacy involved in the care of a leaking body (Seale,1998) and contemplating the impact of future suffering on self and family members could potentially be implicated. Whether first-hand experience of such negative aspects of dying in others may influence a desire to control the timing and manner of future death is unclear. The possibility also exists that support for the right to die movement by non-terminally ill adults may be mediated by personal experience of the end stages of others' lives.

### 1.2.2 Desire for hastened death: suffering observed

*“How people die remains in the memory of people who live on.”*

Dame Cicely Saunders<sup>19</sup>

Personal experiences with dying and death can shape attitudes toward, and preferences about future death (Lam, 1982). McNamara et al (1994) recount instances where hospice and hospital nurses hold memories of deaths of relatives and patients cared for in hospital settings in the past, reminding them about better ways of dying.

Memories of repeated exposure to death may persist over months or years and remembered exposure to dying and death can either induce or reduce death anxiety (Bluck et al, 2008). Past experiences of “intolerable deaths” can influence patients’ interest in physician-assisted suicide (Ganzini et al, 2009) and suffering seen in others being responsible for inducing desire for hastened death has been identified in other studies of terminally ill patients (Verpoort et al, 2004; Hallowell, 2006; Chapple et al, 2006). The diverse components of suffering seen in patients in association with requests for hastened death are known to vary between individuals (Verpoort et al, 2004).

Experience of caring for dying persons has also been associated with positive attitudes toward euthanasia (Wilson, 2000), suggesting suffering observed in others can also be implicated in anticipatory desire for hastened death. Cartwright (2003) contends patient deaths have the ability to change carers’ attitudes toward their own deaths, and to induce desire in them to avoid similar experiences through affirming pro-euthanasia attitudes. Potentially, joining a right to die society could therefore be a product of suffering observed in others.

### 1.2.3 Desire for hastened death: suffering and pain

Pain and fear of pain have emerged as one of the most frequent cited aspects of suffering in studies of desire for hastened death (Vig and Pearlman, 2004). Fear of

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<sup>19</sup> <http://www.dyingmatters.org/site/about-us>

future pain and inadequate pain relief is a reality for older people (Gott et al, 2004) and dying patients and their families (Steinhauser et al, 2000). Since its inception, the palliative care movement has developed and refined the ability to provide highly effective control of pain and palliative care offers optimal end of life care (Kirk and Mahon, 2010) but it is acknowledged that palliative care cannot always achieve relief of suffering in dying individuals (Maddocks, 1996; Georges et al, 2006), and within palliative care and across other diverse care settings a pain free death is not guaranteed (Chapple et al, 2006, Holloway, 2007). Doubts have been raised that people dying from diseases other than cancer can expect their pain to be adequately controlled (Seymour et al, 2007). Fear of pain in dying might therefore be one concern that contributes toward desire to join a right to die society.

#### 1.2.4 Suffering: dignity, humiliation, and embarrassment.

Desire for death with dignity is a core tenet of the right to die movement and 'dying with dignity' is also used in reference to good palliative care (Kellehear, 2009c). Loss of dignity is one of many reasons cited by terminally ill persons in association with their desire for hastened death (Chochinov et al, 2002), Loss of dignity has also been cited as one of the most important concerns for patients who request hastened death in the Netherlands (Georges et al, 2007).

Definitions of 'good death' in the US include the concept of "death with dignity", and "there is growing support for the idea that human dignity is largely lost when the life of a terminally ill person is prolonged by technology" (Proulx and Jacelon, 2004). Proulx and Jacelon also contend that if dying patients are "passively compliant with societal norms, family wishes, or health providers' recommendations" their dignity may be compromised. These assertions are made on the premise that others may not view the dying patient as being as fully human as they are, that dignity is dependent on patients' ability to question social roles and on having a "voice to choose the circumstances of their death". Detailed accounts of what dignity means to people are not always clear (Jacobson, 2007). Allmark (2002) views the meaning of dignity being related to personal qualities that transcend indignities, although the nature of indignities is undefined. Various domains included in patients' concepts of personal dignity are becoming increasingly understood (Chochinov et al, 2002, Jacobsen, 2007). In one study of older people resident in care homes, dignity relates to levels of independence,

levels of symptom distress, effects felt by losses of homes and personal possessions and concepts of privacy as dignity-maintaining when receiving care (Hall et al, 2009).

Suffering experienced as losses of dignity and self through humiliation and embarrassment is reflected in studies presenting dying as “a collection of physical and psychiatric symptoms” (Seale, 1998). Twigg (2000) refers to dominant bio-medicalised models of ageing that reduce individuals to bodies and malfunctions along with more general crude stereotyping, objectifying and depersonalising of older people. Culturally, the act of delegating one’s intimate and personal bodily care to others may be abhorrent (Howarth and Jefferys, 1996). Desire to retain control over the manner and timing of death, represents desire to avoid prolonged disintegration of body, self-identity and social bonds (Seale, 1998). A bounded body is central and fundamental to selfhood (Kirkham, 2007; quoting Lawton, 2000) and Kellehear (2009c) refers to dying peoples’ “dismay and distress” when their bodily integrity fails. Maintaining a healthy body is central to self-management (Rose, 2007); thus bodily disintegration during an often lengthy dying process challenges self-efficacy and personal agency.

In tracing the history of manners related to excretion of body wastes, Elias (1939) describes a radical polarisation of social attitudes having taken place between the Middle Ages and the 20<sup>th</sup> Century; in earlier times “rustics” were said to be uninhibited in relieving themselves wherever they chose (Elias notes advice given to inspect the state of chairs before being seated) although at the same time higher social classes were being encouraged toward more modest behaviour. Now, in contemporary western societies, conventions surrounding bodily hygiene are important; privacy a social norm and unpleasant body smells considered socially unacceptable and stigmatising. Mary Douglas (1996) describes how negative attitudes toward dirt, pollution, contagion, taboo, fear and defilement have shaped social attitudes in terms of purity and impurity, and have influenced beliefs, behaviour and values. Disgust elicited by exposure to unpleasant smells is reinforced by product advertising promoting cleanliness, sanitisation and deodorisation over filth and decay, sending powerful value-laden messages about cleanliness versus dirt and stench (McPherson and Moran, 1994). In public spaces such as restaurants, for example, people find unpleasant body odour unacceptable (Martin, 1995). Studies of ageing and terminally ill patients demonstrate an association between loss of bodily integrity with its malodorous consequences, and loss of dignity, humiliation, stigma and disgust in



patients themselves and their carers (Lawton, 1998; Twigg, 2000; Brittain and Shaw, 2007). Since time immemorial, attitudes and customs relating to odour have been integral to different societies' customs and values (Claasen et al, 1994). Silence surrounding the dirt and decay associated with the dying body can be seen, according to Foucault, as a facet of discourse (Armstrong, 1997). Silence as discourse queries what cannot be said by ageing and terminally ill individuals suffering from malodorous bodily failures, due to culturally exerted inhibitions. In tracing the history of social attitudes toward natural functions, Elias (1939) shows how civilizing influences have applied behavioural restraints in relation to bodily emissions. Modern western societies associate the decaying body with revulsion and disgust (Brittain and Shaw, 2007), in relation to both sight and smell. As Lawton (2000) implies, loss of bodily autonomy and body boundedness associated with unpleasant odours are for society in general, topics for denial or avoidance.

Unpleasant body odours transgress socially sanctioned behaviour (Elias, 1939). Odours attendant on disease-induced bodily disintegration and human waste are less commonly articulated as causes of humiliation and embarrassment compromising self and dignity (Twigg, 2000). Twigg et al (2011) quote Lawler (1991 and 1997) to contend that nursing texts and discourse rarely articulate the realities of frontline bodywork in relation to dirty body work, with nurses eventually retreating from direct involvement with bodies through progression toward management; direct work with bodies in healthcare settings having migrated to less elite workers thus reinforcing stigma associated with polluted bodies (Twigg et al, 2011). Lawton (2000) noted how patients, carers and hospice staff expressed repulsion toward leaking malodorous bodies, associating them with "fetid animals festering in their own dung".

The uncivilised body (Gilleard and Higgs, 2000), in this context a leaking, foul-smelling body, culturally represents an abnormal and unacceptable feature of ageing. Bodily boundedness and bodily cleanliness are central to contemporary notions of disease and hygiene (Lupton, 2003). Maintaining bodily cleanliness at the end of life is perceived by patients, bereaved family members, physicians and other care providers as minimising patients' emotional suffering. Individuals whose bodily smells are repulsive to themselves and others are likely to feel shame, low self-esteem, and experience social isolation, anxiety and depression (Rehman, 1999). Vomiting, loss of control of bowel/bladder, and unpleasant smells have been cited (by proxy

respondents) as factors influencing desire for hastened death (Seale and Addington-Hall, 1994).

Loss of control of body functions is closely associated with humiliation and embarrassment (Twigg, 2004). Acquired urinary and faecal incontinence promote fear of odour, embarrassment and fear of loss of control plus shame, depression and diminished quality of life (Bordeianou et al 2007), often accompanied by high rates of psychological distress (Bogner et al, 2002). Studies of urinary incontinence sufferers indicate severe adverse effects on quality of life, social ostracism, stigma and fear of humiliation (Hagglund and Wadensten, 2007; Edgley, 2002)). Breaches of socially-conditioned behavioural norms (Elias, 1978) associated with loss of control of body boundedness in ageing and terminal diseases, and the reactions of others are likely to challenge self-esteem, compromise social interactions, and challenge personhood.

Bad smells have the capacity to embarrass, upset and repel others (Lawton, 2000) and disgust is likely to add to the distress of both carer and persons being cared for. Carers and care workers are intimately involved in “dirt, decay, decline and death”(Twigg, 2000) with some care workers finding body wastes and smells, phlegm, snot, vomit and false teeth most difficult to cope with and eliciting disgust. Haidt et al, (1994) suggest disgust is a likely reaction in individuals in intimate contact with those ageing and ill individuals whose leaking and disintegrating bodies emit unpleasant smells.

The body “occupies a territory where language itself becomes ...awkwardly polarised between the medical-clinical and the vulgar-demotic” Twigg (2000), illustrated by stigmatising references made to body odours as found in racist discourses (Claasen et al, 1994). Stigmatisation of persons with lung cancer interviewed by Chapple et al, (2004) experienced stigmatisation, primarily through overt avoidance by others or through being blamed for causing their illness, with negative consequences for their self-image. Similarly, Wilson and Luker (2006) interviewed people with cancer who perceived themselves to be both socially stigmatised and fearful of other negative possibilities occurring. Stigma is said to induce negative social identifications and self definitions (Charmaz, 2000). Stigma applies derogatory labels. Smelling bad is likely to be inherently stigmatising. Charmaz suggests that people often dissociate the underlying reason for a person’s malodour from a persons’ behaviour and stigmatise

through blaming them for their condition. The stigmatised person experiences fear, guilt and shame as a result. Also “guilt and shame increase when chronically ill people view themselves as socially incompetent... through inability to uphold basic social rules about cleanliness” and body functions. Stigmatisation therefore mounts an assault on the integrity of the reflexive and emancipated self. The work of Seale (1998), Lawton (2000) and others supports the notion of loss of self in the face of bodily disintegration causing body malodour.

In healthcare settings, medical discourse relating to disintegrating bodies and malodorous leakages tend to class them as symptoms to be treated, serving to distance professionals from association with lewd or humorous colloquial discourses referring to bodily emissions (Brittain and Shaw, 2007), at the same time symbolising medicines’ power and status (Lupton, 2000). Medical discourse is also seen to help professionals to create a space in which they can work (Seale, 1998), framing themselves as objective observers of patients’ reactions to their suffering (Perakyla, 1989).

Open discussion of loss of dignity through loss of control of body functions in association with bodily decay and strong smells being poorly tolerated in developed societies (Elias, 1985), is constrained by social convention (Elias, 1939). With body cleanliness” a central discourse in contemporary notions of disease and hygiene” (Lupton, 2003) loss of body integrity transgresses contemporary social values. Unspoken prohibitions prevent public discussion of smells associated with terminal illnesses and the dying body (Street and Kissane, 2001). Open acknowledgement of challenges to dignity by more unpleasant aspects of loss of bodily integrity is hindered, both for patients and professionals.

Prospective fears about loss of bowel/bladder control in persons with cancer/ALS (Ganzini et al, 2009) may be grounded in past experiences of unpleasant smells associated with illnesses and dying. Autobiographical memories, i.e. “episodic memories: recollected events that belong to an individual’s past” may be olfactory; autobiographical memories of unpleasant smells can be recalled at a future time (Rubin,2005). A smell-induced memory will, according to Rubin, bring back associated visual, auditory and spatial components of the memory triggered initially by the smell.

The evocative qualities of remembered unpleasant smells thus have the potential to cause episodic recall of distressing events as associated with ageing and/or dying bodies.

A persuasive case is offered for anticipated fear of self-compromising and unpleasant aspects of bodily disintegration in ageing and dying having some influence over decisions to join a right to die society.

### 1.2.5 Suffering: dementia and loss of self

The UK Alzheimer's Society's statistics identify 820,000 people with dementia in the UK, costing £23 billion per annum. This figure is projected to rise to over one million people by 2025. The prevalence of dementia rises with age, affecting women more than men (Alzheimer's Society, 2010) and over 20% of people with dementia are aged over 85 years (Gastmans and de Lepeleire, 2009). Pre-existing advance directives allow euthanasia to be legally performed for people with advanced dementia in the Netherlands (Gastmans and de Lepeleire, 2009). The UK's Mental Capacity Act (2007) now permits people to appoint someone in advance to make health-related decisions for them in the event of loss of mental capacity, that, while not allowing death to be hastened, enables an advance decision to refuse treatment to be enacted (Mental Capacity Act, 2005<sup>20</sup>).

It has been argued that dementia in later life is a social construct, a 'monster'; a "growing plague" created by medical technologies without regard for quality of life, through pursuit of ever increasing longevity with huge socially and individually damaging consequences (Brown, 2008). Dementia is a "public failure of individuals' claims to self-mastery and self-control" (Gilleard and Higgs, 2000), characterised by loss of self and identity (Harman and Clare, 2006). Dementias challenge the physical health and wellbeing of those who provide care, and older carers can be especially burdened by the added domestic responsibilities of dealing with incontinence and aberrant behaviours (Clarke, 2001). In dementias, where the body can remain functional while brain cell destruction progressively eliminates mind and self, Descartes's theory of dualism of mind and body ("I think therefore I am" [Cohen, 1996]),

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<sup>20</sup> <http://www.legislation.gov.uk/ukpga/2005/9/section/24>

provides a theoretical frame that recognises how dementia creates a schism between body and mind in which mind becomes progressively irretrievable while bodily systems continue to function to a greater extent. So although Turner (1996) suggests that sociology of the body rejects Cartesian mind/body dualism, dementia's course does appear to follow a process of separation between mind and body with progressive loss of personhood in the dualistic tradition. Fear of dementia, conceptualised as the body without a thinking mind (Shilling, 1993), with consequent loss of self-determination and ability to control the body - is evident among the general public. With age a significant predictor of support for being allowed to die in the presence of dementia, 50% of white respondents favour PAS and euthanasia for themselves and their partners in the case of severe dementia (Williams et al, 2007), but ethnic origin determines levels of agreement. Public support for hastening death in cases of dementia is greater among members of the Dutch general public than among Dutch physicians (62% v 6%; Rietjens et al, 2005) and 40% of cognitively normal older persons (>65) regard the loss of mental faculties as being "worse than death"; a majority favouring no life-sustaining procedures in the event of severe dementia (Gjerdingen et al, 1999). In light of dementia's devastating consequences for self and others, it can be expected that some individuals would not wish to 'do' advanced dementia. Desire to evade the consequences of advanced dementia and to prevent imposing the burden of dementia on others is likely to be implicated in decisions to join a right to die society. Dementia seen in others may be implicated in such decisions (Hallowell, 2006) and individuals may be concerned about maintaining themselves as they are customarily seen by others (Seale, 1996).

#### 1.2.6 Suffering: tired of living and/or tired of dying

Becoming tired of prolonged living or dying is cited by patients as a reason for desire for hastened death (Rurup et al, 2005; Magnusson, 2002), and for some, being tired of life may not necessarily be associated with severe illness. It is feasible to speculate that desire to manage future risk of severe symptom burden accompanied by weariness of prolonged dying processes might provide a further inducement for joining a right to die society. Becoming tired of life in older age resonates with the findings of Seale and Addington-Hall (1995) that very elderly females are more likely than others to favour death coming sooner rather than later. Quill (2004) suggests some patients become "tired of dying", when dying is prolonged. But although becoming tired of life due to symptom burden in terminal illnesses has been associated with requests for

hastened death, Magnusson (2002) acknowledges that such requests may also be due to inadequate care being provided.

### 1.2.7 Social suffering and social death

*“Because we are socialised into a social existence, its fading leaves us unable to be satisfied without one and results in feelings of helplessness and emptiness”*

Emile Durkheim, (1897) in Berk, (2006).

The onset of chronic disability in older age is likely to decrease peoples' ability to participate in accustomed social activities (Gannon and Nolan, 2007), a form of social death. The self as a social entity becomes diminished by social death, defined as “the cessation of the individual person as an active agent in others' lives”; dying persons may cease to exist socially through others' withdrawal from them although this may not necessarily occur (Mulkay, 1993). Wilkinson (2006) proposes “social suffering” as representing “the cumulative sufferings of everyday life”, and how modernity has exacerbated the hurts people inflict on each other; arguing a case for linkage between social suffering, health and risk through people being made “vulnerable to experiences of suffering”. He further argues for “the painful realities of suffering” being absent from social discourse, through populations being categorised with various “technical problems” (e.g. disability) to be addressed efficiently and with regard to cost. Hence he questions the point at which risk discourse is used to conceal rather than explain “the painful social realities of human experience”. Determinants of social death, as seen through the eyes of carers of people with dementia (Sweeting and Gilhooly, 1997), include situations when:

- The sufferer's life is believed to be a nuisance, carer looks forward to death
- The sufferer's life is seen to be hardly worth living, the carer is thinking ahead to the death
- The sufferer is ignored if present, their carers sees no point in acknowledging them
- The carer pays only slight attention to the sufferer

The transition between independent living and entering a nursing home symbolises separation, social segregation and approaching death (Mulkay, 1993). “The nursing home is a location greatly feared by people in the wealthy countries that paradoxically love to build them” and social suffering is potentially consequential on segregation of dying older people in nursing homes through stigmatization, abandonment, loneliness, infantilisation and loss of social agency (Kellehear, 2007); also helplessness, being placated, ignored, labeled and denigrated (Kellehear, 2009b). Syme (2008) cites diminished contact with family and friends, having to live with people not of their choosing, confinement for the benefit of others rather than themselves, segregation from mainstream culture, losses of freedom, role and lifestyle and loss of meaningful companionship as examples of social suffering.

#### 1.2.8 Suffering, fear of future suffering and planning for the end of life

Planning for the end of life has manifested itself in diverse forms throughout cultures and centuries. Planning for death in the Stone Age, according to Kellehear (2007) required individuals to assure their kin obligations were met. Durkheim, (1897) also refers to planning for the replacement of functions necessary for the wellbeing of the tribe or social group in the context of planning for the end of life.

Planning for the end of life (including ending life) in contemporary individualistic cultures reflects notions of personal autonomy, self-emancipation and desire to extend habitual control of living to dying. In contrast to the more ritualistic end of life planning of much earlier times, planning now covers a wide range of functions represented by wills, powers of attorney, life insurances, advance funeral preparations, and, for right to die society members, contingency planning for hastening death. Matters of most importance to patients in planning for the end of life include identifying proxy decision-makers, having financial affairs in order, knowing family members are prepared for the death and having funeral arrangements in place (Steinhauser et al, 2001). Latterly the UK’s Mental Capacity Act (2007) promotes advance planning for mental incompetence through two avenues; a lasting power of attorney whereby people can appoint in advance a person who has the power to make health and welfare decisions on their behalf in case of loss of mental capacity, and advance decisions to refuse treatment. However, planning for the end of life is neither common to all cultures, nor to all individuals. While many people actively engage in preparations for death, open

awareness in dying is not common to all cultural backgrounds (Kellehear, 2009b), therefore, apart from plans made over the longer term pre-terminal illness, closed awareness would be likely to inhibit any last minute planning.

Joining a right to die society represents a degree of preplanning for the end of, and for ending lives, driven by fear of future suffering in dying. Length of membership of the US Hemlock society is associated with the likelihood of practical preparations having been made for eventual death (Fox et al, 1999). Unrelievable or intolerable suffering is cited in UK right to die society websites (Dignity in Dying; Friends at the End) as a reason for legalisation of physician assisted suicide in the UK. Joining a campaigning movement such as the right to die movement can be seen as one form of pre-planning for death as campaigning activities are aimed toward achieving a legal option for hastening death to be made available, should this be needed in future. In the absence of such legislation, UK right to die societies offer various forms of assistance with end-of-life planning (Table 1).

Table 1: Pre-planning for death: information and advice offered by UK right to die societies

UK right to die society	Support toward end of life planning
Dignity in Dying: partner charity Compassion in Dying <sup>21</sup>	Advice on: <ul style="list-style-type: none"> <li>• Advance decisions</li> <li>• Lasting Powers of Attorney</li> <li>• The Mental Capacity Act</li> <li>• Summary care records</li> </ul>
EXIT (Scotland) <sup>22</sup>	<ul style="list-style-type: none"> <li>• Living will forms</li> <li>• Written Information: self-deliverance, voluntary euthanasia and departing drugs</li> </ul>
FATE <sup>23</sup>	<ul style="list-style-type: none"> <li>• Living will forms</li> <li>• DNR Order forms</li> <li>• Information and advice</li> <li>• UK Guide to Dignitas</li> </ul>

<sup>21</sup> <http://www.compassionindying.org.uk/>

<sup>22</sup> <http://www.euthanasia.cc/index.html>

<sup>23</sup> <http://www.friends-at-the-end.org.uk/>



Other forms of pre-planning for the end of life can involve active preparations for future suicide or assisted suicide. Pre-planning activities widely publicised by the media include membership of Dignitas, culminating in eventual assisted suicide in Switzerland (The Times, 15/07/09). Australian Dr Philip Nitschke (nicknamed Dr Death) is reported to have held workshops in the UK promoting an "exit bag", drugs from Mexico, morphine and "DIY Peaceful Pills" (Sky News, 05/05/09). Magnusson (2002) refers to obtaining lethal drugs through theft as a means of executing plans for ending life. Humphry (1992) gives practical advice including instructions for a do-it-yourself suicide using a plastic bag plus lethal drugs. A group of older Australians involved themselves in a project (the Peanut Project) to learn about how to manufacture a lethal suicide drug (Nitschke and Stewart, 2007).

It has not so far been established to what extent members of UK right to die societies might engage in pre-planning activities such as those offered by the societies of which they are members, or in illicit activities in planning for eventual death. This study reports on an initial attempt to address this knowledge gap.

#### 1.2.9 Threats to self: influence of observed suffering in humans and animals

As argued in Section 3.2.2, the experience of observing suffering in others can be instrumental in inducing desire for the option of hastened death for the future in order to avoid similar suffering, and joining a right to die society is a potential product of suffering observed in others. This argument can also be applied to suffering observed in companion animals, for whom the option for euthanasia to end their suffering is available and subject to legal requirements in the UK (Animal Welfare Act, 2006).

In studies of patients and others who express desire for hastened death, suffering perceived to be intolerable is sometimes represented through discourses about suffering animals whose lives would be ended in similar situations. "...you wouldn't put a dog through this..." (Lawton, 2000); "... we're kind and we put animals down...but when it comes to human beings...it's cruel. We wouldn't do it to our pet dog..." (Elliott and Olver, 2008)... "if it's good enough for the family cat or dog, it should be possible for us (doctors) to do it to humans" (Magnusson, 2002; "...I would want someone to do to me what they would do to any ordinary animal..."(Chapple et al, 2006). These quotes

illustrate perceptions of a morally unacceptable disjunction between compassionate euthanasia for suffering companion animals on one hand and euthanasia or physician assisted suicide being denied to suffering humans on the other.

Rachels (1986) argues that the Western tradition “places too much value on human life” in comparison with animal lives, through drawing attention to higher animal attributes shared with humans such as complexity of social lives, communication abilities and intelligence. But although morally appealing, unlike Rachels (1986), Bachelard (2002) and Elliott and Olver (2008) suggest the animal argument about compassion or mercy denies moral and social differences between humans and animals. This moral difference is of interest to this study in relation to how medicine’s imperative to save life is balanced against patients’ lived experiences of dying and it is argued that perceptions of this imbalance may exert some influence on decisions to join a right to die society,

As experts in animal euthanasia, the position taken by members of the veterinary profession regarding human euthanasia adds a further possibility for considering the human versus animal version of compassionate dying. Similarly to humans involved with human patients, vets experience distress in the face of prolonged animal suffering (Bartram and Baldwin, 2010). It has been suggested by Bartram and Baldwin (2008) that the veterinary role of facilitating good deaths for animals may induce belief in death (in humans) as “a rational solution to intractable problems” and a “favourable inclination toward euthanasia of humans”. Some evidence exists for positive attitudes toward hastening human deaths being held by UK veterinarians (Chilcott, 2007; Allen, 2007; Atkin, 2007; Bowlt, 2007), although how widespread such views may be within the profession is unclear. One study of Swedish veterinary surgeons’ attitudes toward hastening human death shows a high level (75%) of support for physician assisted suicide (Lerner et al, 2011) suggesting that some vets might invoke the principle of beneficent paternalism in human euthanasia, similarly to their practice with animals in which euthanasia is justified, unlike in humans, through animals lacking ability to exercise autonomy. (Lerner et al, 2011). Bartram and Baldwin (2010) associate permissive attitudes in veterinary surgeons toward human euthanasia and physician assisted suicide with suicidal thoughts and behaviour, and the incidence of occupational suicide is high in the veterinary profession (Mellanby, 2005; Mosedale,

2009). Whether veterinary suicide statistics include older, terminally ill members of the veterinary profession is not known.

Nevertheless, the argument advanced is that personal experience of observed suffering (in animals or humans) can be a powerful influence on observers, and experience of companion animal euthanasia can potentially induce both members of the public and members of the veterinary profession to consider joining a right to die society. The wide experience of animal euthanasia by members of the veterinary profession in particular is likely to be implicated in those vets who hold positive attitudes toward hastening death through euthanasia as a model for humane human death.

### **1.3 Threats to self: the body**

The disintegrating, leaking body has already been discussed in section 3.2.4 in the context of threats to self and joining a right to die society. This section focuses on the dysfunctional body and the aesthetic body in relation to threats to self.

The body and its external appearance represent self identity (Lupton, 2003) and the externally perceived identity of the ageing self is mediated by physical bodily appearance. The outward appearance of the body can be closely linked with assignment of social identity by others (Hockey and James, 1993). Drawing on the work of Goffman, Shilling (1993) argues that acceptance by society as “a competent and worthwhile human being” is dependent on body management. The contemporary cultural focus on body image and anti-ageing technologies reflect society’s negative images of older age that have become increasingly institutionalised (Gilleard and Higgs, 2000). The importance of the lived-in body through health, illness and dying, its symbiotic relationship with self, self-agency and self-efficacy, its appearance, function and boundedness are all inextricably linked with perceptions of self and social status (Hockey and James, 1993). Maintaining a healthy body has become a central focus for many people (Rose, 2007); representing control over the body and how individuals conduct their lives. The importance of the relationship between the body and the self is emphasised through conceptualising the body as “a practical mode of coping with external situations”, as an entity to be controlled in order to protect individual

competence to function, as a centre of power, discipline and self-control and as a mediator of competent social agency (Giddens, 1991). The body provides a means for displaying the self to others, and Giddens contends being trusted as a competent member of society is conditional upon bodily control. How individuals experience embodiment in a socially influenced milieu requires regular interventions into body functions to uphold desired social status (Giddens, 1991) in order to promote and maintain individuals' reputation for independence (Seale 1998)

In consumer cultures, body maintenance and appearance are concerned with optimum health, functioning and external appearance, requiring maintenance and repair (Featherstone and Hepworth, 1982). As a result, the ageing body is socially constructed as unnatural in modernity, with ageing representing a diminution in status (Twigg, 2006). Bodily deterioration over the course of terminal illnesses is liable to bring advancing disability and detrimental aesthetic changes in body image intimately linked with concepts of self-perception and self-“intactness” (Öhman et al, 2003). The concept of loss of self through ageing and loss of an accustomed body image that represents competence and functionality to the outside world, in particular in relation to acquiring a terminal illness, might therefore arguably influence some individuals to join a right to die society due to a desire to pre-empt the loss of an accustomed self.

## **2. Advances in biomedicine and contemporary dying**

*Of old when folk lay sick and sorely tried  
The doctors gave them physic and they died.  
But here's a happier age: for now we know  
Both how to make men sick and keep them so.*

Hilaire Belloc

*“We are getting nearer what is distinctively medical when we ask ourselves about the economics, logistics and morality of keeping people alive by medical intervention and medical devices...At what point shall we say we are wantonly interfering with nature and prolonging life beyond what is proper and humane?”*

(Medawar, 1982).

With ageing, dying and death as natural life events universally experienced by humans (Clark, 2001), accelerating changes in attitudes toward, and practices surrounding them have become a feature of modernity. Illich (1975), Kemp (2002) and Kellehear (2007) draw attention to historical changes taking place in life expectancy, in causes of death, in experiences of death and in attitudes toward dying and death, accompanied by, and to an extent influenced by bio-medical and technological advances. Brown (2008) argues that ageing, dying and death in developed societies are now played out within medicalised frameworks in which increasing longevity has given rise to new and more prolonged ways of dying and ageing has become increasingly conflated with the dying process. Conrad (2007) maintains that society has become increasingly medicalised due to “powerful social forces” internal and external to medicine. The social consequences are that an expanding range of human conditions have become medicalised, resulting in both benefits and harms to individuals and society (Conrad, 2007). Medicalised dying has, according to Scarre (2009), negative consequences for dying persons since this involves viewing dying solely through medical professionals’ disciplinary lens; exclusion of other valid viewpoints can prevent understanding of the meaning of peoples’ emotional responses to dying and what dying means to them in light of experiences in their past lives.

In the UK, over 65s are projected to rise from 16% (2006) to 22%, with people 85 and over forming 4% of the population by 2031 (National Statistics online, 2008). Brown (2008) asserts that death in older age groups is on average preceded by ten years of irreversible chronic ill health accompanied by with inexorable and cumulative cell death in all organs including the brain. With so many older people ill and dependent for longer than at any previous time in human history (Logue, 1993), lengthening life spans are likely to create major social issues (Spragins, 1999). Inevitably, increasingly extended lives will be accompanied by greater incidence and duration of chronic and life-threatening diseases and associated disabilities.

Medicine has moved beyond its previous role in restoring health to one of transforming human capacities; new norms created by ‘biomedical artifice’ having become a reality (Rose, 2007) and the capacity for the body to survive in poor health with multiple pathologies enhanced. Kaufman (2004) contends that a major consequence of the bio-medicalisation of ageing is for the aged body being seen “simultaneously as a diseased entity, a site for restoration and a space for improvement” and as such, medical

interventions to thwart the advancement of bodily ageing “permeates the social environment”.

Natural dying and death in this new era of transformative medicine is thus overshadowed by a dominant medical model in which extension of life and staving off death is a primary goal of medicine. Norms of clinical practice and ageing in modernity emphasise longevity, with death having become relegated to a “technical matter” (Giddens, 1991), representing ‘medical failure’ (Strange, 2009; Walter, 1994). Advances in medical technology have fundamentally increased the medical profession’s ability to extend life (O’Neill et al, 2003) with death having become something to be fought against rather than accepted (Thornton and Phillips, 2009). Buckman (2000) believes there is inadequate preparation of future doctors for dying and death during medical training because training is overshadowed by an overriding aim to save life. Also, Buckman suggests the prevailing medical culture surrounding dying patients is imbued with concepts of blame associated with patient deterioration and death reinforced during medical training through the overriding principle of saving life.

Heightened possibilities of death-postponement inevitably raise cultural expectations of increased longevity but might also serve to increase public resistance toward life extension in older age and terminal diseases. Kaufman (2000) suggests negative public reaction toward life-extending technologies (in this instance artificial ventilation) is responsible for the US right to die movement’s extension. Although medical advances in treatment of cancer, heart disease, dementia and other chronic conditions are highly valued in reducing mortality and disability (Ebrahim 2002), some individuals may dread extension of dying through application of life-prolonging technologies (Walter 2003). Lives can be maintained to an extent that may be “beyond the limits of what many would consider reasonable quality” (Waddell et al, 1996). Medical interventions can be “costly, painful and futile in the final stages of illness” (Spragins, 1999) and clear differences exist between medically-defined and patient-defined suffering (Terry and Olsen, 2004).

With new threats toward idealised “good death” arising through lengthening dying trajectories, I argue that evolution of newer ways of dying consequent on biomedical advances plays an important part in the right to die movement’s continuing existence.

The right to die movement poses a challenge to medicine's ability to extend life through its aim to free its members from socially and medically imposed but unwanted prolongation of life, through challenging the current balance between medical power and patient autonomy (Parker,2000). Anticipated threats toward future quality of life might influence some individuals to join a right to die society. Fox et al (1999) suggest that members of the right to die movement view the medicalised model of dying and death as saying " you must endure pain, indignity, alienation and loss of liberty in order to physically exist as long as possible and you must not give up (die) because others want you to physically exist...". However, this particular viewpoint relates to US culture and in the UK, the palliative care and hospice movements' aim to "affirm life and regard dying as a normal process" with care focused on symptom relief and support for patients and their families through the dying process (National Council for Palliative Care, 2011) rather than active life-extending treatments, is the antithesis of a medical model in which life extension is paramount.

While tensions exist between respecting patient autonomy in daily clinical practice and practitioners' inability to fully realise this ideal, particularly if this might involve a patient's desire for a hastened death (McNamara, 2004), medical practice within the palliative care and hospice movement, whose guiding imperatives are relief of symptoms and suffering (Ashby, 2009) contrasts with the over-medicalised approach said to be prevalent outside of this movement. For patients previously subjected to more aggressive forms of life-extending medical interventions, access to palliative and hospice care, in which death is accepted, seen as a normal, natural and inevitable part of life (Ashby, 2009), has been shown, in the opinion of proxies, to confer more highly rated care from doctors and nurses, greater preservation of patient dignity and more consistent pain control than hospital based care settings (Addington-Hall and O'Callaghan, 2009). Hospice patients exhibit high levels of satisfaction with their care in relation to written information, communication by staff and how well this was understood, time given to make decisions about care, privacy needs, the hospice environment, responses to calls for help and support if another patient died (Hastie et al, 2009) although questions about the efficacy of symptom control were absent from this study.

## 2.1 Medicalisation, power and governance

Western medicine has developed into a form of surveillance medicine in ways that emphasise the dualism of body and mind through practices that treat the body separately from peoples' understanding of it (Higgs, 2008). It has been argued that medicalisation of society and the human body have "replaced religion as the social guardian of morality". (Turner, 2008). Medicalisation of society is believed by some sociologists, including Illich (1976), to exert a repressive form of medical power and influence despite its inability to effectively treat a range of diseases (Lupton, 1997). This negative concept of medical power differs from Foucault's argument for medical power as a positive, productive good in society through acting as a resource for diagnosis and treatment of diseases and as a disciplinary power in the medical encounter, although this concept also has its critics (Lupton, 1997).

Furedi (2004) maintains society is subject to social control exerted through the medicalisation of problems of everyday life having been re-classified as "illnesses, disorders or syndromes". He contends this process of medicalisation has extended from the body to encompass cultural and social experiences of being. Additionally, he imputes this process with having created a culture in which people are no longer perceived to be competent to manage their lives without professional guidance, linking into a new culture of vulnerability of self to risk. Conrad (2007) describes an expanding sphere of medical social control, exemplified by medical surveillance and treatments that "change the behaviour, body or psychic state of individuals". Conrad also suggests the pharmaceutical industry exerts a powerful influence over societies and medical social control through its vested interests in changing norms in order to market their products.

It has been recognised that some US physicians are concerned about prolonging lives they judge to have no quality, and which they would not want replicated for themselves or their family members (Kaufman (2000). Also, Carmel (1999) suggests some doctors might impose life-sustaining treatments on older patients, on the ground of patients' best interests, under conditions in which they would not wish to undergo similar treatments for themselves. In a study of 355 US oncologists, Howard et al (1997) concludes that many participants (48%) could imagine a situation in which they would desire euthanasia for themselves, in some cases for non-terminal as well as terminal



illnesses, and those who desired hastened death for themselves would be more likely to provide it for their patients. These studies raise questions about whether and to what extent doctors' personal views might differ from their professional views, and whether, in some instances, views might change over time or in the face of retirement and ageing. Doctors might even join a right to die society because they lack confidence that professionals would always treat them as they might wish to be treated themselves. Also, concerns about potential differences between professional and patient values and those of family members might provide another reason for doctors joining a right to die society.

Medical and nursing staff control the manner (and the timescale) in which many people die (Costello, 2001) and doctors have authority to determine patients' "best interests" (Chapple et al, 2006). But Hardwig (2000) contends there are major problems in inferring knowledge about others or accessing their minds; only the individuals concerned best know their own "beliefs, desires, motives and intentions". The idea that dying patients may not be willing to share their feelings and concerns with others and may wish to retain "emotional privacy" from professionals and others (Terry et al, 2006) may hinder outsiders' attempts to determine competent patients' "best interests"; outsider decisions about best interests may therefore not coincide with those of a competent patient, especially in situations where a patient may consider their best interests are in dying. In this scenario, "best interests" as determined by a doctor may not always coincide with patient or family determined "best interests" or with doctors' own "best interests" should they find themselves in a similar situation. It is possible that individuals who might wish to determine their own best interests and wish to take action to assure their best interests are served might join a right to die society in order to assert more control over the manner and timing of death.

## **2.2 Techno-medicalisation of dying and death**

Fox et al (1999) aver humans have a love-hate relationship with (medical) technology. Medicine orchestrates contemporary dying and death, rendering it culturally meaningful through negotiating culturally appropriate deaths (Timmermans, 2005) that are techno-medicalised and fulfil socially mediated expectations of both members of the public and the healthcare professions. Although very great benefits are unquestionably derived through the techno-medicalisation of dying and death in modern Western societies, I

argue that medicalised culture also has the potential to threaten patient and family wellbeing during technologically extended dying processes, creating a possibility for influencing decisions to join a right to die society.

Continuing advances in medical technology serve to change both the nature of risks of dying, and risks in dying (Beck, 1992), from the perspectives of both doctors and patients. Although medical advances in treatment of cancer, heart disease, dementia and other chronic conditions are highly valued in reducing mortality and disability (Ebrahim, 2002), some individuals dread a dying process extended through life-prolonging technologies (Walter 2003). Given that such fears might arise through personal experiences of dying and death, it is feasible to question whether technological imperatives to save life could potentially obscure dying patients' best interests in having a good death prioritised in some instances. It has also been suggested that, "despite its early intentions", palliative medicine has become more likely to contribute to the medicalisation of dying, Clark (2002). Medical interventions can be "costly, painful and futile in the final stages of illness" (Spragins, 1999) and with medically-defined and patient-defined suffering differing in conceptualisation (Terry and Olsen, 2004), risk of dying badly appear likely to exist.

### **2.3 Good and bad dying in a medicalised culture**

With newer ways of dying, greater life-extending possibilities and new options for good or bad dying and death experiences having emerged in modernity, whether medicalised deaths are experienced as "good" or "bad" will also be influenced by culture, religious beliefs and life experiences. Also, concepts about good and bad dying are susceptible to conflicting criteria between individuals within cultures (Williams, 1990). In his study of elderly Aberdonians, Williams notes that among the variant versions of good death in this community, conforming to accustomed rituals surrounding of dying still persists in peoples' ideas about a good death.

Hospice care is primarily aimed at achieving a good death for dying people (Clarke, 2001). Decline in mortality over the past Century, and medicalisation of the dying process, have resulted in ways of dying not always compatible with the hospice good death ideal (McNamara et al, 1994) although this ideal is achieved to a high degree for patients cared for within both hospice and palliative care services and in other care

settings. Yet in terminal disease, both good and bad deaths may be experienced in any care setting, including hospice, as Lawton's (2000) study of one hospice demonstrated.

Increasing longevity does not necessarily guarantee good quality of life, nor well managed deaths for all. Evidence shows how patients can fear medical prolongation of dying (Steinhauser et al, 2000; Singer et al, 1999). The complex nature of dying trajectories in older age poses difficulties in determining whether individuals are either living or dying with their diseases (Lloyd et al, 2010). In addition, increasing longevity brings an exponential rise in the incidence of dementia, creating ways of dying that are "increasingly tragic and antisocial" (Kellehear, 2007).

The media tends to represent dying as a heroic struggle for life in the face of overwhelming odds (Seale, 2004) although death notices in UK national broadsheets convey a sense of death as a more passive experience through referring to the deceased having "died peacefully", implying a good death. Yet how dying trajectories preceding reportedly peaceful deaths are experienced by dying persons are largely hidden from public view. Accounts of bad deaths are necessarily provided by proxies post-death, making it difficult to assess objectively how bad, good or "good enough" (McNamara, 2004) the experience of dying might have been for the dying person. Proxy opinions about bad or good death must necessarily be viewed with caution (Teno, 2005). Patrick et al (2001) define the quality of dying and death as "the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died as reported by others" and present a proposed instrument for measuring the quality of death and dying. However, length and intensity of suffering experienced during the dying process as rated by patients pre-death and by professionals and family members after death is omitted from this instrument.

It is unrealistic to suggest that all death experiences will be polarised between the extremes of good and bad; but if dying and death could be consistently good enough, whether right to die societies would continue to exist is debatable. Perceptions and experiences of bad forms of dying would be arguably more likely to contribute toward pro-right to die beliefs but if the ideal stated by the National Council for Palliative care who "believe that everyone approaching the end of life has the right to the highest

quality care and support, wherever they live, and whatever their condition” were to be more widely realised, the right to die movement could lose its momentum, although as previously acknowledged, palliative care cannot always fully prevent patient suffering (Maddocks, 1996; Georges et al, 2006).

### 2.3.1 Concepts of ‘Good death’

The concept of a good death is “highly individual and dynamic... changeable over time, and based on perspective and experience”. (Kehl, 2006). One feature of individualistic societies is the good death through promotion of personal autonomy in dying that includes both palliative care and voluntary euthanasia (Walter, 2003). Palliative care and the right to die movement who share ideals about achieving good deaths can be seen as “products of the same mindset”, both “find support in individualistic societies that promote personal autonomy”, both acknowledge the existence and importance of death and both “enlist the aid of medical science to bring it under human control” (Walters, 2004). While everyone holds individual views about what constitutes a good death for themselves, Clarke (2001 [2010]) cites Clark (2002) who proposes common features of a good death in modern western cultures to be death free of pain, with open awareness, at home with family and friends, death in which conflicts and unfinished business has been resolved, death in which personal growth has occurred, and death in which individual preferences for the manner of death are fulfilled.

Historically, cultural and social concepts of good death were dependent on dying in ways that conformed to community expectations of positivity and meaning, being understood as such by the dying person (Kellehear, 2007). Ariès’ (1976) concept of ‘tamed death’ over many centuries is one in which death is accepted, prepared for, and follows expected rituals in the presence of others. In Medieval Europe religious strictures defined good death through religion’s concern during those times with avoiding eternal damnation (Thornton and Phillips, 2009) and the endurance of suffering enhancing the value of death in Catholicism (Walters, 2004).

Hales et al, (2008) maintain good death is not open to being defined as an objective truth. In modernity, constructions of good death are becoming “eclectic, highly individualised or located in specific sub-cultural groups” (McNamara, 2004) and

dependent on social and cultural norms (Walter, 2003), religious belief, age, economic and professional status and political interests (Lloyd et al, 2010). Steinhauser et al (2000) contend that what constitutes a good death is not fully understood; nor is the concept of a “good death” uniform within cultures or age groups (Gott et al, 2008) although some cross-cultural commonalities are found (Seale and van der Geest, 2004). A review of nine studies about the quality of dying identifies seven common broad quality domains<sup>24</sup>, but also shows how perceptions of good death vary between studies, methods, study participants and their status as professional, patient or proxy (Hales et al, 2008).

With the aim to ensure a good death for patients in the UK becomes more widely guaranteed, a good death for everyone has become a nationally recognised objective in the UK (Ellershaw et al, 2010). The Liverpool Care Pathway was introduced by the UK Department of Health in 2009, aiming to widen access to palliative end of life care provision for dying patients with a “good death” as the desired outcome. The quality of end-of-life care is material to quality of life for dying patients and for their experiencing a good death (Steinhauser et al, 2002), but patient and professional views about quality end of life care tend to reflect different priorities; avoidance of inappropriate prolongation of dying being an established concern for patients (Singer et al, 1999). Hospice care is rated more highly than hospital care by relatives of deceased patients in their last three months of life, in the domains of being kept informed about patients’ condition, receiving understandable explanations about patients’ condition, treatment or tests, not receiving upsetting information and ability to discuss worries and fears. Sufficient nursing care available, confidence and trust in nurses and perceptions of care patients’ received are all rated more highly in hospice rather than hospital care (Addington-Hall and O’Callaghan, 2009). Delivery of quality end of life care includes adequate pain and symptom control, withholding inappropriate life-sustaining treatments, retaining sense of control, relieving burden on loved ones and strengthening relationships (Singer et al 2000). Steinhauser et al, (2002) maintain that patient and family views about what constitutes a good death offer better quality indicators of care than process-based measures. Symptom relieving practices such as continuous deep sedation until death, for example, may not always be provided where there is clinical need due to religious beliefs, ethnicity and speciality of doctors influencing their attitudes of doctors toward ethical decisions about intent (Seale,

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<sup>24</sup> Physical experience, psychological experience, social experience, spiritual or existential experience, the nature of health care, life closure, death preparation and circumstances of death

2010). This has implications for patients' death experiences and the "peacefulness" of their dying.

### 2.3.2 Patient and public concepts of a good death

It is important to reflect in this context that all individuals regardless of role and status, are by definition members of the public and will hold diverse views about good death. However, personal views and professional views may differ dependent on role played in society, and how individuals' may choose to present themselves in public. As noted in section 4.1 for example, healthcare professionals' views about good death for themselves may not coincide with their views about good death in patients.

Effective pain management and avoidance of pain are recurrent themes across studies of terminally ill and older patients' views about good death. Other ideas about good death include features such as dying in ones' sleep quietly and with dignity, (67 hospice patients: Payne et al, 1996); dying in one's sleep to avoid pain, to avoid knowing death was imminent or to die quickly, peacefully or easily (26 terminally ill men: Vig and Pearlman, 2004); participating in clear decision-making, preparation for death, completion (life review, resolving issues, saying goodbye), contributing to the well-being of others and affirmation of the whole person (75 focus group participants [professionals, patients, recently bereaved family members, chaplains and hospice volunteers]: Steinhauer et al, 2000). In older age, peoples' views about good death include relief of pain and distressing symptoms, comfort, ability to retain some self-control, an "easy passing", with terminal sedation provided to facilitate good death should extreme and unrelieved suffering occur (Seymour et al (2002). As well as freedom from pain, other factors cited by older people are awareness or unawareness of prognosis, dying at home, getting affairs in order and funerals paid for, and sudden death to be desirable features of a good death (Gott et al, 2008). Effective pain management is clearly important to older people because, with reference to Brown's (2008) model of prolonged dying in older age, older age offers opportunities for prolonged and painful suffering before death. Pain is known to be highly prevalent in older people, under-treatment of pain an issue, and achieving optimal pain control complex and pain in frail elders significantly under-researched (McLachlan et al, 2011).

Past experiences of good and bad deaths often inform concepts of good and bad ways of dying (Vig and Pearlman, 2004). Exposure to deaths of other people has been shown to heighten awareness of death in hospice patients, who can derive either comfort or distress from the experience (Payne et al, 1996).

Whether suicide (and by association, physician assisted suicide) constitutes a good death is contentious although Lester (2006) proposes suicide could be appropriate if it was the culmination of a life prolonged by inappropriate medical interventions, if it were consistent with a person's lifestyle or if it were to take place at the right time for an individual. Lester also proposes death by suicide could be a good death if it were based on rationality, citing suicide as a reaction "to a lingering, painful and incurable illness" as one arguably rational act. These concepts concur with the views of patients' relatives in the Netherlands for whom euthanasia and/or assisted suicide constitute a good death because they "contribute to the quality of the end of the patients' life because their wishes are respected and further suffering is prevented (Georges et al, 2007). Suicide when death is a certainty also might be a rational choice between two evils such as dying by incineration or by jumping, as occurred following the attack on New York's Twin Towers on September 11<sup>th</sup> 2001 (Smith, 2011).

### 2.3.3 Professional concepts of a good death for patients and themselves

Professional roles are likely to shape attitudes toward good and bad death (Steinhauser et al, 2000). Medical and nursing staff perceptions of good death for patients tends not to focus solely on the patient experience; organisational, procedural and treatment matters are also seen as integral to good patient death. Holloway (1996) [a doctor] cites representations of good death (in old age) as being prepared for, patient fear of death being overcome, death being pain free, harm to patients either prevented or permitted if benefit outweighs any harm, good medical decisions made, patient dignity respected, death at home where possible, patients being told the truth and being involved in decision making. Professionals' own interests being met is considered as a component of a 'good' patient death as noted by Smith (2000) who asserts that a good death is one which best suits dying individuals and their family members, at the same time protecting the integrity and values of professionals. In a narrative study of US physicians (DeVecchio Good et al, 2004) accounts of good deaths included concepts of 'expected', 'peaceful', and 'timely'; treatment of the patient

was 'rational/coherent, 'appropriate' and facilitated 'smooth, peaceful or comfortable death', accompanied by 'effective communication with patient, family and team'. Some commentators such as Walters (2004) have argued that what professionals may consider to be a "good death" can compromise patient autonomy and choices about dying when under the care of palliative care services, although palliative care rhetoric places great importance on patient autonomy . Costello (2006) suggests nurses' views about good death are socially constructed to include elements of control, orderliness, and management of patients in ways that benefited patients, relatives and nurses themselves; this construct of good death being dependent in part on the extent to which patient deaths disrupt ward routine and implying passivity on the patient's behalf.

#### 2.3.4 Concepts of 'Bad death'

Kellehear (2007) describes bad deaths as matters for public concern and political and moral battlegrounds. His characterisation of bad deaths draws attention to their potentially detrimental effect on dying persons, survivors and communities.

Conceptually, deaths may be deemed good or bad according to cultural and personal values and expectations. Robinson et al (2010) draw on risk perception literature to explain why people would regard some deaths being "worse than others"; death of a child being worse than that of an adult; death preceded by 'unusual' pain and suffering; a third party being responsible for a death; inequitable death due to social disadvantage and relative levels of suffering to be expected between different diseases. It is the lived experiences of such negative aspects of dying and death, from patient and public perspectives, and risk of replication of similar ways of dying in the future that may be associated with membership of a right to die society. Culturally, a bad death might be seen as one that had failed to conform to important values and rituals (Sarhill et al, 2001) depending on the culture involved.

#### 2.3.5 Patient and public concepts of bad death

Terminally ill patients are known to fear negative experiences in dying (Singer et al, 1999; Vig and Pearlman, 2004). Negative experiences involving severe suffering in dying, exemplified by deaths observed and perceived as bad, arguably may play a part in influencing individuals' to join a right to die society. It has already been established that fear of dying badly is strongly associated with patient requests for hastened death.



Patients and family members may fear bad dying more than death, and dying persons may be fearful through anticipating inadequate pain and symptom control (Steinhauser et al, 2000).

Although freedom from pain has been repeatedly cited in studies of members of the public and patients as a component of a good death, evidence of under treatment of pain in older and dying persons (McLachlan et al,2011) suggests that peoples' fears about painful dying may be grounded in perceptions of a reality in which there is no guaranteed access to effective pain control in circumstances leading to eventual death, and to join a right to die society is to seek some certainty of avoidance of an excessively painful bad death for the future.

The media constructs 'dying alone' as a bad death (Seale, 2004), but this does not appear to be a primary concern identified in studies of patients, family members and older people. Kellehear (2009a) argues a case for dying alone to represent, in some instances, a triumph of personal agency and ability to exercise choice and autonomy, to actively dissent in the face of stereotypical attitudes that deem dying alone as necessarily lonely and "bad"; risks of increasing surveillance, dependency or institutionalisation may therefore encourage some individuals to actively ensure their choices and preference for dying alone can be realised.

### 2.3.6 Professional concepts of bad death

In general, professional concepts of bad death must necessarily be the antithesis of professional concepts of good death as cited in section 4.3.1. DelVecchio Good et al (2004) summarise bad deaths from a professional perspective as unexpected, chaotic or prolonged; care and treatment decisions being irrational, lacking coherence, futile or overly aggressive and as featuring adverse events leading either to painful dying or to hastening death. Communication issues affecting patient, family members or clinicians are also cited.

### 3. Burden

Minimising physical and financial burden on families is a common feature identified in studies of concepts of the good death (Kehl, 2006). The likelihood of being seen as a burden to family, friends and others increases with advancing age (Seale and Addington-Hall, 1995) and concern about burden to others is more likely to be expressed by dying older women than by men (Seymour et al, 2010). People fear that significant others may be required to bear the burdens of lengthy illnesses, caused through the shift away from past sudden deaths from infectious diseases to modernity's more lengthy and slow deterioration at the end of life (Martin et al, 2000). Desire to alleviate burden on others is frequently mentioned by patients who express a wish for hastened death. Advance care planning associated with concerns about burden to others (Levi et al, 2010) and prospective desire to avoid placing burden on others are further factors associated with attitudes toward life-prolonging technologies (Arber et al, 2008) and right-to-die society membership (Blevins et al, 2005).

In the diversity of cultures in Western societies diversity of experiences and social beliefs surround mortality (Howarth, 2007). Attitudes toward placing burden on others are culturally mediated (Howarth and Jefferys, 1996). For example, in a review of cultural conceptualisations in studies of hospice care, burden to families, professional carers and society as a whole at the end of life is identified as a particular concern to Chinese participants; Arab participants are said to be the least worried about burdening their families, possibly due to the wider support networks available in their communities (Bosma et al, 2010). For people dying of AIDs in sub-Saharan Africa, significant worries concern financial burden on families in terms of food, medicines, water and funeral costs in addition to physical or social burden (Gysels et al, 2011). For the dying Muslim patient, obstacles toward following ritual requirements can place greater burden and distress on family members (Sarhill et al, 2001).

Unwanted burden on others and unwanted dependence on others may also be seen as a rejection of the infantilisation of being a patient, imputed by Hockey and James (1993) to be a "dominant model of dependency in contemporary Western cultures". Older and terminally ill patients are significantly concerned about becoming a burden on others through loss of independence (McPherson et al, 2007). Desire not to burden others, motivated by genuine concern for others, is one factor in expressed desire for

hastened death (Seymour et al, 2004; Chochinov et al, 2007). Knowledge and understanding of burden on others may, for instance, be informed wholly or in part by previous life experiences of caring for others and with intimate knowledge of family relationships, commitments and resources.

But it is interesting to note that some studies of patients omit drawing any distinction between 'feeling' and 'knowing' when referring to burden-related patient talk. Medical discourse repeatedly refers to patient 'feelings' of being a burden as a symptom of distress, or as an indicator of 'vulnerability' (Finlay and George, 2011). This apparent semantic and conceptual assumption serves to separate patients' expressed sense of burden from reality; burden having become a 'symptom' rather than a reality based on the patient's knowledge of the lives and circumstances of their own significant others. Providing care is known to impose a number of heavy social, emotional and health-related burdens on carers; adverse effects of burden on carers and families is well established (Twigg, 2000; Hirst, 2005) and widely prevalent across patient and non-patient populations (McPherson et al, 2007). In a review of literature on the effects of caring for a patient with cancer, Stenberg et al, (2010) identify 70 domains relating to carer burden drawn from 192 studies that include physical health, social and emotional problems, and financial and other burdens on carers.

The seldom-articulated concept of dying patients' desire to avoid burdening others as a socially responsible and considerate wish has been suggested by Eliot and Olver (2008). 'Knowing' (as opposed to 'feeling') oneself to be a long-term and difficult burden for others in chronic or terminal illness is acknowledged by Gunderson (2004) to have the ability to induce excruciating suffering. Competent older and/or dying patients are likely to be fully aware of the realities of the impact of any burden they may place on significant others, informed by intimate knowledge of family relationships and resources. It is also possible that patients' have previously experienced providing care for dying family members or professionally, for patients, thus being familiar with the negative impact the burden of care can impose on carers.

Placing a perceived excessive or intolerable level of burden of care, including physical, emotional and financial burden, on others might arguably lead to desire to implement burden-avoidance strategies. Joining a right to die society could represent desire to

avoid burdening others through exploring options for preventing prolongation of life or for hastening death should a future burdensome physical/mental state arise.

#### **4. Desire for hastened death: a role for altruism?**

*“Being good to one’s children is the obvious example”.* Richard Dawkins

The Oxford Dictionary (<http://www.oed.com/>) defines altruism as “selfless concern for the well-being of others”; and (attributed to Zoology), “behaviour of an animal that benefits another at its own expense”.

“a motivational state with the ultimate goal of increasing another’s welfare”. (Mastain, 2006)

Auguste Comte is believed to be responsible for coining the term “altruisme” to refer to feelings antithetic to selfishness and conflicting with egotistic tendencies that needed to be subdued on moral grounds (Scott and Seglow, 2007).

Social scientists have been accused of reluctance to acknowledge the influence exerted by genetic/biological factors on human behaviour, in particular, altruism. (Fowler et al, 2008). But arguments have been presented suggesting that human altruism can be explained from an evolutionary-biological theoretical perspective. As Dawkins (2006) notes:

*“The most obvious way in which genes ensure their own ‘selfish’ survival relative to other genes is by programming individual organisms to be selfish....a gene that programs individual organisms to favour their genetic kin is statistically likely to benefit copies of itself... being good to one’s children is the obvious example but it’s not the only one.” And “We now have four good Darwinian reasons for individuals to be altruistic, generous or ‘moral’ towards each other...”*

Pursuit of a link between biological and sociological accounts of human altruism is reflected in a socio-biological account of altruistic behaviour in real life circumstances

derived through Game Theory (Fehr and Fishbacher, 2003). This conceptual approach offers a model through which inferences could be drawn about altruistic motivation associated with expressed desires for hastened death by terminally ill patients, or by members of the right to die movement. Based on biological principles West, Griffin and Gardner, (2006) suggest altruism may arise from a 'selfish' desire to derive pleasure through helping others, similarly to Convey et al (2010) who describe "an empathetic response to enhance the welfare of another which generates a benefit to the giver..."; the benefit defined as "emotional and psychological wellbeing generated internally from doing the altruistic act." However, Monroe (1996) asserts that altruism toward others cannot be fully explained on the grounds of self-interest and that some altruistic acts can be spontaneous and heroic. Another model without self gain suggests altruism toward family members resulting in their gain (cessation of burden) could be an outcome of a hastened death (Lehmann and Keller, 2006). But relieving burden on others through hastening death is not always interpreted as altruistic, but as a duty "when continuing to live will impose significant burdens - emotional burdens, extensive care-giving, destruction of life plans and...financial hardship - on ...family and loved ones" and "there is a greater duty to die if your loved ones' lives have already been difficult or impoverished..." (Hardwig, 2000).

The notion of seeking to hasten death for altruistic reasons is rooted in the past, when altruistic and/or dutiful suicide was practiced in earlier pan-theistic societies and condoned in the Stoic philosophy of ancient Greece (Durkheim, 1897). Examples of socially approved altruistic suicide cited by Durkheim include Danish warriors killing themselves to escape an ignominious death in bed through old age; elderly Goths who would hurl themselves from a height when weary of life; and Spanish Celts whose entry to a good afterlife was believed to be conditional on their suicide.

Durkheim's classifications of suicide assist in exploring the idea that altruism is in some part responsible for individual decisions to join a right to die society. Durkheim describes suicide as a product of the social environment, proposing three categories of altruistic suicide:

- Death imposed by society as a duty - obligatory
- Death as a question of honour - optional
- Death due to joy of sacrificing life (mystical suicide + martyrdom)

The idea that hastening death could be seen as an act of altruism was being discussed during the 1930s in the context of attempts to legalise euthanasia in the UK. Kemp (2002) records a founder member of the Voluntary Euthanasia Legalisation Society, Dr Charles Killick Millard, having proffered the idea that euthanasia would come to be regarded as something heroic, “an act of true altruism, to be applauded, not deprecated”. But the converse, continuing to live, could be another facet of altruism. Deciding to stay alive (i.e. not to hasten death) in order to avoid distress to close others, or to undermine a loving relationship or a carers’ altruistic commitment to providing care could be perceived as a heroic act of altruism (Gunderson, 2004). But Gunderson argues that if accepting care on this basis leads to severe suffering, decisions made not to hasten death need not be absolute and in this case, hastening death in order to benefit an individual as well as their kin could be seen as an act of altruism in order to avoid placing further burden on or causing distress to their carers or family members.

Warnock and Macdonald (2008) question professionals’ failure to recognise patient desire for hastened death as a genuine and commendable altruistic desire to avoid burdening others by a lengthy dying process. Altruism, arising through concern for others, expressed as an intention to relieve family members of burden of care and from witnessing patients’ deterioration has been associated with desire for hastened death in the presence of unbearable suffering (Dees et al, 2010). In studies of desire for hastened death by terminally ill patients for whom avoidance of burden to others is sought (Hudson, et al, 2006), altruism rarely appears to be associated with any positive moral value or duty, nor is the concept of social responsibility frequently mentioned in the context of altruism, although altruistic action taken in the interest of others driven by concern for others may well be experienced as one of the last positive acts through which a dying person can contribute to the wellbeing of their family and friends while upholding their own sense of self and, to them, an acceptable measure of control through seeking assistance to die (Eliot and Olver, 2007). But as Gunderson (2004) suggests, staying alive without hastening death may also be a last positive act.

McPherson, Wilson and Murray’s (2007) study of patients with advanced cancer suggests desire to avoid burdening others is altruistic, arising from a sense of social

responsibility to avoid imposing physical, social, emotional or financial burdens on others. Participants in this study employ various strategies to alleviate these burdens, but for some the hastened death is a desired option based on altruism. Other studies of dying patients cite altruism manifesting through concerns expressed for partners, family members and/or their carers (Seymour et al, 2004; Gott et al, 2008) and patients' desire to enhance the wellbeing of others by minimising their burden and distress in caring for someone with a terminal illness. Cultural differences have been noted in patient concerns for family members and/or carers. Scottish participants expressed concern about how carers would cope following the death while for Kenyan participants, fears were about physical and financial burden placed on family members (Murray et al, 2003).

Altruism associated with desire to fulfil obligations to others, or with acting to prevent burden to others, can also be associated with the act of making DNR statements as an act of agency, doing so as socially responsible and considerate adults (Eliot and Olver, 2007). The notion of altruistic suicide as a social responsibility cited in this study bears some resemblance to Durkheim's (1897) classification of suicide imposed as a social duty in the sense that although not imposed in contemporary western societies, suicide might be seen by some individuals to be a socially responsible action in light of the high costs to society and the State of providing protracted end of life care.

In their study of dying patients, Eliot and Olver propose that patients' DNR statements are both an enactment of patient autonomy and altruistic in intent to avoid causing burden and suffering to others, in the belief that suffering observed induces suffering in observers. Patient desire to avoid wasting medical resources through maintaining life post cardiac arrest if terminally ill, or to avoid burdening society through diverting resources from more deserving others are also discussed in Eliot and Olver's study.

Monroe's (1996) analysis of the concept of altruism in entrepreneurs, philanthropists, heroes/heroines and rescuers of Jews in Nazi Europe proposes altruistic behaviours to be seen as part of a theoretical continuum ranged between rational actors (motivated by self interest) and heroes (whose selfless heroic acts pose risk of death). Her study shows that neither religion, social status, wealth nor educational levels were critical determinants of altruistic behaviour. Monroe's model offers another explanatory

framework for altruism in the context of right to die society membership suggesting that altruistic intent confers personal satisfaction (psychic good) on the altruist; altruism can be pursued for material gain, altruism may be reciprocal, conferring benefit on both parties; altruism may be used to alleviate guilt; altruism may be practiced to win approval from others; altruism may be a personality-based predisposition toward behaviours involving care and nurture of others, or altruism may be based on a cost-benefits calculation. From a psychological perspective, a study of the lived experience of spontaneous altruism suggests emotions such as love for others or spirituality can account for peoples' altruistic behaviour (Mastain, 2006).

Applying a rational choice framework to the question of altruistic behaviour in hastening death suggests a conceptual link between altruism as a product of individualism, choice and innate self-regard..., although associating all forms of altruism with self interest is questionable (Abell, 1996). The Swiss penal code supports the view that suicide can be a rational act and condones assisting suicide for altruistic reasons (Hurst and Mauron, 2003).

Clearly, whether altruism plays a substantive part in decisions to join a right to die society remains open to debate but in some situations, terminally ill persons' expressed desires for hastened death due to desire to avoid burden to others are arguably a manifestation of altruism arising through concern for others, (albeit based on perceptions of burden that may or may not be realistic); in light of this altruism could also be implicated in decisions made to join a right to die society. Connections between the 1930s eugenics movement and financial burden on the State are discussed in the following section, but in relation to altruism, the eugenics issue is still likely to nuance any discussion about altruism and hastening death as seen in the disability movement's attitudes toward legalisation of hastened death in the UK (Disability Rights Commission, 2005).

## **5. Socio-economic factors in end of life issues**

Desire to avoid imposing financial burden on others emerges repeatedly in US studies of patients (Kehl, 2006) and has also been cited by UK residents close to death as a justification for hastening death (Chapple et al, 2006). In the US, these concerns tend



to be associated with the costs of care, but for NHS patients, desires not to burden others financially are likely to have different connotations. Individuals' attitudes toward how their existing resources are to be used might arguably, amongst other reasons, be material to certain individuals' decisions to join right to die societies or, if terminally ill, request hastened death.

Dying and death bring both negative and positive economic consequences for dying individuals, their beneficiaries and healthcare organisations. Modern healthcare systems are utilitarian due to their finite resources and questions have recently been raised about whether utilitarian imperatives might have begun to outweigh moral/ethical obligations in the practice of medicine within modern health care systems (Garbutt and Davies, 2011). Similar questions may be applied to the basis for right to die society members' desire for hastened death options, and the underlying reasons why they may desire such options. The idea that personal desire for access to hastened death might also be based on utility associated with pragmatism as well as moral/philosophical arguments, involving both personal and more global resource-related concerns is arguably a possibility.

Medical support for allowing the practice of hastening death of patients on the grounds of utility conflicts with medicine's moral/ethical duty to save lives, although medicine's ability to save lives regardless of cost is necessarily constrained by utilitarian resource limitations. Hence, the balance between moral/ethical principles and utilitarian/pragmatic constraints creates moral dilemmas for doctors in relation to medical management of dying and death. A further challenge to medicine's moral/ethical duty manifests through the moral and political economies of hope; infusing patients with hope while extending their lives resulting in financial benefit to research and development of treatments (Rose,2007).

Systemic tensions between utilitarian and moral/ethical issues in healthcare provision are reflected in economic issues associated with contemporary end-of-life health policy and the law. Increasing longevity accompanied by extended dying (Brown, 2008) has serious economic consequences for societies. Dying patients themselves have expressed concern about using resources that in their view might better be diverted to more deserving cases (Eliot and Olver, 2007). Epstein (2007) argues that economic

arguments for hastened death may be justifiable, despite being morally repugnant to many people and institutions, although the substance and quality of healthcare provided in living and dying are already economically orchestrated. Epstein contends that discussion of links between dying/ death and economic factors is hidden from public discourse, although doctors' are increasingly subject to economic pressures through being employees in a repeatedly re-organised NHS. Such contemporary issues surrounding dying and death hark back to the eugenics movement of the early 20<sup>th</sup> Century, whose relationship with euthanasia has been neglected in terms of judging who might be better off dead (Kemp, 2002) (and by association, how organisations and individuals might benefit financially from legalising euthanasia). Radical views about hastening death for economic reasons are evident in Gisborne's (1928) belief that resources were being wasted in existing systems in which 'mere existence' appeared to be valued more highly than 'happiness and usefulness'. This view was considered progressive at the time, being expressed in the context of his interest in the eugenics movement and his support for euthanasia for mentally defective individuals in order to relieve the nation and families of financial burdens of their care (Kemp, 2002). Since Gisborne's time and following the ethnic cleansing carried out by the Nazis in the 20<sup>th</sup> Century, discussion about economic implications of hastening death have become and remain a deeply sensitive topic, widely considered as unacceptable.

Over half a Century later, Bliss (1990) asks why huge sums are spent on extending lives that older people no longer enjoy, and suggests older people can be concerned about money spent on residential care which they would rather go to their families. Bliss contends many older people do not wish to avail themselves of life-extending treatment and financial considerations are implicated, in some instances, in treatment decisions. Socio-economic end-of-life burdens on western societies are set to increase in light of the growing rise in the older population (Karlsson et al, 2006) and with increasing longevity associated with extended dying and rising numbers of the very old, economic burden on the State for medical and social care and financial burden placed on families and on older people themselves are set to increase (McCrone, 2009). One example of economic burden on the State is the incidence of cancer, projected to increase by 2% per annum with costs of cancer care increasing exponentially due to its rising incidence along with costs associated with new developments in technologies (Bosanquet and Sikora, 2004). Against this background, it is acknowledged that discussion about costs at the end of life can be difficult but McCrone argues that costs

and cost-effectiveness are important considerations for those involved. Lester (2006) offers a cost-benefits analysis of suicide in which the benefits of suicide to individuals may outweigh the costs. Brewer (2010) maintains:

*“I do not think that a considered desire by individual patients to save the NHS from pointless expenditure, that could be better directed to the living rather than the dying, is necessarily a bad thing. I have heard many altruistic members of right-to-die societies express such thoughts”.*

Socioeconomic factors exert a pervading influence on planning future healthcare provision for an increasing older aged population, on individuals' concerns about their own end of life resources (potentially informing anticipatory desire for hastened death), and more controversially, on the ongoing campaigning for legalisation of physician assisted suicide in the UK. Escalation of costs involved in extended end of life care place economic burden on national resources, taxpayers, health and social care services, patients, and on their family members; this being infrequently mentioned in end of life studies (Epstein, 2007). Palliative care services are already insufficient to reach all who could benefit and palliative care funding for the future will require more resources and greater focus on cost-effectiveness (Gomes et al, 2009). Increased ageing and numbers of aged persons bring higher levels of disability and those who perceive themselves to be socio-economically disadvantaged experience longer periods of morbidity and disability over the latter years of life than others (Matthews et al, (2005); Matthews et al, 2006). But again, in capitalist systems, financial benefit is also gained by companies supplying goods and services required to support delivery of care and treatment for people during extended older age and at the end of life.

In the US, economic burden on patients and family members can be a serious end-of-life concern due to limits placed on access to sufficient or good quality care by health insurance providers (Emanuel, 1998; Givens and Mitchell, 2009). US Hemlock Society members also acknowledge the “economic price-tag” associated with being kept alive (Fox et al, 1999). In the UK, although the health care system provides universal end-of-life care independently of direct cost to individuals, the quality of care is known to vary between hospitals and palliative care facilities (Neuberger, 2003). NHS rationing of some high-cost life-sustaining drugs has become an economic necessity<sup>25</sup> on the

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<sup>25</sup> NICE Technology Appraisal Guidance (<http://www.nice.org.uk/>)

grounds of cost/benefits which inevitably result in reducing ability to extend some lives through use of technologies. Terminal diseases impact socio-economically on patients' financial resources and those of their carers with regard to costs of obtaining or providing care; family members' employment, financial situation and social life may also be compromised (Higginson and Constantini, 2008). Desire to avoid imposing financial burden on others has been identified as one justification for hastening death (Chapple et al, 2006) and a review of 105 studies concerned with burden on others cites instances where fears about financial burden on others are raised (McPherson et al, 2007).

Despite this tension between economic and moral considerations being highly contentious because of its links with 20<sup>th</sup> Century Nazism, individualism, self-emancipation, personal autonomy and altruism are likely to be responsible for leading some individuals to consider resource-related issues in terms of themselves, their families and the wider society of which they are part, in the context of joining a right to die society.

## **6. Discussion**

I hypothesised that reflexive self identity is implicated in pro-right to die attitudes. I have shown how maintaining self identity and agency is important to those individuals who, through reflexive self-adjustment, work to maintain those positive attributes of self and identity that confer functionality, respect and full citizenship in society. The ability to exercise autonomy and choice, or the belief that one is free to exercise autonomy and choice is shown to be an attribute of the ideal self, and persons of higher educational status are more likely to be concerned about the self they present to the world in terms of identity and control reflexively created, adapted and maintained. Also as Gilleard and Higgs (2000) have observed, people with the greatest material and cultural benefits are those most likely to distance themselves from the negative consequences of becoming fourth agers, It follows therefore that threats toward the wellbeing of these selves are likely to be resisted, and indeed are encouraged to be resisted as evidenced by the contemporary cultures of retaining youthfulness and undertaking maintenance of bodily functionality. But multiple threats posed to the self inevitably become irresistible through irreversible bodily and mental decline, in chronic and terminal illnesses and in

older age. Because people are “forced to seek individualised solutions to self-identity” (Higgs and Rees Jones, 2009), equally people may find themselves forced to seek individualised solutions to impending loss of self identity, especially in circumstances such as terminal illnesses or in the slow disintegration of body and mind accompanying the fourth age in which accustomed self-identity is subject to multiple threats and losses.

I argue therefore that threats toward the self imposed by longevity, prolonged dying, diminished quality of life and suffering accompanying these experiences are likely to influence attitudes toward dying and death. The reflexive self in modernity, and threats posed toward its integrity, arguably contribute toward the continuing existence of the right to die movement; reflexivity of self and individualism being likely to characterise those individuals who join the movement

Right to die societies in general and FATE in particular, are concerned with widening the prevailing limits in deathstyle choices to include a legal right to a hastened death. Previous research into right to die society membership shows older age, higher social class and gender with females outnumbering males to be characteristic of right to die society members’ self -identity. These trends in right to die society membership suggest that members fall into the category of those persons who would be most likely to place high value on self identity and as a consequence, more likely to seek pre-emptive solutions to risks and threats posed to self through terminal illnesses and/or fourth age decline in which death is ultimately inevitable. Also, deathstyle choice as an expression of autonomy, and as a choice exercised to avoid risks and threats to self associated with end of life bodily and intellectual decline, and also to avoid anticipated negative experiences associated with dependence and end of life care, is likely to be characteristic of persons willing to contemplate exercising a tyrannical choice in that options for either slower or hastened dying are themselves inevitably subject to multiple risks to the self.

I hypothesised that Individuals who join FATE are likely to have personal experiences of caring for terminally ill others. Evidence shows that desire not to experience dying in ways similar to those seen in others is grounded in the personal experiences of the

suffering of others. Suffering has the capacity to make people vulnerable through suffering's adverse effects on the self.

I hypothesised that altruism is implicated in decisions made to join a right to die society and theories concerning the nature of altruism/altruistic behaviour do support the possibility that altruism could be involved in decisions made to join a right to die society. As Hardwig (2000) contends, death that comes too late can harm both the dying person and their loved ones; according to Hardwig, a 'right' time to die for persons who, in their own and in their family members' views, would be better off dead suggests that a decision made by the dying person to hasten their death could be interpreted as both a duty and a reciprocally altruistic act. In Taylor's (1998) writing on the interpretive sociology of suicide, he suggests that although suicide is generally modelled as a product of mental disorder, very different interpretations of suicidal acts or intent can be drawn from alternative sociological approaches. He cites studies of suicidal persons' written testimonies detailing the reasons for their act as providing valuable resources for making interpretations that differ from mental disorder causality. He also cites the notion of submissive suicide in which desire to die can be due to acceptance that life is over to all intents and purposes; that death has become an ally, a friend, helping an individual to "leave the field with dignity and grace". It is feasible to suppose that this conceptual version of suicide might include altruistic motivational elements, as dying with dignity and grace at a time of one's choice could be ultimately less traumatic for close others than prolonging the dying process to a possibly more distressing end.

If altruism is indeed a factor in peoples' motivation to join FATE, the concept of reciprocal altruism as described by Monroe (1996) applied to the act of hastening death to the benefit of both the dying and the living might be conceptualised in Durkheimian terms as a combination of altruistic and egotistic suicide. But Durkheim's work on suicide and how he relates it to social forces has been challenged by those who have explored suicidal behaviour in terms of quasi-intent and risk taking (Taylor, 1998) with greater orientation toward the psychological state of persons involved. But Monroe (1996) suggests for some individuals, altruism can be an innate aspect of social behaviour practiced unquestionably, regardless of mental state. Thus desire for hastened death to avoid harms and distress to others may arise from personality traits

inherent in an individual's psyche, their view of the world and how they engage with it, even when it comes to approaching death.

I propose that concern for others, as expressed by FATE members, can be altruistic in nature when it is a precursor for planning an altruistic act of hastening death with intent to prevent continuing life to disadvantage or distress others. Altruistic concern for others that lead to actions to pre-empt conditions that relate to such concerns, suggest that concerns for expressed for others in the context of decisions to join a right to die society can be altruistic in origin.

The ideas about altruism cited in this review are arguably relevant in understanding how prospective fear about burden/dependence on others could be a further possible reason for joining FATE. In studies of terminally ill patients, fears are shown to be held about becoming a burden on others or being dependent on others. Hastening death to avoid burdening others as a reciprocally altruistic act could be seen by some individuals to confer benefits on both themselves as a dying person who believes themselves to be better off dead, and their family members. This argument views death as a benefit to the patients and patient death as a benefit to family members. But staying alive could also be interpreted as a reciprocally altruistic act to avoid distress to others and this argument proposes a benefit to the dying person through knowing they have avoided causing distress to family members and to family members for 'premature' loss of their loved one being avoided. Biologically, some authorities suggest that humans may be genetically disposed toward benefiting their kin, therefore seeking a hastened death could be a manifestation of biological altruism but whether or not this idea might be credible in humans is open to debate. Some studies do suggest that altruism is a reason for patient desire for hastened death but altruism might equally influence patients to stay alive. Hence the debate about any relationship between altruism and peoples' personal reasons for joining the right to die movement remains open. Desire not to waste national healthcare resources, or to avoid depleting personal resources in order to benefit kin could be another reasons for joining a right to die society, driven by altruism or pragmatism or, as one study suggests, the action of a responsible citizen. This viewpoint links the concept of having a right to die with concomitant duties and responsibilities toward others. Morally, altruistic acts that benefit society as a whole are applauded. But whether the same moral positivism can be applied to persons seeking a hastened death remains a question for moral

philosophy as altruistic hastening of death with intent to benefit society as a whole is neither concordant with contemporary social norms nor widely morally acceptable. But it can also be argued that hastening death can be a reflection of altruistic moral positivism in a society in which escalating costs of care for older persons pose an increasing financial burden on the State and on society as a whole.

I hypothesised that socio-economic factors are involved in decisions to join FATE. Economic issues in health service provision for older people impact on the care of dying persons of all age groups. National and personal resource issues associated with the end of life care may also be a consideration for persons who have joined a right to die society. Nationally, means for extending certain lives are too costly to implement (Smith, 2000). Recent public debate about costs of life-extending cancer drugs is one example of the cost/benefit debate surrounding life extension. Whether monetary cost/benefits surrounding dying and death in terms of the cost of care or financial disadvantage to family members might be considered by patients and their family in relation to hastening death, and whether death may be welcomed on the grounds of cost/benefit as a reason for joining FATE is a possibility.

Previous studies of right to die societies have not explored how the movement might be driven by pervading cultures of risk avoidance and risk management. This review cites evidence of patient desire for hastened death that suggests, for FATE members, a pre-emptive death option is likely to be seen as a benefit due to the risks they may face during the dying process, particular aspects of which they fear most, based on personal experiences of patient suffering. They join FATE to help manage perceived risks of future suffering during a 'bad dying' process, that can become extended through current norms in healthcare culture and practice. Evidence suggests such fears for the future may have some grounds for existing, as despite advances in palliative care services, they are neither universally available, nor able to guarantee adequate relief for all suffering in dying. However, continuing advances in quality care of the dying are likely to diminish the incidence of intolerable suffering in dying, although with a rising older population, the cost/benefits of quality end of life care provision continues to be a national issue.



I questioned whether anticipation of future suffering would be a significant factor influencing decisions to join FATE. The review shows how the term 'suffering' is a descriptor referring to a complex and individually determined set of objective and/or subjective experiences with a collective capacity to compromise physical, mental and psychological wellbeing. It also shows how a patient's experience of intensity of suffering can be difficult to articulate and difficult for healthcare professionals to access. There is also the question of whether patients' accounts of the intensity of their suffering are believed by healthcare professionals, due to the power imbalance inherent in the patient/professional relationship and due to the perceived vulnerability of ageing and dying persons. Also as Giddens (1991) has noted, trust as a responsible citizen is dependent on bodily control which suffering patients may lack, promoting trust issues in professional encounters. Higgs (2008) quotes Goffman's idea of 'body idiom' that allows people to be classified and graded according to their appearance and body language. This suggests that patients whose body control and appearance diverge from the norm due to age and or illness will be immediately disadvantaged in the medical encounter in terms of what they say being trusted or taken seriously. Entering this disadvantaged status in respect of the medical encounter is a further possible source of suffering.

Providing a dying person is mentally competent, the intensity of dying persons' physical suffering is likely to be more amenable to measurement than the more subjective elements of a person's total suffering experience. As such, fear of future suffering, perceived difficulties in conveying its intensity to healthcare professionals in the course of dying and lack of trust that intensity of suffering would be believed by professionals offers a further area of influence in decisions to join FATE. Loss of self is also likely to be implicated due to vulnerability to loss of self in dying found in suffering patients. This applies particularly in the case of dementia which has been shown to be particularly feared by members of the public.

Finally, a new study of FATE members (Richards, 2011) first became available in July 2011. This is an ethnographic study of 'death activism' in older people that explores the organisational focus, beliefs and activities undertaken by FATE members and contrasts these with those of the larger Dignity in Dying right to die society. It shows that although campaigning activities and provision of living will forms are common to both, radical differences exist between these two right to die societies both in

organisational terms and in what they offer for their members. While FATE is run by older people, providing information, help and advice to its members about practical methods for hastening death, either by suicide or through accessing assisted suicide from the Swiss organisation Dignitas, Dignity in Dying has sought to gain respectability through becoming professionalised, is run by younger people, and campaigns for end of life 'choice', exclusively of legalised physician-assisted suicide in the last few months of life. In contrast, FATE seeks to legalise hastened death justified by suffering.

Although Richards broadly acknowledges some of the reasons why FATE members choose to join the organisation, my study differs substantially from hers as it focuses less on the organisational focus of UK right to die societies, placing greater emphasis on how social theory and socio-cultural features of contemporary UK society serve to support the continuing existence of the right to die movement. My study, unlike hers, also explores reasons why FATE members have acquired their beliefs in the right to die movement's aims and the fears FATE members hold about their own dying and deaths that would be likely to inform their activism. These questions have previously been subject to little academic attention by sociologists.

## Chapter 4: Method

This chapter describes the methodology used in developing the study design, and in identifying appropriate methods for data collection and analysis of data. Why these methods have been chosen, their strengths and weaknesses, and possible alternative approaches are discussed.

Social research on why people join right to die societies is limited to studies of the US Hemlock Society and one study of members of the UK Voluntary Euthanasia Society (now Dignity in Dying) of which the original paper is unavailable. None of these studies reported in detail on peoples' reasons for joining a right to die society as addressed in this study. Nor to my knowledge has a social theory-based model been developed showing how societal and cultural norms surrounding risk, ageing, dying and death bear some responsibility for the right to die movement's ongoing existence. There have been many previous studies identifying dying patients' reasons for desire for hastened death and these have been used as a baseline for seeking to understand through this exploratory study the reasons why people join FATE.

Development of social theory and the philosophy of social science evolved through reflection about the nature of knowledge by thinkers such as Kant, Hume, Descartes, Freud (Delanty, 1996). The nature of knowledge in the social sciences is subject to debate according to proponents of differing epistemologies relating to the process of knowledge acquisition; broadly either through rationalist/positivist or constructivist/interpretivist approaches to research (Feilzer, 2010). Philosophers of science conceptualise the advancement of knowledge via a diversity of processes. According to Lazar (1998), Durkheim saw sociology as the scientific study of "social facts" while Karl Popper takes a rationalist approach through proposing that scientific development takes place through a cyclical process of research-based theory development followed by successive falsification of previous theories. Thomas Kuhn focuses on constellations of knowledge shared within academic disciplines - dynamic paradigms - that advance knowledge through a process of successive scientific revolutions and Feyerabend supports a diversity of methods for gaining knowledge; but others such as Clifford Geertz and Charles Taylor maintain that an interpretive/constructivist approach to knowledge generation is essential in the social

sciences; this tradition tending to favour qualitative research methods that “seek to grasp the meanings that individuals and social groups give to their actions and institutions” (Lazar, 1998); thus the approach of choice for the purposes of this study. Ultimately, regardless of methodology chosen, the most important question is whether the research has enabled the researcher to find out what they want to know (Feilzer (2010) quoting Hanson, 2008)

## **1. Methodology**

Particular issues exist in social research in terms of how congruity between thought and reality can be established and how meaning generated can be influenced by the researchers’ own interests, thinking and interpretation of data (May, 2011). My own background as a healthcare professional, with experiences of dying and deaths over many years has not only generated my interest in this area of research but has influenced my attitude towards my own future death and how this may be experienced. My interest in the right to die movement stems from both life experiences and the spectre of dementia lurking in my genes, and therefore these form an inevitable part of the research process. How I am situated in the research process brings advantages and disadvantages. It has been advantageous for me to have a number of friends who are members of FATE and Dignity in Dying, enabling me to gain access to FATE and its Council members who proved keen to allow me to carry out this research into its membership, and willingly co-operated with distribution of the questionnaire and later, offering venues in Glasgow and London for interviewing members. It was also advantageous in that a majority of research participants felt able to speak freely to me when disclosing their reasons for joining FATE, experiences, often of a sensitive nature, beliefs and end of life intentions. This is likely to be due to my being seen as “one of them” and also my research being seen as ultimately affording benefit toward FATE’s cause. I was also invited to attend some of their meetings and this was advantageous for the purposes of conducting the research as members were able to identify me as an approved person undertaking a legitimate inquiry into their reasons for joining FATE. But the disadvantages of my position relate primarily to the extent to which I am able, or unable, to maintain neutrality, dispassionate observation and reflexivity in inductive qualitative data analysis. But objectivity is associated with positive science and King and Horrocks (2010) aver that total objectivity is humanly impossible. May (2011) asserts that pursuit of objectivity necessarily involves distancing oneself in order to “socially situate” responses, but confirms that personal

values affect all aspects of research and no researchers can act in an entirely objective role, placing them in a role to inform their research, but not to saturate its insights. To maintain this balance as a means, not an end, emphasises the importance of reflexivity in constantly questioning my approach to all aspects of the study.

In order to address the overarching research question of why people join a right to die society, I chose mixed methods to identify **who** (quantitative/demographic data) are the people who join FATE and the reasons given for **why** they joined FATE requiring a qualitative approach. Hanson (2008) argues that there is a growing diversity in sociological methodological practices that the quantitative/qualitative dichotomy does not adequately represent and further, that conceptual boundaries between objectivity and subjectivity in positivist science are fundamentally blurred, contending their separation has become a tradition in sociology due to “separatist forces “ in its politics. Quantitative data focuses on measurement of information about the social world that can be expressed in numerical formats (King and Horrocks, 2010) and in this study, using mixed methods research embodies the subjective/objective relationship between quantitative and qualitative methods as complementary opposites in a dynamic research process. Quantitative data was required to identify age, gender and social class of research participants, and qualitative data was required in order to understand facts, beliefs and opinions. Quantitative data can also be derived from qualitative data concerned with social construction; this was also useful in the context of this study.

### 1.1 Methodology in questionnaire design

In phase 1 of the study, survey methodology was chosen as this approach was initially the one most certain to reach the whole membership of FATE. In order to capture data that answers research questions, good questionnaire design must necessarily focus on principles of good practice established by Moser and Kalton (1971), namely through considering how questions are framed in order to ensure construct and content validity, while considering questionnaire length, content and simplicity and conciseness of language in order to optimise the number and quality of responses. Principles of questionnaire design require questions to be specific, using simple unambiguous language (Moser and Kalton, 2004). For the purposes of this study, I was seeking both facts and opinions from my questionnaire.

## **1.2 Methodology in interviewing research participants**

People derive personal meaning and significance through life by constructing a complex framework of beliefs and values that “categorise, characterise, explain and predict the events in their world” (Jones, 2004). Qualitative interview methods are particularly useful for accessing peoples’ attitudes and values (Byrne, 1998), this being a primary aim of this study. Interview methods seek to establish a non-hierarchical relationship between researcher and participants in order to encourage participants’ disclosure of information, while at the same time maintaining a dispassionate and non-judgemental approach (Miller and Glassner, 2004). Minimally directive depth interviews that facilitate people to tell their stories in their own terms) are characterised by flexibility in wording questions and the use of probing questions (Jones, 2004) and this approach was useful in the context of the study. The quality of data obtained from interviews is dependent on a number of factors including relative class, professional and educational status between interviewer and interviewee, ability of the interviewer to listen and to show interest in interviewees’ talk and the quality of rapport established (Grbich, 1999). As my own social class and educational status was similar to most people I interviewed, this helped facilitate the volume of useful data obtained. King and Horrocks (2010) quote Willig (2001) to show how personal beliefs, interests and experiences can potentially compromise researcher objectivity, while also noting that personal experiences can also be useful in informing research provided researchers are objective in their interpretations and reported findings. Interviewers inevitably come to interviews with their own theories and values but these must not be allowed to compromise understanding of the interviewee (Jones, 2004). Also, establishing trust and comfort between interviewer and interviewee help to encourage disclosure. Where sensitive topics are to be discussed, an ability to show sensitivity and empathy toward participants are also important and as the interviews I conducted aimed to facilitate optimum disclosure on topics related to the research question, efforts were made to create a safe atmosphere in which people felt comfortable to tell their stories.

## **1.3 Methodology in content analysis**

Analysis of the content of qualitative data drawn from questionnaire and interviews relies on coding schemes that facilitate identification and ordering of themes and concepts drawn from text. The reliability of content analysis is subject to its accuracy,

reproducibility and stability over time (Weber, 2004), although validity is a problem dependent on researchers' definitions of concepts and measures. Braun and Clarke (2006) view thematic analysis as a foundational method for qualitative analysis, quoting Boyzartis (1998) who describes it as a tool for use across different methods of qualitative analysis. Tonkiss (1998) cites the advantages of using thematic analysis on textual material due to its ability to derive meaning from peoples' talk and this method served to fulfill the primary aim of the study. Interpretive content analysis (Tonkiss, 1998) and thematic narrative analysis (Riessman, 2008) both refer to similar concepts of thematic analysis suitable for use in a wide variety of texts including stories emerging from interview data (Riessman, 2008).

Thematic analysis methodology involves coding of themes that may be achieved either using coding software, especially on large datasets, or manually. Problems associated with content analysis concern the reliability or consistency of thematic classification and validity, especially in the absence of triangulation by more than one investigator (Weber, 1990). Coding schemes in qualitative analysis may be either pre-determined or developed following identification of themes drawn from the literature and data as occurred in this study. Repeated reflexive scrutiny of thematic categories and assignation of codes was essential, involving repeated reading of qualitative text and questioning interpretation of meanings and assignation of thematic categories in order to ensure optimum reliability and validity.

#### **1.4 Methodological considerations in reporting research data: reflexivity**

Qualitative research is a joint product of the researcher and study participants (Ashworth, 2008). Reflexive sociology is characterised by critical self-reflection about assumptions made during the research (epistemological reflexivity) and about how personal beliefs and experiences (personal reflexivity) might have influenced the research (King and Horrocks, 2010). Reflexivity throughout the research process must also cover how results, conclusions and depictions of participants are represented in writing up research (King and Horrocks, 2010). Researcher reflexivity is grounded in self awareness and awareness of influences exerted by previous life experience and work, ability to appraise their effect through self-questioning and the need to acknowledge the perspective gained from past personal learning; also to ensure that themes are not the product of existing beliefs but drawn from the data (McGhee et al,

2007). The role of self in interviewing study participants, and the influence exerted on participants must be recognised by the researcher (King and Horrocks, 2010). Critical reflexivity is also relevant in the analysis of data transcribed from recorded interviews. Researchers face a dilemma in transcribing peoples' talk in the extent to which it is edited to make it more coherent and readable (Atkinson, 2004). In this study, spoken accounts were recorded verbatim with minimal editing only to restrict certain repetitive habits of speech such as "you know". As interview participants were mainly highly articulate, little editing was necessary and themes quoted in the study are all virtually verbatim.

Much reflexive thought has gone into this study, during the course of the research design, during the interview process, in the data analysis process, in representing participants data in order to provide unbiased accounts of participants beliefs and opinions, in presenting the findings and in drawing conclusions in order to employ the reflexive process in my aim to adhere to high standards of research practice in producing this thesis.

## **1.5 Research ethics**

Kant's deontological moral ethics as applied to research are concerned with the avoidance of harm or offence to research participants and research ethics dictate moral principles of behaviour in conducting research, in this instance, social research (May, 2011). Ethical principles governing sociological research cover governance of research procedures and practices, ethically approved research, moral ethics in professional conduct, maintaining confidentiality, anonymity and physical safety and the welfare of research participants and the researcher (King and Horrocks, 2010). Ethical approval must be gained from the relevant institution before a research project may commence. In terms of professional codes of ethical research practice, King and Horrocks highlight the necessity of obtaining informed consent, maintaining strict confidentiality, the absence of any deception, participants being informed of their right to withdraw from the study, and information provided to participants about the aims of the research and access to any publications arising from the research. In conducting this research, I have therefore striven throughout to adhere to those ethical principals required of academic researchers.



## 2. Preparatory work

Preparatory work for this study of FATE<sup>26</sup> members commenced with identification of an overarching research question followed by a literature review from which the supplementary research questions were drawn.

Ethical approval for the study was initially obtained from Brunel University's School of Social Sciences Research Ethics Committee in 2006, and subsequently endorsed by Queen Mary University of London School of Medicine & Dentistry Research Ethics Committee in 2008.

The FATE Council was approached to request permission to conduct a survey of their members. Council members approved the proposed study in principle but were unwilling to disclose any identifying information about their members. However, they were willing to include a questionnaire in their routine mail out of the society's newsletter. Data collection commenced in 2008.

## 3. Study design

The overarching research question in this study asks "who joins a right to die society and why?" To obtain answers to this question, I decided to conduct a survey of FATE members via a postal questionnaire, followed by face-to-face interviews with a sample of volunteer respondents. The reasons for using an initial postal survey were twofold, firstly because FATE agreed to distribute a questionnaire via their routine newsletter mail out which would enable me to gain access to the whole membership, and secondly because it appeared unlikely that all FATE members would be computer literate and able to access an e-mail or internet-based survey, both of which were considered and rejected on these grounds. Snowball e-sampling was also considered but rejected owing to the likelihood of obtaining a larger sample of respondents via a postal questionnaire, and also because unknown numbers of FATE members could be anticipated to be computer illiterate.

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<sup>26</sup> <http://www.friends-at-the-end.org.uk/>

#### **4. Data collection methods:**

I constructed a survey questionnaire (Appendix 1), aimed at seeking answers to the research questions, to collect both quantitative and qualitative data. The questionnaire which includes both fixed-choice and open-ended questions, was developed with four primary objectives:

- a) To investigate the demographic characteristics of FATE members to enable comparison with demographic profiles of previous studies of US right to die societies.
- b) To develop a greater understanding about who joined FATE, their reasons for doing so and to identify peoples' underlying beliefs and values and their origins, which had not been attempted in previous studies of right to die society members
- c) To explore the relationship between personal religiosity and support for the right to die movement
- d) To identify people willing to take part in interviews in order to explore reasons for joining FATE in greater depth

Development of the questionnaire commenced with a literature review of previous studies of members of right to die societies (Lam, 1982; Holden, 1992; Fox et al, 1999; Cossman et al, 2002; Blevins et al, 2005) to discover whether any insights had been gained previously into the reasons people gave for joining right to die societies. Information was also required about the demographic profiles and religiosity of members identified in those studies. Questions seeking demographic data in this study were similar to those asked in previous studies of members of the US Hemlock Society in order to compare findings with those of this study. But unlike some previously conducted studies, details were not sought about income as a basis for assignment of social class as this was felt to be overly intrusive, particularly as the survey was concerned with seeking other very personal and possibly distressing information. Instead, FATE members were asked to state their occupation or previous occupation from which social class could subsequently be assigned.

Studies involving terminally ill patients who requested hastened deaths (Emanuel et al, 1996; Emanuel et al, 2000; Lavery et al, 2001; Kelly et al, 2002; Johansen et al, 2005; Pearlman et al, 2005; Chapple et al 2006; Chochinov et al, 2002 and others) were used to inform questions asking FATE members about particular fears they might have about their future deaths that could possibly have influenced them to join FATE. Questions were also included about peoples' experiences of others' dying and deaths based on evidence that personal experiences of dying and death can induce pro-hastened death attitudes (Verpoort et al, 2004; Hallowell, 2006; Chapple et al, 2006; Ganzini et al, 2009). Questions were also included about religiosity in order to establish the incidence of religiosity among FATE members, and how religious beliefs, if held, might be reconciled with membership of this organisation. Finally, respondents were asked to indicate whether they would be willing to take part in a face-to-face interview, and if so, to provide contact details.

An initial draft of this questionnaire was piloted amongst a sample of nine FATE members to test its face validity. Subsequently a final version was printed and sent on to FATE for distribution, accompanied by stamped addressed envelopes provided for return of completed questionnaires.

I decided to follow-up the survey with face-to-face interviews as they offer a means for conducting a deeper exploration of 'facts' populating the interviewees' social worlds that account for individuals' views and opinions (in this case, beliefs, values and experiences) (Byrne, 1998) in relation to their membership of FATE. The knowledge I expected to gain through the interviews would be both objective and subjective, as I was specifically seeking to gain a more detailed picture of individuals' understanding of their own beliefs, values and experiences in relation to their having joined FATE, through using interviews to facilitate free disclosure of these.

Interviewees were provided with an information sheet and signed consent forms were completed prior to the interviews (Appendix 2). Interviews were semi-structured and guided by an interview schedule (Appendix 3),

## 5. Data analysis methods

Excel software was used to record the survey data because it provides a practical method for ordering and analysing both quantitative and qualitative data from the survey, and complex statistical analysis of data was unlikely to be needed in this study. Data were entered into an Excel spreadsheet allowing it to be categorised, ordered and counted.

A non-specific qualitative thematic analysis method not dependent on any particular specialist methodological approach (Seale, 1998) was chosen for analysis of qualitative data from the survey and interviews. For the purpose of this study, thematic analysis was the chosen analysis method because of its utility in enabling frequently occurring common themes found within and across datasets to be categorised. Thematic analysis also allowed identification of any less frequently occurring or idiosyncratic themes. Secondly, as the use of narrative to illustrate beliefs, values and opinions was found to be a common factor amongst interviewees' accounts of why they joined FATE, thematic analysis of narrative content was an effective method for deriving meaning from narrative data.

The choice of qualitative thematic analysis was made to fulfil the aim of identifying themes representing the phenomenon being investigated in order to answer the "why" question being asked about right to die society membership. Qualitative thematic analysis provides a useful method for creating a nexus of related themes from which an understanding of respondents' beliefs, values, experiences and fears about dying and death could be drawn. It also enabled broad conceptual categories to be created through interpretation of the data. My primary aim in using thematic analysis was to gain a detailed understanding of peoples' versions of why they joined FATE. Although an ethnographic approach would also have involved analysis of participant talk arising during fieldwork (Grbich, 1999) ethnography places greater emphasis on how people construct and make sense of social life surrounding a particular phenomenon (Potter and Wetherell, 1987). Understanding meanings drawn from participant talk was an important aim of the analysis of qualitative data in this study in order to code themes appropriately. Discourse analysis was also considered for analysing these data; if discourse analytic methods had been chosen as a primary analytic tool, they would also reveal meanings contained in participant talk, but because analysis of textual

construction of discursive accounts (Willig, 2008) was not the primary focus of interest in answering the research questions, thematic analytic methods was chosen as the principal analytic tool. For this reason, the study is neither primarily focused on the discursive strategies employed by participants, nor on an ethnographic approach toward right to die membership, but more exclusively on peoples' versions of why they joined FATE and what themes and meanings could be drawn from explanations given for having done so.

Objectivity of the researcher is needed to present a dispassionate and non-judgemental account of participants' contributions, regardless of how controversial these may be (Miller and Glassner, 2005). In aiming to maintain objectivity along with optimum validity of interpretation and coding of themes, a reflexive approach was taken in which qualitative data were re-read and re-visited repeatedly with continual review and refinement of coding of themes that finally produced a hierarchical scheme for ordering and categorising qualitative data. This scheme is described in detail in section 7 below.

## **6. Interview methods**

The method I chose for interviewing study participants was grounded in the need to identify what people believed were the specific factors underlying their decisions to join FATE and why such factors might have arisen during peoples' life course.

I decided that thirty interviews would be likely to provide sufficient data to broadly represent a range of views and beliefs to be explored in greater depth. Because people who volunteered to take part in interviews were widely distributed across the UK, selection of participants for interviews was made firstly through convenience sampling based loosely on participant location either in or near Glasgow or London and secondly through purposive sampling based on interview potential for generating optimally interesting data. Having found so many health/social care professionals responded to the survey, I considered that interviewing them would be of particular interest. To this end, purposive sampling focused firstly on accessible health/social care professionals and secondly on those accessible survey participants who had

returned interesting and detailed responses; “information-rich cases” (Richards, 2011). The interviews aimed to explore in greater depth the responses people had made in their completed questionnaires and to encourage interviewees to elaborate on experiences, beliefs and views. Twenty four interviews were conducted face to face and a further six by phone due to accessibility issues. Candidates for phone interviews, who were mostly too difficult to access face to face because of their location, were chosen due to their particularly interesting survey responses. Interviews were guided by an outline interview schedule (Appendix 3), recorded and transcribed for analysis.

Informed consent to participate and permission to have their interview recorded was obtained from each interviewee before each interview commenced (Appendix 2).

Interviews were informal and unstructured with an interview schedule used as a guide along with the responses people had already made to the initial survey. There are advantages and disadvantages to this approach. Grbich (1999) notes how informal guided interviews in which a more conversational approach is taken can assist extensive exploration of a topic in contrast to structured interviews in which the balance of power shifts toward the interviewer. Also, people tend to modify their behaviour depending on the social context (Potter and Wetherell, 1987). In this study, I considered creating a power hierarchy in interviews to be unhelpful in seeking to obtain the sort of information the study demanded and efforts were made to create a social context in which people’s behavioural mode would be one more likely to facilitate free disclosure.

Transcriptions of the interview data were analysed, identifying a range of themes germane to peoples’ given reasons for joining FATE.

I considered avoidance of participant harm, distress and maintaining confidentiality to be the primary ethical issues involved in interviewing participants. Ali and Kelly (1998) note potential harms to participants during qualitative interviewing might involve issues of trust and integrity between researcher and research participants. Therefore I have been careful to ensure that participant confidentiality and anonymity has been maintained throughout the writing of this thesis. My own safety when interviewing

participants in private spaces was also considered and therefore I carried a mobile phone. Complying with the requirements of the Data Protection Act is a further area in which efforts have been made to ensure the security of data collected. I judged that potential harms to this particular group of study of participants could be possible through public disclosure of material that might cause embarrassment and distress. Harm to participants could also be caused through over-intrusive probing into painful topics, therefore any probing I undertook during interviews was necessarily handled with sensitivity and tact. For example, recounting experiences involving the dying and deaths of close others could potentially be distressing for participants. A further example of potential harm caused through public disclosure of personal identity emphasised the need to preserve participants' anonymity and this was therefore considered carefully. For example, one individual who died at Dignitas shortly after being interviewed had their name withheld by their family from media reports and distress could have been caused to family members if that person's identity were to become known at a later date in connection with this research. For some other research participants, information disclosed about their personal opinions, or about past or intended actions could have compromised their standing in their respective communities or in their professional lives should their identities be revealed. Participants could also potentially be harmed if their identities were revealed through having expressed negative opinions about individuals, organisations or services. People with a public profile could be harmed by disclosure of personal information and personal opinions that they would not wish to be made public. I therefore considered it important to assure participants of their anonymity and confidentiality in order to encourage them to speak freely.

## **7. Coding and sorting the data**

Because this present study was conducted by me as a single researcher, coding reliability and validity were tested through a reflexive approach involving repeated scrutiny and re-interpretation of the qualitative data and checking and re-checking meanings and how these should be coded in the context of the research questions. The importance of reflexivity, the capacity to reflect on actions, values and language during the research process, led me to continually question the meaning and interpretation of data during the coding process. It also led me to reflect on how each interview was conducted and the quality of data obtained, and how participants might

be helped to feel confident enough to optimise disclosure of their beliefs and experiences during the interviews.

Qualitative data from surveys and interviews were initially coded under the following headings:

- a) Autonomy/control/power/choice
- b) Qualities of self
- c) Rights/justice/democracy
- d) Harm/cruelty/inhumaneness
- e) Medicalisation
- f) Suffering
- g) Concern for others/burden on others
- h) Concerns for self
- i) Personal experiences
- j) Preparedness/planning
- k) Stories/meanings

Themes identified were highlighted in text using colour coding as this provided a clear visual marker identifying and distinguishing between themes in order to count and sort them into thematic categories. Themes were repeatedly checked over time to maximise accuracy and objectivity of identification. Following this initial phase of analysis, the codes initially identified were re-grouped with all themes identified (Level 2, Table 1) assigned to seven broadly overarching thematic categories (Level 1, Table 1) which in turn were grouped under seven related higher level concepts, debates and theories constructing the thematic hierarchy shown in Table 1.



Table 1: Thematic Hierarchy Model

Higher level concepts, debates and theories: background						
Theories of self	New social movement theory	Medicalisation theory	Theory of altruism	Ethics/morality	Socio-economic theory	Risk theory
Level 1 themes						
Feared threats to self	Activism	Good/bad professionals	Concern for others	Personal philosophy	Resource-related themes	Pre-empting future risk to self
Level 2: sub-themes						
Anticipatory fears of threats to self: • Pain • Serious disease • Loss of self through cognitive decline • Residential/hospital care • Burden • Disfigurement • Loss of control • Loss of dignity • Loss of autonomy • Loss of bodily integrity • Loss of independence • Loss of quality of life	• Membership of organisations • Active involvement in media and politics • Active involvement in FATE functions	• Keeping alive v letting go • Perceived systemic issues in health and social care • Technology/overuse of technologies • Positive/negative accounts of care • Relevant experiences (professional/non-professional) • Covert/overt assisted death	• Avoidance of harm to others • Avoidance of burden on others • Compassion for others • Desire to benefit others	• Religion • Harm/ • Cruelty • Kindness • Rights/autonomy • Choice	• Desire to conserve personal and national resources • Fear of resource limitations	• Risk avoidance strategy • Contingency planning for end of life

Level 2 sub-themes assigned to ‘threats to self’ represent a range of fears associated with future self-compromising bodily, cognitive, situational or existential losses which were either feared, seen as unacceptable or desired to be actively avoided. The quotes that follow contain themes that symbolise threats to the self involving “being kept alive”, pain, loss of dignity, serious diseases, cognitive decline, residential care and loss of autonomy contained in the following quotes:

*“All this technology is nowadays to keep people alive in conditions which are not particularly pleasant and often very painful”*

*“I was diagnosed with a very serious chronic/terminal illness. It is guaranteed to cause me a lot of pain and distress when I die. This is my biggest fear in life. Not death but the process”*

*“...I have watched people die hideous deaths with very little or no dignity...”*

*“...little by little losing yourself and everything that made life worth living long before you die, that’s the horrifying thing.”*

*“The isolation of nursing homes where you are sitting round a room with the TV blaring and that to me is like hell on earth....”*

*...loss of personal autonomy is very vital to me. It’s always been vital...I’ve got to be trusted and I’ve got to have my autonomy”.*

Level 2 sub-themes assigned to ‘activism’ are illustrated by quotes in which participants reported interest in taking an active role in FATE’s activities. For example:

*[joined because...] “...I wanted to campaign for change of Scots law”.*

*“FATE asked us to write to all the SMPs...I had at least two almost positive responses...”*

Level 2 sub-themes assigned to ‘good/bad professionals’ were drawn from expressions of positive and negative opinions about professionals and health/social care services. Examples shown include themes about ‘keeping alive’, positive and negative opinions about care, and covert assisted dying:

*“...most of all I fear being kept alive when quality of life is nil”.*

*“...everything seems to be concentrated on giving you that little bit longer however miserable it is...”*

*“... medical science is actually brilliant...in keeping you alive...it just won't allow you to let go, it won't allow you to go peacefully...”*

*“...had wonderful care in the hospice ward”*

*“...had all the palliative care in the world... was in a hospice ... it didn't make it any less ghastly”.*

*I have seen many cases of bad practice and lack of common humanity in "caring" professionals”.*

*“Care of elderly in UK is terrible”*

*“I think young doctors and so on they just haven't got that sort of breadth of vision...”*

*It's this departmentalising of a patient so there's no case conference...where you think about the whole patient...”*

*“[the doctor]...he bowled in quite unexpectedly.....and rushed out again within about 5 minutes and in about 20 minutes she was dead...”*

Level 2 sub-themes assigned to 'concern for others' include themes related to concerns about harming and burdening others and desire to benefit others:

*“For them to watch me deteriorate as I watched my (parent) is too painful to consider”.*

*“I'm more concerned about other people than I am with myself actually. I think I'm concerned that I don't want to put other people through misery while I am dying.....it's for others that I'm concerned really”.*

*“wouldn't like to be a burden on [child] in any way...certainly wouldn't be the right sort of thing to happen at all”.*

Level 2 sub-themes assigned to 'personal philosophy' include comments about religion, cruelty, kindness, rights and choice as shown in the following quotes:

*“...I’m not religious now...I would hope and think we lead a pretty Christian life without being in attendance...[belief in having a right-to-die] doesn’t conflict at all.”*

*“I do believe...and I go to church...No [conflict], not at all. I think it’s a kindness to let people die sometimes rather than... I think it’s cruel for people to be kept alive when their quality of life is really not worth being kept alive”*

*“...the bottom line for me is I regard it as one of a human being’s rights to decide that he’s had enough”*

*“I’ve always felt very strongly that people should have a right to personal choice as long as it doesn’t impinge on other people...I’ve always thought about ethics and the morality of different things...I was brought up as a Christian and I suppose in a way that’s a Christian legacy that it makes you think in those terms.”*

Level 2 sub-themes assigned to ‘resource-related themes’ include both personal finance-related and health service resource-related themes

*“if I live a very long time my money will run out...”*

*“I would not like to think I was using medical resources and medical time which was largely to no effect... which could be used better elsewhere...”*

*“... using up all your resources so there’s nothing left for your children and a lot of people would far rather forego some of that such as nursing home care, having to give up their home and so on so that their children can benefit...”*

Level 2 sub-themes assigned to ‘pre-empting future risk to self’ relate to themes concerning management of future risks and contingency planning for dying and death.

For example:

*“I am putting together a contingency plan in case of life-limiting or disabling illness”.*

*“I joined Dignitas about 25 years ago...that was my contingency plan”*

*"I do have the medicine...as a safety precaution..."*

## **8. Discussion**

In general, there are a number of potential difficulties in researching this topic. Firstly, gaining access to research participants may be difficult. Right to die societies are liable to act as gatekeepers in the interest of maintaining the confidentiality of their members. Also, they may not be willing or interested in taking part in an academic research project, nor to inform their members about this option. Initially this was my experience having first approached Dignity in Dying. Of course other methods could have been employed to gain access to a sample of right to die society members - through snowball sampling, through web-based questionnaires or through recruitment via social media websites but all these methods have their drawbacks in their ability to reach a reliable, sufficient or relevant sample.

Secondly, if a right to die society consents to take part and distributes a survey to all its members as FATE did, confidentiality made it impossible to follow up on non-responders to optimise the response rate.

Thirdly, right to die society members may have no interest in taking part in research and may not be prepared to disclose to anyone the sort of information being sought in this study.

Fourthly, the credibility and motives of the researcher may be questioned leading to non-cooperation. Also people may be embarrassed or wary of disclosing information that may potentially compromise them in some way in their private and/or public lives, or may believe that exposing their values and beliefs to a stranger could be too stressful or distressing. People may also potentially be too ill to contemplate taking part in a study like this.

In the event, the main difficulty encountered in commencing this study was failure of my initial approach to Dignity in Dying. Following that, and having gained consent from FATE to proceed, the main difficulties I encountered were related to resourcing the research although I was fortunate to be awarded the Phil Strong Memorial Prize which helped greatly in funding the research.

I approached data collection by devising methods that aimed at the most practical ways of obtaining information from participants to address the research questions but as previously noted, FATE's policy of preserving its members' confidentiality prevented disclosure of members' names and contact details to me for the purpose of conducting the survey independently, preventing my ability to follow up non-respondents in order to increase the response rate which was not as high as had been hoped for.

The questionnaire design, while generating data that answered the research questions, would have benefited from greater clarity in defining the meanings of questions seeking information about close involvement with caring for people who were terminally ill and/or close to death. In some instances responses differentiated between the two questions but others did not appear to recognise any difference. It was useful to have included open questions as inviting people to expand on topics produced varied and interesting data not captured by closed questions. There was a good response to the request for people to volunteer to take part in interviews with 59% responding in the affirmative. Embarrassing questions were avoided in terms of identifying social class because it was anticipated that people would be reluctant to disclose detail of income as had been sought in previous Hemlock Society studies. To avoid this, professional status was requested from which social class could be derived.

Resource constraints necessarily limited the number of interviews that I could conduct, as participants were widely spread throughout the UK. I anticipated that all interviews would be conducted face to face but this became impossible due to minor difficulties in accessing all members selected for interview. One member who was eventually interviewed by phone had forgotten to attend a face to face interview and others were either unable to meet at central locations, or could not be accessed due to the distances involved.

Finally, in view of the ethical issues surrounding confidentiality and avoidance of harm to research participants, in writing up the results I have taken great care to preserve their confidentiality throughout this thesis. In several cases this has meant omission of some data when attributing quoted material in order to prevent as far as possible any chance of participants being identified.

# Chapter 5: Results (Part A):

## Survey of Members of Friends at the End (FATE): A quantitative and qualitative analysis

Chapter 4 presents the results of a quantitative and qualitative analysis of surveys completed and returned by one hundred and sixty two members of Friends at the End (FATE): a 41% response rate. At the time the study was conducted, FATE had a UK-wide membership of 400 (male 156[39%] and female 244 [61%]) including 30 [7.5%] medical doctors). No other membership data were made available due to the society's concern to protect its members' confidentiality.

The main objectives of this survey were:

- e) To compare the demographic profile of FATE members with previous studies of US Hemlock Society members
- f) To gather information about membership including that of other right to die societies and to understand more about factors that have influenced decisions to join one or more UK right to die society
- g) To gain a more detailed insight into people's personal reasons for joining FATE
- h) To explore individual beliefs and values and how and why these had been acquired
- i) To gain a greater understanding about people's fears and concerns associated with dying and death in relation to their membership of FATE
- j) To explore the impact of personal experience of dying and death on decisions made to join FATE
- k) To understand more about religiosity and its relationship to decisions to join FATE
- l) To identify members willing to be interviewed in greater depth about the information they provided in their responses to the survey

## 1. Analysis of quantitative data (n = 162)

### 1.1 Age

Table 1: Age (n = 162)

Under 50	51-60	61-70	71-80	81-90	Over 90	Age not disclosed
21 (13%)	20 (12%)	37 (23%)	52 (32%)	26 (16%)	3 (2%)	3 (2%)

A majority (118) of respondents (n=159 [74%]) were aged between 61 - 94 years. Of 36 health/social care professional members of FATE, 35 provided information on age; 29 of these 35 (83%) were aged between 61 - 94 years.

### 1.2 Gender (n = 162)

More females (n = 95, 59%) than males (n = 67, 41%) responded to the survey. A similar gender ratio is broadly replicated across the whole membership of FATE.

### 1.3 Professional status (health/social care professional/other) and social class

One hundred and fifty seven (97%) of the 162 respondents gave information about their occupational background. Table 2 shows occupational background of respondents divided by health/social care professional and other:

Table 2: Professional status and social class (from SEC three point scale)

Professional status (n = 157)	Social class I	Social class II	Social class III
Health/social care professionals*	36 (23%)	0	0
Other	96 (61%)	22 (14%)	3 (2%)
Total - all	132 (84%)	22 (14%)	3 (2%)

\*HSCP

The 36 HSCPs were from medical (12), nursing (7), paramedical (8), social work (7), dental (1) and veterinary (1) professions.



Gender differences were found between health/social care professionals and other respondents. Professional status by gender shows women twice as likely to be health professionals than men among the health/social care professional respondents whereas gender was more evenly distributed amongst other respondents (Table 3):

Table 3: Professional status and gender

<b>Gender (n = 162)</b>	<b>Health/social care (n = 36)</b>	<b>Other (n = 126)</b>
Male (n = 67)	9 (14%)	68 (54%)
Female (n = 95)	27 (29%)	58 (46%)

## 1.4 Membership of other right to die societies

People were asked whether they had previously been, or were currently members of two other UK right to die societies, Dignity in Dying and EXIT.

Table 4: Membership of other right to die societies

<b>Right to die society (number of responses)</b>	<b>No</b>	<b>Yes: (number of members past or present)</b>
EXIT (n = 159 [98% response rate])	100 (63%)	59 (37%)
Dignity in Dying (n = 157 [97% response rate])	90 (57%)	67 (42%)

Thirty seven (63%) of the 59 people who were or had been members of EXIT said they had left the society. Seventeen (25%) of the 67 people who were or had been members of Dignity in Dying said they had left the society.

Table 5: Reasons given for leaving other societies

<b>Reasons given:</b>	<b>EXIT (n = 35)</b>	<b>Dignity in Dying (n = 17)</b>
Expelled from membership	6	1
Subscription lapsed	4	1
Left as FATE preferred group	9	7
Left through dissatisfaction /dispute	16	8

## 1.5 Reasons given for joining FATE

In an open question people were asked why they had joined FATE. Themes drawn from the responses were counted and arranged under the nine broad headings shown in column 1 Table 6. Themes drawn from responses in which people mentioned more than one reason for joining FATE were counted and sorted under the appropriate headings.

Table 6: Reasons given for joining FATE [n=156]\*

Reason	Number (%) HSCP**	Number (%) Others	Number (%) All
Joined because of experience of terminal illness (self or close other)	17 (49%)	43 (35%)	60*** (38%)
FATE seen to be most appropriate society to meet individual needs	17 (49%)	30 (25%)	47 (30%)
Left another right-to-die society to join FATE	12 (34%)	14 (12%)	26 (17%)
Joined to obtain information and advice	4 (11%)	22 (18%)	26 (17%)
Joined to support the right-to-die movement	6 (17%)	19 (16%)	25(16%)
Rights-based reasons cited for joining (all)****	6 (17%)	15 (12%)	21 (13%)
Joined due to interest in Dignitas	3 (9%)	17 (14%)	20 (13%)
Joined to seek ways to avoid suffering/to avoid undue suffering	4 (11%)	13 (11%)	17 (11%)
Belief in right of choice (i.e. re manner and/or timing of death)****	4 (11%)	9 (7%)	13 (8%)
Other	4 (11%)	5 (4%)	9 (6%)
TOTAL (=100%)	35	121	156

\*in 6 cases reasons were not given

\*\* HSCP: health and social care background

\*\*\* Four had a terminal illness themselves

\*\*\*\* Rights-based reasons given for joining FATE include: “the human right” to decide timing of death, the right to choose “how to die with dignity”, and belief in principle in having a legal right to die.

## 1.6 Professional experience of working with dying patients

Seventeen (47%) of the 36 people with health or social care professional backgrounds said they had worked with dying patients during their careers.

## 1.7 Personal experience of dying and death (n = 160)

Fifty three (33%) people said they had had no personal experience of dying and death and 2 people did not respond to either question about personal experience of dying and death.

Table 7: Personal experience of dying and death

Personal experience of close involvement	Number (%) YES	Influenced decision to join FATE
1. Caring for someone terminally ill (n=157*)	88 (56%)	51 (58% of 88)
2. Caring for someone close to death (n=153**)	91 (59%)	51 (56% of 91)

\*5 people did not respond

\*\*9 people did not respond

## 1.8 Providing care for others

Of the 88 people who said they had been closely involved in caring for someone who was terminally ill, excluding care given in a professional capacity, 56 people said they had been closely involved in caring for one person who was terminally ill and 14 persons said they had cared for more than one person who was terminally ill.

Of the 91 people who said they had had close involvement in caring for someone who was close to death, 53 said they had been closely involved with one person who was close to death and 8 with more than one person close to death.

Table 8: Persons cared for

Persons cared for	Close involvement/ terminally ill (n=88)	Close involvement/ close to death (n=91)
Parents	43 (49%)	58 (63%)
Partners	28 (32%)	18 (20%)
Patients	15 (17%)	15 (16%)
Siblings	8 (9%)	4 (4%)
Relatives	4 (4%)	3 (3%)
Friends	5 (6%)	7 (8%)
Children	1 (1%)	0
WW2 deaths	0	2 (2%)
Assisted suicides	0	3
<b>Total episodes:</b>	<b>102</b>	<b>107</b>

Of the 88 people who reported having had close involvement with someone who was terminally ill, 38 people named the patient's diseases. Five people had been involved with two terminally ill persons and one with three and in 1 case death was associated with 2 diseases (45 care episodes). The diseases associated with these forty five caring episodes were cancers (26), neurological diseases (5), dementias (11), and other (4)

Twenty five of the 91 people who said they had had close involvement in caring for someone who was close to death named the patient's diseases. Five of these 25 people were involved with 2 deaths (30 care episodes) and in two cases a death was associated with 2 diseases. Diseases associated with these 30 care episodes were cancers (18), heart conditions (4), brain injury/stroke (4), and other (7), cited as causes of death.

From the 88 people who said they had cared for someone with a terminal illness, 50 (57 %) indicated that close involvement with, and/or caring for someone had influenced them to join FATE.

From the 91 people who said they had had cared for persons close to death, six responses indicated that the people who had died had had access to assistance in dying

Twenty one (60%) of the 36 people with health or social care professional backgrounds said they had been closely involved and/or cared for their own family members or friends

## 1.9 Religious belief

Table 9: Religious belief (n = 159\*)

Religious belief YES	Religious belief NO
57 (36%)	102 (64%)

\* three people did not respond to this question.

People were asked to indicate their degree of religiosity and the 57 who owned to having religious belief rated their belief as shown in Table 10:

Table 10: Religiosity (n = 57)

Degrees of religiosity	Number (%)
Strongly religious	10 (18%)
Moderately religious	24 (42%)
A little religious	23 (40%)

Of the 57 seven respondents who claimed to hold religious beliefs, all but three indicated that they felt no conflict between their religious beliefs and their commitment to the aims of the right to die movement as enacted by FATE.

## 1.10 Fears for self

Table 11: Levels of concern about future hypothetical suffering (n = 158)\*

	<b><i>Not at all concerned</i></b>	<b><i>A little concerned</i></b>	<b><i>Somewhat concerned</i></b>	<b><i>Very concerned</i></b>	<b><i>Extremely concerned</i></b>
1. Loss of control	8(5%)	2(1%)	11(7%)	24(15%)	113(72%)
2. Dependence on others	7(4%)	4(3%)	11(7%)	40(25%)	96(61%)
3. Loss of dignity	7(4%)	6(4%)	18(12%)	26(16%)	101(64%)
4. Burden to others	10(6%)	4(3%)	19(12%)	30(19%)	95(60%)
5. Severe pain	10(6%)	11(7%)	17(11%)	43(27%)	77(49%)
6. Disability	13(8%)	6(4%)	24(15%)	48(31%)	67(42%)
7. Social isolation	36(23%)	16(10%)	40(25%)	29(19%)	37(23%)
8. Disfigurement	44(28%)	28(18%)	32(20%)	21(13%)	33(21%)

\*In four cases respondents did not answer the questions

Highest levels of concern expressed for self in contemplating possibilities for future suffering identify social isolation and disfigurement being of least concern, while dependence on others, losses of dignity and control, burden to others, severe pain and disability attract higher levels of concern.

Table 12: Highest levels of concern (very + extremely concerned) by HSCPs/others

<b>Very/extremely concerned</b>	<b>HSCP (n = 35*)</b>	<b>Other (n = 123)</b>	<b>Total (n = 158)</b>
Dependence on others	28 (80%)	108 (88%)	136 (86%)
Loss of dignity	27 (77%)	100 (81%)	127 (80%)
Loss of control	18 (51%)	107 (87%)	125 (79%)
Burden to others	26 (74%)	99 (80%)	125 (79%)
Severe pain	29 (83%)	91 (74%)	120 (76%)
Disability	22 (63%)	93 (75%)	115 (73%)
Social isolation	14 (40%)	52 (42%)	66 (42%)
Disfigurement	10 (29%)	44 (36%)	54 (34%)

\* One HSCP did not answer this question.

Overall, dependence on others was of greatest concern to both professional and lay groups. HSC professionals tended to be less concerned than other respondents about loss of control.

## **1.11 Willingness to be interviewed**

A total of 99 (61%) people indicated they were willing to be interviewed and provided contact details.

## **2. Analysis of qualitative survey data**

Respondents were invited to answer five open questions asking for more details about their personal reasons for joining FATE:

- a) Why did you join FATE? (and where relevant, why did you join other right to die societies?)
- b) Have you ever been closely involved in caring for a person who was terminally ill; if yes, in what capacity (please describe)?
- c) Have you ever been closely involved in caring for a person who was close to death; if yes, in what capacity (please describe)?
- d) If yes to b) and c), did these experiences influence your decision to join FATE in any way (please describe)?
- e) Is there anything else that particularly concerns you about your own death (please describe)?

### **2.1 Reasons given for joining FATE and details of what influenced members to join (n=156)**

Multiple reasons were cited for joining FATE and most respondents cited more than one reason for doing so. Many respondents indicated they joined FATE in preference to another right to die society. Some had migrated from another society to join FATE,

while others retained dual memberships with other right to die societies. Almost 40% of respondents cited experience of terminal illness in self or others as a reason for joining.

### 2.1.1 FATE as a preferred right to die society

Forty one people stated they preferred FATE over other right to die organisations. Preference for FATE was expressed in terms of its perceived superiority over other right to die societies, and perceived shortcomings of other societies.

*"...[the other society] is a gutless organisation, too concerned with keeping its nose clean to do the right thing - for instance supporting Dignitas. Many of the people I most respected have left in disgust and joined FATE". (P27, female, 70s)*

*"FATE is much more proactive and definite in its views". (P28, female, 70s)*

*[joined] because....I found [another society] too disappointing in their advice and found FATE to be more to my liking". (P113, male, 90s)*

*"[joined because FATE was] a new organisation with none of the unconstitutional problems of [another society]".(P152,female,60s)*

*"...FATE is an excellent example of furthering the cause of voluntary euthanasia with worthy people at its helm since its inception..." (P138, male, 70s)*

### 2.1.2 Commitment to supporting the movement

In expressing their commitment toward supporting the right to die movement, people offered various explanations for why the ethos of the movement resonated with their core beliefs. Some people stated they joined in order to support the movement through campaigning:

*"[joined] to campaign to legalise voluntary euthanasia". (P78, female, 40s)*

Core beliefs were expressed here in terms of human rights:



*“joined to support the movement for legalising euthanasia and medically assisted suicide, based on a strong conviction that a terminally ill individual should have the human right to decide the timing of his/her death. This conviction is strengthened by personal experiences”. (P110, male, 70s)*

In both of the following two quotes, pro-choice beliefs in a right to die were stated, in one case these beliefs were seen to be in accord with other pro-choice social issues:

*“[joined] because I believe that people with terminal illness should have the legal right to choose the time and circumstances of their death”. (P137, male, 60s)*

*“(joined because) convinced of the aims and objectives of FATE in being (able) to have a choice on the manner of death and any medical treatment that I may have to experience. This is consistent with my pro-choice views on abortion and women's rights”. (P151, male, 40s)*

Choice in dying was cited in the context of deaths from dementias; fears about loss of mental capacity being a theme that rose repeatedly in both survey responses and interviews:

*“[Parent and grandparent]... both had Alzheimer's and I felt so strongly as did they that they had a right to choose how to die at least with some dignity”. (P127, female, 40s)*

The human versus animal question was raised on a number of occasions throughout responses to the survey and in subsequent interview data. Human and animal deaths are contrasted here with reference to human dignity and choice:

*“(joined because) I believe people should be accorded the same dignity as animals at the end of life and should have the right to choose to hasten their death in face of terminal illness, a debilitating condition and great suffering”. (P144, female, 40s)*

Choice in dying as a civil liberty was expressed by this respondent with a legal background:

*[joined because]... I have been involved in the civil liberties movement for most of my adult life and I saw the question of choosing the time and manner of one's death as a civil liberty because it is based on the individual's autonomy”. (P50, male, 80s)*

Others expressed negative views about care in older age and/or terminal illnesses in the context of joining FATE. This individual also implied a pusillanimous approach is taken by authorities over the question of legalising hastened death in the UK:

*"[joined] because I hold very strongly to its principles. Care of elderly in UK is terrible. Moral courage lacking in powers that be". (P22, female, 40s)*

Desire to avoid death following a protracted dying trajectory, characterised by inexorable loss of physical function or pain led to this individual's decision to join FATE:

*[[joined] to support the drive to obtain a change in legislation to allow people to die with dignity and where possible to avoid a prolonged painful death when terminally ill or to avoid the effects of a prolonged wasting disease resulting in inevitable death". (P21, male, 70s)*

Experience of parental deaths instigated membership of FATE in order to challenge the current ethos surrounding death and dying, due to perceptions of duplicity in the system:

*"[My parent's] death in particular convinced me that the current double standards / deceit / hypocrisy are totally unacceptable. I therefore sought to help promote discussion and a change in the law by joining Dignity in Dying and FATE". (P64, female, 70s)*

In addition to beliefs about a right to choice in dying as a reason for joining FATE, reasons given here reflect perceptions of a deficit in public understanding about the right to die movement's aims and objectives:

*"(joined because) (a) issues that concern FATE need to be better understood by the public; (b) to become more aware regarding others' own outlook; (c) in favour of public education on these matters. (d) Against cruelty. (e) In favour of personal choice". (P150, male, 50s)*

### 2.1.3 Terminal illnesses in self or others as a reason for joining FATE

Terminal illnesses were cited as reasons for joining FATE. Members said they joined either because they were suffering from a terminal illness themselves, or because of the terminal illness of partners, parents or friends. The following two comments contain themes relating to acquired terminal illnesses, anticipation of suffering and anticipation of the consequences of progressive loss of motor function through motor neurone disease:

*“I was diagnosed with a very serious chronic/terminal illness. It is guaranteed to cause me a lot of pain and distress when I die. This is my biggest fear in life. Not death but the process. (P102, male, 20s)*

*“[joined because of] diagnosis of MND ...and progressive loss of control of body”. (P119, male, 70s)*

In this response a daughter acts as proxy on behalf of a parent in order to seek information on parent’s behalf:

*“[joined because parent] was diagnosed with MND... and has been very interested in voluntary euthanasia”. (P54, female, 30s)*

Desire to avoid replicating ways of dying previously experienced in others occurs repeatedly throughout the survey data. Here this is cited as a reason for joining FATE:

*“[partner] was diagnosed as terminally ill with cancer and inoperable. I joined to avoid a possible similar painful end to my life”. (P13, male, 50s)*

### 2.1.4 Seeking information and advice

FATE offers a range of information and advice commensurate with that offered by other UK right to die societies, but is unique in offering additional information to individuals seeking access to Dignitas. Of those who said they joined FATE specifically to seek information and advice, 20 people expressed interest in Dignitas.

*"[joined] because FATE seemed to be, as indeed it is, a direct practical route to Dignitas, Zurich". (P158, male, 70s)*

*"[joined because another] society refused to associate with Dignitas". (P77, male, 50s)*

This quote suggests that some sympathy may exist at governmental level for the right to die movement's aims:

*"I joined as a result of a newsletter from our MEP who said it was a group that could be helpful in providing information... and particularly Dignitas which up to now I had found it very difficult to access...".(P62, female, 70s)*

In some instances, terminal illness was given as a reason for seeking information about Dignitas for themselves or others.

*"Been diagnosed with [x] disease. Wanted to find out about Dignitas". (P90, female, 20s)*

*"[joined because] a friend who has MND wanted information on Dignitas. I couldn't get it in any other way". (P147, female, 60s)*

Other participants cited need for information and advice on living wills and on options for hastening death as reasons for joining FATE:

*"[joined] to get information about ways to commit suicide so that I could avoid a slow, lingering, undignified (and possibly) painful death. (P5, female, 50s)*

*"[joined] so I could obtain information on living wills and seek information on end of life decisions". (P76, male, 40s)*

Management of risk and contingency planning is evident in these reasons given for joining FATE:

*"[joined because] I saw... [an] ad in the Guardian and wanted to know more about Dignitas. My [disease] means that I may face a painful death.... and... I want a possible way out". (P2, female, 60s)*

*"[joined] ... to have access to Dignitas, should this become necessary".(P148, male, 80s)*

*"[joined because] I was given details by Dignitas as I wished to be able, should the need arise, to be able to end my life". (P149, male, 70s)*

The contingency planning theme is repeated in these quotes in terms of seeking information, help and advice about non-specific suicide methods, should they be needed in the future:

*"[joined] to obtain information about reliable methods of suicide mainly for use in the event of dementia". (P18, female, 60s)*

*"[joined FATE because]... good way of finding information on assisted dying. If necessary I want the means to end my life peacefully, painlessly and with dignity". (P140, female, 30s)*

*"[joined FATE] because I wish to have access to help and advice should I decide I wished to end my life because of disability or illness". (P49, female, 80s)*

#### 2.1.5 Personal experiences of dying and death

People justified their reasons for joining FATE through giving accounts of others' dying and deaths (parents, partners, relatives, friends and patients). The same theme (personal experiences of dying and death) also emerged in answer to subsequent questions reported in section 2.4.

*"[parent] died... a difficult harrowing death despite requesting "a pill" that could hasten his slow and painful demise. I hoped that our experience could be shared with others to make a change in the law so that with adequate safeguards, people could die with dignity". (P84, female, 50s)*

*"[parent's] decline in health and suffering in illness, in particular, made me aware of the vulnerability and uncertainty concerning the medical shortcomings in this regard. Also, knowledge of relatives and friends traumatic experiences of dying." (P60, female, 60s)*

### 2.1.6 Risk management and contingency planning

As already shown in Section 2.1.4, reasons given for joining FATE were presented in terms of contingency planning to manage perceived risk of undesirable ways of dying in the event of a perceived need to do so. This next participant had been in contact with Dignitas prior to joining FATE, illustrating how a collaborative relationship exists between the two organisations:

*“I was given details [about FATE] by Dignitas as I wished to be able, should the need arise, to be able to end my life”. (P149, male, 70s)*

This response represents determination to protect the ability to act autonomously should a choice be made to hasten death, and to protect close others from any negative consequences of actions taken on behalf of the participant. Belief in the right to die is thus associated by this participant with responsibilities toward others:

*“[joined] To ensure that if I want to die, no one will interfere or act against anyone who assists me”. (P122, male, 70s)*

This next quote suggests that mistrust of care services can be an element informing perceptions of need to make contingency plans that might include hastening death:

*“[joined because].... I am putting together a contingency plan in case of life-limiting or disabling illness. I live alone and have no family and so cannot rely on anyone else to look after my interests...” (P155, male, 40s)*

Fears about dementia, and avoidance of future suffering were cited in the context of contingency planning to evade dying in circumstances that were deemed undesirable.

*“[Partner] was diagnosed as terminally ill with cancer and inoperable. I joined to avoid a possible similar, painful end to my life”. (P13, male, 50s)*

*“[joined] to obtain information about reliable methods of suicide mainly for use in the event of dementia”. (P18, female, 60s)*

### 2.1.7 Convenience of access to FATE

Some joined FATE as its location was preferred:

*“Prepared to be a member of only one such organisation so chose FATE as it was Scottish based”. (P48, male, 70s)*

*“[joined] to support the... movement locally”. (P71, male, 60s)*

### 2.1.8 Other reasons given for joining FATE

Fear of being ‘kept alive’, fear of dependency, and contrast between animal and human deaths were also cited in the context of reasons for joining FATE.

*“...as I got older, I began to realise how many people are just being kept alive - but not living...” (P12, female, 80s)*

*“[joined because of] wish not to live dependent on others...” (P124, female, 60s)*

The animal versus human theme emerged in the context of the belief that painful deaths are condoned for humans but not for animals. Differences were also seen between animals and humans in the context of the degree to which dignity may be preserved and suffering prevented. The argument that sanctions should be taken against doctors for failing to address suffering in dying humans in the same manner as would happen for vets implies belief that this situation is morally unacceptable:

*“... vets would be struck off if they permitted animals to die as painfully and in as much stress as most humans are currently condemned to do”. (P81, male, 70s)*

*“...I believe people should be accorded the same dignity as animals at the end of life and should have the right to choose to hasten their death in face of terminal illness, a debilitating condition and great suffering”. (P144, female, 40s)*

One individual’s response referred to their personal beliefs conflicting with their religion’s teachings in the context of why they had joined FATE:

*“... I am a Roman Catholic and the God I know and respect would not want me to suffer, despite the views of the Catholic Church. And believe me, a lot of Catholics feel the same”. (P23, female, 70s)*

## **2.2 Health/social care professionals’ reasons for joining FATE**

Reasons given for joining FATE by health/social care professionals taking part in the survey tended to be broadly similar to those most frequently occurring across the whole sample; in addition professional experiences were cited in some instances.

### 2.2.1 Doctors

Two of the twelve responding doctors cited quality of life themes and one cited professional experience:

*[because] quality of life more important than length”. (P25, female, 60s)*

*“(because) ...when life was no longer worth living, had no quality, there should be autonomy for self-administered medication to end life”. (P31, female, 70s)*

*“Professional experience influenced decision”. (P118, male, 60s)*

### 2.2.2 Nurses

Nurses also cited professional experiences as reasons for joining and for not wishing to die in similar ways to the patients they have cared for:

*“...I have watched people die hideous deaths with very little or no dignity. I have seen them suffer over weeks and months before death. Some people have not wanted to die in this manner but do not have means or information on how to die any other way. I do not want to die in this manner”. (P140, female, 30s)*

*“In my professional life I have seen many people who wished to die, but could not. I do not want to suffer the same fate myself”. (P129, male, 40s)*



This nurse accuses their profession of condoning patient suffering through neglecting the distress causing patients to wish for death to be hastened:

*“Professionally we neglect the dying patient who wants “help” to die. I have seen too much pain and suffering in the “name” of care of dying patients”. (P88, female, 60s)*

Like other health/social care professionals, social workers also cited professional experiences as having influenced them to join FATE. The perception that care services lack compassion toward suffering in dying patients is replicated:

*I have seen many cases of bad practice and lack of common humanity in “caring” professionals. (P9, female, 70s)*

*“[joined because of] professional and personal experiences with end of life issues”. (P162, female, age not disclosed)*

### 2.2.3 Media-related reason given for joining FATE

One person with a health/social care background attributed their decision to joining FATE to media information:

*“An article in the Guardian newspaper about the help given by FATE to someone who travelled to Switzerland for an assisted suicide led to my contacting FATE”. (P115, female, 60s)*

## **2.3 Why people joined other right to die societies**

Dignity in Dying, formerly the Voluntary Euthanasia Society (VES), was the first right to die society in the UK, preceding EXIT, formerly the Voluntary Euthanasia Society Scotland (VESS) by four decades. Long-term pro-right to die attitudes were cited as one reason for joining both of these societies prior to FATE’s existence.

### 2.3.1 Dignity in Dying (previously VES)

People indicated they had joined Dignity in Dying due to long term belief in its aims and objectives, their desire for legalisation of hastened death, personal and professional experiences of dying and death and fears about the effects of nuclear war.

*"I joined VES in the early 90s because I espouse their aims and objectives and had done so for many years". (P62, female, 70s)*

*"...Hoped it would succeed to make legal "assisted suicide"".(P89,female,80s)*

*"Dignity in Dying seemed more media savvy and so stands a better chance of influencing a change in the law". (P155, male, 40s)*

*"Because of my experience as a student nurse...".(P157,HSCP, female, 60s)*

*"[joined because of] watching [partner] suffering from mesothelioma". (P46, female, 70s)*

*"...my initial joining was at that time related to fear of nuclear war and I wanted the knowledge of how best to acquire the means of killing myself and my two children quickly and painlessly if war came, rather than have them suffer an horrific slow death from radiation poisoning..." (P125, female, 70s)*

One person observed they were not a member of Dignity in Dying because:

*"...I do wonder if legalising it could leave it open to abuse". (P12, female, 80s)*

### 2.3.2 EXIT (formerly VESS)

Because EXIT (VESS) provided practical advice on life-ending strategies, people joined in order to access this information.

*"[joined]...for access to "self-deliverance" information as part of my contingency plan..." (P155, male, 40s)*

*“Exit was producing a booklet that gave details about euthanasia”. (P7, male, 90s)*

*[joined because...]* *Innovative publishers of original (in UK) 'how to' booklet in pre-web days”. (P73, male, 70s)*

Long term pro-right to die beliefs were also cited:

*“I joined VESS in 198... Since adolescence I have believed in the right of choice for self deliverance - which belief has grown stronger over the years”. (P138, male, 70s)*

*“I joined VESS because I believe strongly in the right of the individual to decide her own fate. I was involved in the battles over contraception and abortion, and euthanasia and physician assisted suicide are the logical last goals to win”. (P89, female, 80s).*

Other reasons for joining EXIT involved desire to become an activist and consequent on an organisational policy decision:

*[joined because...] “...I wanted to campaign for change of Scots law”. (P141, female, 80s)*

*“I joined VESS when the Humanist society of Scotland adopted support for voluntary euthanasia as a society policy”. (P58, male, 80s)*

### 2.3.3 Multiple memberships of all three societies

Respondents who said they retained membership of all three right to die societies did so because of their commitment to the movement:

*“I felt obliged to support all UK organisations fighting for the right to die with dignity and thought an English organisation might have a better chance of getting legislation through”. (P5, female, 50s)*

*“I support all organisations that promote euthanasia and I wish to be kept fully informed”. (P159, female, 50s)*

## 2.4 Personal experiences of caring for others, dying and death

In two separate questions respondents were asked:

- a) whether they had ever been closely involved in caring for someone who was terminally ill and
- b) whether they had ever been closely involved in caring for someone who was close to death

If they had experienced one or both of these situations, they were asked in what capacity, and whether these experiences had exerted any influence over their decisions to join FATE.

People who said they had personally experienced caring for someone who was terminally ill had provided care for partners, parents, siblings, friends, other relatives and patients. In their answers to this question they commented on their roles, diagnoses and circumstances surrounding the person being cared for.

*"I was my wife's carer for many years with her MS". (P4, male, 60s)*

*"My husband who had lung cancer and then a brain tumour. I nursed him at home, but he had to go into the local cottage hospital for the last 6 weeks..." (P12, female, 80s)*

*"As a carer for my wife who was diagnosed as being terminally ill with ovarian cancer one year before her death". (P21, male, 70s)*

Burden and stress experienced by carers of dementia sufferers are highlighted by these responses:

*"(sibling) was in advanced Alzheimer's and I visited regularly to care for...and give (another sibling) relief so that (they) could take holidays". (P100, male, 70s)*

*"I cared for my mother for 4 years while she suffered from vascular dementia". (P26, female, 70s)*

Those who said they had cared for someone who was close to death commented on both positive and negative aspects of their experiences. The first two quotes describe

perceptions of desire for hastened death being present despite dying reportedly not being accompanied by distressing levels of suffering:

*“Death followed 6 months after diagnosis. Final weeks in NHS special care - could not have had better treatment but said “wish I could commit suicide”. (P103, female, 90s)*

*“x was fortunate as...had no pain but lay for days, sleeping and drifting in and out of consciousness - literally waiting to die. Had x been given the choice ...would have chosen to die”. (P120, female, 40s)*

The animal theme was again employed to convey perceptions of unacceptable suffering resulting from dying having been prolonged through resuscitation in the presence of life-threatening co-morbidities:

*“(Parent) was resuscitated after a heart attack and took 2 weeks to die (...already had throat cancer)...slow and miserable death contrasted with that of my elderly cat who was still purring as she was put down in seconds by the vet”. (P2, female, 60s)*

Again, prolonged dying was an issue for family members involved:

*“I spent several weeks at (parent’s) bedside discussing the difficulty of dying. My (children) and I tried to protect (other parent) as best we could from some of the daily indignities as we waited minute by minute for several weeks, all pretty frightened by the process”. (P75, female, 60s)*

Those who confirmed their experiences as carers had influenced them to join FATE talked about how these had informed their pro-right to die attitudes:

Joining FATE was due to suffering seen in persons cared for, demonstrating perceptions that acute suffering is condoned in healthcare services:

*“Also, (parent) was in a great deal of pain for a long time before... died. It was “blessed release”. (P5, female, 50s)*

*“I was appalled by the suffering allowed, with at the time, apparently no solution or help”. (P143, female, 70s)*

Diminished control over circumstances surrounding death, and physical incapacity in dying others were cited as factors influencing people to join FATE:

*“At the time it seemed unfair that a person had no control over how they could die”.*  
(P13, male, 50s)

*“The thought of being incapacitated by a stroke but still being mentally alert terrified me”.* (P143, female, 70s)

Personal experience of the carer role served to reinforce perceptions of need for the legalisation of assisted dying:

*“Firmed up my resolution that the law should be such that, where possible, people should be allowed the opportunity of avoiding unnecessarily painful deaths”.* (P21, male, 70s)

*“These experiences left me with a determination to join and speak up for organisations which existed to work for changes in the law which would make euthanasia legal”.*  
(P59, female, 70s)

*“My (parent's) death in particular convinced me that the current double standards/deceit/hypocrisy are totally unacceptable. I therefore sought to help promote discussion and a change in the law by joining DiD/FATE”.* (P64, female, 70s)

A health/social care professional respondent also referred to negative experiences of end of life care, conveying a critical perception of the prevailing social, moral and political climate:

*“Socially, morally and politically I think it is not acceptable for others not to allow an individual personal control/choice over their end of life decision. I have seen many cases of bad practice and lack of common humanity in “caring” professionals”.* (P9, female, 70s, HSCP)

Most people whose said their experiences of caring had not influenced them to join FATE indicated they had already joined the right to die movement prior to their experiences as a carer.

*“Belief in voluntary euthanasia pre-dated my (parent's) illness”. (P26, female, 70s, HSCP)*

*“Already a member when parents deteriorated”. (P118, male, 60s, HSCP)*

*“These experiences merely confirmed the beliefs I had had since a young woman”. (P125, female, 70s)*

In this instance, a media report was said to be responsible for having become sympathetic toward the right to die movement:

*“At age 13 years, I read in the (then) Manchester Guardian that a father had been charged with murdering his young son; the boy was in, or near, the terminal stages of leukaemia. It seemed to me to be very probably that the young boy was in a state of severe pain and suffering”. (P158, male, 70s)*

## **2.5 Individuals’ concerns about their eventual death**

Finally, people were asked whether there was anything else that particularly concerned them about their own deaths. Some responses merely reiterated individuals’ pro-right to die beliefs. One individual’s concern was about “being there”, somewhat reminiscent of Woody Allen’s famous quote: “I ‘m not afraid of death; I just don’t want to be there when it happens”<sup>27</sup>. Others cited particular fears and concerns held about dying and death; the following themes being drawn from these responses.

### 2.5.1 Concerns relating to self-hastening death in the future

Themes arising here reflect individuals’ doubts and concerns about the practicalities of suicide methods, timing, actions, attitudes of others and fear of divine reprisal on committing suicide, said to be due to religious indoctrination in childhood:

*“My real concern is that I am unable to decide when and how I want to die and am unable to arrange for “others” to help if I so wish”. (P33, male, 70s)*

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<sup>27</sup> [http://www.goodreads.com/author/quotes/10356.Woody\\_Allen](http://www.goodreads.com/author/quotes/10356.Woody_Allen)

*"I have tablets to end my life if it became unbearable. Would I have the courage to do so? Would friends support my wishes?" (P152, female, 60s)*

*"When living becomes a burden to myself and to others I want to be able to end it with dignity and composure. I would like my family and friends to accept my wish without feeling ashamed". (P37, male, 60s, HSCP)*

In this response, committing suicide was associated with irrational fear:

*"I have an irrational fear there may be an evil God who sends me to hell". (P40, female, 60s)*

Anticipated difficulties associated with planning suicides through Dignitas reflect doubts about meeting criteria for Dignitas' services, and the timing of suicide being dictated by ability to travel to Switzerland:

*"That if I have no terminal medical condition I will not qualify for Switzerland". (P93, female, 80s)*

*"That I may die earlier than I need to if I have to trek off to Zurich while the going is good". (P2, female, 60s)*

### 2.5.2 Concerns associated with the process of dying

Unspecified concerns about the dying process, not death itself, were raised:

*"Dying is not the problem, the manner of dying is". (P44, female, 70s)*

*"Death itself does not concern me - just the manner of it..." (P52, male, 60s)*

Themes here reflect awareness of various negative aspects of dying that could potentially make dying slow, painful, and subject to the will of others.

*"The process of dying in pain". (P128, female, 60s)*



*“Dying may be difficult and I would want death made quick and easy”. (P88, female, 60s, HSCP)*

*“That no matter what pain and discomfort I'm in, and whatever the inevitability of death, there will be people who, because of THEIR beliefs, would seek to prolong it”. (P105, male, 60s)*

*“Should (dying) be a long drawn out experience”. (P87, male, 70s)*

Physical symptoms were of particular concern to these next two respondents. The contents of the first quote suggest the respondent may have a health/social care professional background, but this was not reflected by data on occupational status provided.

*“...uncontrollable vomiting, diarrhoea, fungating lesions, bedsores, pyrexia, dirty smells. Inevitable brain damage, (even PVS/coma/stroke), transient or permanent loss of 5 senses, soreness, discomfort (unrelieved by a water bed), confusion. All of the above are much worse when they are intractable”. (P101, female, 40s)*

Being able to die at home was important for this respondent:

*“Nausea, sickness, blindness, paralysis, inability to swallow. Dying in surroundings other than my own home...” (P106, male, 70s)*

### 2.5.3 Loss of agency

Concerns about losing control and choice arising in circumstances surrounding dying and death were reiterated in responses to this question, with references made to disability, quality of life, personal relationships, location of death, loss of self, loss of accustomed role in life and loss of agency through opposition.

*“I fear a long disabling decline when I am no longer in control and quality of life has gone”. (P17, female, 80s)*

*“Loss of control, once less independent, over (dying) process. E.g. want close friends not family around me. Being fully alert but totally infirm - living Hell!” (P22, female, 40s)*

Freedom to enact autonomous decisions was seen to be dependent on dying at home.

*“The loss of choice should I be in hospital or similar setting. I like to make my decisions and be able to carry them out”. (P88, female, 60s, HSCP)*

Concerns about ability to retain agency and personhood in the future were reflected in the next two responses. The first demonstrates mistrust of doctors; the second desire to retain accustomed self and status as an individual:

*“Having my choices taken away by medical practitioners without any regard to my wishes and views”. (P151, male, 40s)*

*“I would like to die somewhere where I am valued as an individual, not just a “case””. (P89, female, 80s, HSCP)*

Ageing was associated here with concerns about personhood and agency being demeaned by others:

*“Not being taken seriously or having my opinions taken into account. I think this is more likely to happen if I am old when I die...” (P135, female, 20s)*

Loss of agency was seen in terms of becoming useless and no longer able to help others:

*“I dislike strongly the idea of feeling useless. I have always liked to feel that my life has helped others. It is this very slow decline into uselessness that I find so difficult...” (P7, male, 90s)*

Agency becoming compromised through compulsion by opponents of the right to die movement concerned this participant:

*“Very concerned that those opposed to “right to die” will force their beliefs on us and hinder our cause to come forward”. (P53, female, 70s, HSCP)*

Losing privacy was also associated with loss of control:

*“Loss of privacy. I need to remain in control of my home environment and the people in it”. (P130, female, HSCP, 70s)*

#### 2.5.4 Concerns about encountering opposition

Anticipation of opposition to plans or failure to respect stated wishes in living wills/advance directives were of concern:

*“My only concern in connecting with my own death is whether a living will will be loyally honoured and executed”. (P110, male, 70s)*

*“The main thing is that hospital doctors may try to over-ride my living will either because of their own religious beliefs or because of fears of repercussions”. (P50, male, 80s)*

*“I am concerned that paramedics will revive me before finding my DNAR statement”. (P141, female, 80s)*

Family opposition to ending life at Dignitas was thwarting this participant’s desire to end their life, seemingly active compulsion to desist was being exercised by family members..

*“I would like to travel to Dignitas. But my family are totally opposed and are preventing me from going”. (P91, female, 60s)*

#### 2.5.5 Concerns about loss of mental capacity

Loss of mental capacity recurs again in responses to this question. Dementia was feared for both loss of control and for its potential physical and behavioural consequences.

*“I don't dread death per se; but I dread dementia and its consequences”. (P18, female, 60s)*

The potentially hereditary nature of dementia poses a threat for the future:

*“Mother suffered latterly from Alzheimer’s, am very concerned it is a condition which I may also suffer from”. (P24, female, 60s)*

This participant expressed an intention to hasten death should the onset of dementia become evident:

*“Dementia...I would avoid at all cost... any impending dementia would be unacceptable personally and would take own life”. (P31, female, HSCP, 70s)*

Decision-making in the future could be compromised in the presence of dementia; this was a particular concern raised here:

*“I am concerned that a gradual loss of mental capacity might render me incapable of making decisions concerning withdrawal of life sustaining treatment”. (P58, male, 80s)*

Retaining sufficient capacity to make end of life decisions in the presence of dementia troubles this participant:

*“If I suffer from Alzheimer’s I would be unable to prove I could choose to die as I would not be considered sound of mind”. (P127, female, 40s)*

Loss of mental capacity associated with pain and bodily malodour and unpleasant behaviour is of concern:

*“Alzheimers, being unpleasant, being smelly and suffering from pain”. (P160, male, age not disclosed)*

### 2.5.6 Unsuccessful suicide attempts

People expressed concerns about the consequences of failed suicide attempts:

*“It is time that medically assisted death is a legal option as it would be even worse to have a failed attempt with e.g. brain damage”. (P85, female, HSCP, 70s)*

*"...the fear I have is in the method I choose to end my life when the time comes for it, is that it might not be fully successful". (P138, male, HSCP, 70s)*

This participant seeks to pre-empt failure of suicide through rehearsing the procedure:

*"I intend to take my own life and have made arrangements to do so - including practising the procedure. My only concerns are: a) that the helium will in fact "work", b) that I am not suddenly incapacitated by stroke/heart attack before I can take my own life". (P100, male, 70s)*

### 2.5.7 Fears associated with dying alone

Dying alone gave rise to concerns about lacking the comfort of companionship in dying, being without advocates to uphold personal preferences and the consequence of lying undiscovered following death:

*"...the dread of dying totally without someone to comfort me..." (P10, female, 70s)*

*"unlike my parents, I have no one when I reach old age to take care of me (relative or friend)... Old age, decline and death without a carer or representative very much concerns me. I feel that choices are taken from you when you cannot "fight" for yourself". (P60, female, 60s)*

*"Dying at home and not being discovered for some time". (P99, male, 70s)*

### 2.5.8 Pre-empting future contingencies

Perceptions about a need for an escape mechanism as an "insurance", and concern about the impact of suicide on family members was reflected in these next responses. In the first, the concept of insurance provided by lethal drugs obviating the eventual need for hastening death is raised:

*If I had the means (drugs) to take my own life, I probably would hang on to life and bear pain and loss of dignity, knowing that when it became too much for me, I had the "exit" in my own hands". (P82, female, 80s)*

*“Wish to know that there is an exit plan in place that my family can activate”. (P30, female, 60s)*

*“...don't know how to end my life without it showing as suicide - so hard on the family”. (P12, female, HSCP, 80s)*

### 2.5.9 Aversion toward residential/nursing home care

The prospect of future residential/nursing home care also gave rise to concerns and intent to avoid these options:

*“...am now afraid if I get so bad that I have to go into a nursing home. I refuse to do that...” (P12, female, 80s, HSCP)*

*“...being in care I would avoid at all cost. I never want to be in residential care”. (P31, female, HSCP, 70s)*

*“I do not want to be in a nursing home or hospitalised...” (P108, female, 80s)*

### 2.5.10 Concerns for others

Concerns about the impact of the dying process upon close others were raised. Replication of past experiences of distressing deaths were feared because of the distress that could be caused to family members. Avoidance of causing similar forms of distress to others is associated with desire for, and plans made for, a death-hastening option

*“The death of (parent) was an extremely harrowing experience for me. I would not wish any member of my family to have to plead as I did with GP/Nurse/consultant for my wish for euthanasia to be respected”. (P64, female, 70s)*

*It is terrible to think that my(children) may have to experience what I did with my beloved (parent)...For them to watch me deteriorate as I watched my (parent) is too painful to consider”. (P75, female, 60s)*

### 2.5.11 Other concerns

Other miscellaneous concerns were cited relating to quality of future care, to potentially adverse consequences of prolonged dying and to imposition of unwanted extension of life. Lack of confidence and trust in future professional care are evident in these responses.

Concern about future care was raised, based on previous experiences of care for self or others:

*"I have long experience of the UK medical/social care system due to my illness (and previously its effects on my (parent) and have NO confidence in its performance or inclination to honour my requests or preserve my dignity". (P77, male, 50s)*

Fatalistic concerns were raised about expectations of medical care during a lengthy dying process:

*"... I know that due to my medical condition the likelihood of very slow degeneration with no reasonable medical help is my likely fate". (P62, female, 70s)*

Fears were expressed about "being kept alive", against ones' will:

*"...most of all I fear being kept alive when quality of life is nil". (P10, female, 70s)*

*"Prolongation [of life]. Frustration of eventual wish to die". (P150, male, 50s)*

But extension of life was also conditionally welcomed:

*"Concerning my own death: should be postponed as long as possible as long as life is tolerable". (P61, male, 80s)*

This participant's concerns related to fear of their body being unacceptable for medical research in the event of an autopsy following hastening of their own death:

*"I have left my body to medical research...It turns out that they don't accept bodies that have had autopsies [sudden unexplained death demands this]..." (P20, female, 70s)*

Insufficiency of financial resources in later life were raised by two people who cited concerns about finite resources:

*“Running out of money to live comfortably”. (P26, female, HSCP, 70s)*

*“Running out of money soon!” (P71, male, 60s)*

Finally, active ending of life was hoped to be something for family celebration:

*“...The Dutch form of euthanasia would allow me to die with the family around and they could have a party afterwards”. (P89, female, HSCP, 80s)*

### **3. Discussion**

Existing studies of peoples' reasons for joining right to die societies have not so far identified in such detail the diversity of reasons people hold for joining these societies. The results of this survey add to evidence from previous studies (Cossman et al, 2002; Blevins et al, 2005; Lam, 1982) through presenting a more detailed account of factors informing peoples' motives for joining FATE.

Although answers to all the initial research questions can be drawn from these results, they are based on a relatively small sample of UK right to die society members. Therefore these results cannot be extrapolated to membership of other UK right to die societies in the absence of evidence about members of the wider movement in the UK. However, the results do serve to highlight the influence of cultural factors in late modernity that perpetuate right to die activism in the UK today.

Specific differences in function between the three oldest UK right to die societies are shown to be responsible for attracting members whose preferences for one or more over others reflect perceptions of FATE as a superior right to die society on the grounds of the information and advice it provides, and its members' belief in its constitutional integrity.



Other new knowledge drawn from these data relates to the numbers of health/social care professionals who responded to the survey, and the overall number of doctors who are known to have joined FATE. It was unexpected to find how many people with health/social care professional backgrounds had joined FATE. Information about whether other UK right to die societies have similar numbers of health/social care professionals amongst their membership is not presently available. A majority of the health/social care professional FATE members who took part in the study are female, aged over 60 years and beyond working age. Health/social care professionals are likely to be better informed about the technicalities of dying and death, even though retired. The survey results offer some insight into health/social care professionals' reasons for joining the movement, which have not, until now, emerged from previous studies of right to die society members. Studies of UK health professionals' attitudes toward physician-assisted suicide/euthanasia show consistently negative attitudes toward hastening patient deaths (McCormack et al, 2011; Holt, 2008), in marked contrast to those of members of the UK public (Park et al, 2010), yet this study shows that in retirement, some do join FATE. . The length of time pro-right to die beliefs have been held by them, and whether, or to what extent, ageing and retirement might have amended these beliefs is unanswered.

These results establish the gender, age range and social class of those members of FATE who participated in this study, confirming that the demographic profile of participants in this study is broadly similar to that of members of the US Hemlock Society who participated in previous studies, in terms of older age, gender (F>M) and social class (higher). Why more females than males might join right to die societies might be influenced by the relative differences in longevity between the sexes, or by the more traditional role of women as carers, but a definitive explanation for this cannot be drawn from these data.

Blevins et al (2005) report the "key personal characteristics" of persons who support physician assisted suicide as persons who value quality of life at the end of life, and who would be unhappy to lose control. Although this was a small study of US right to die society members, these trends appear remarkably similar to those found here. Individualism and emancipation of the self in modernity are likely to account to some degree for the social class profile of members of FATE. The relative absence of persons from lower social classes is unexplained although social factors such as

educational status, culture and religion would be expected to influence people regardless of social class. But becoming an activist through joining a new social movement such as the right to die movement is not necessarily social class-related; Beck's (2007) concept of new social movements as "an expression of political individualism" implies membership could be dependent on qualities of self independently of social class. However, although public opinion poll evidence suggests a majority of the UK public are in favour of legalisation of hastened death, higher social class is a consistent feature identified in this and previous studies of right to die society membership.

As shown in Chapter 2, Section 4.2.1, an association between desire for hastened death and terminal illnesses is evident in studies of patients and witnessing the deaths of other patients is implicated in pro-hastening of death attitudes in some terminally ill patients. A majority of participants in this study own to having personally experienced terminally illness in others, and in many cases they link these experiences with development of the pro-right to die beliefs that led them to join FATE. This finding shows that experiences of others' dying and deaths is an important factor influencing pro-right to die beliefs, clearly exerting a profound influence on its observers, both professional and lay. This raises questions about whether peoples' perceptions of risk associated with future dying and death can be justified. Anticipation of future suffering emerges as a major concern for study participants, often informed by suffering observed in others; concern about the potential for future suffering is clearly a significant influence in decisions to join FATE. The hypothesis that personal experiences of caring for terminally ill others would be a likely characteristic of members of this right to die society is supported by these results.

I hypothesised that the existence of right to die societies are products of the societies in which they exist. Reasons given for why study participants joined FATE support this hypothesis, in particular due to contemporary demographic changes in longevity accompanied by the newer diseases of older age, the technological ability to sustain lives and ability to prolong the dying process. A further accepted means of managing common social practice implied by some respondents to symbolise an undesirable loss of control over self is society's management of aged persons through placing them in residential care.

The medicalisation of dying and death in modernity has created both benefits and risks of protracted suffering in dying. Clearly, risk of future negative experiences in dying and desire to manage such risks lie at the heart of right to die society membership. It is notable to find that FATE is particularly valued for providing information about access to Dignitas, this service being unique to this organisation. Personal contingency planning as a risk management strategy is reflected in FATE members' interest in, and membership of Dignitas, in order to avoid pre-empt perceived risks in dying. It has already been argued in the literature review that right to die societies and the reasons why people join them are a manifestation of the risk culture existing in the UK today. This survey data shows a risk-averse culture exists among FATE members based on fears for the future, referring to the most highly rated risk factors of extended and/or severe suffering experienced through dependence, losses of dignity and control, burdening others, severe pain and disability . These findings closely mirror terminally ill patients' fears and concerns in many studies and the results of this study show that the existence of right to die societies reflects concerns about how people die in modernity among sections of the general public.

Concerns about burden to others were found to be important to Hemlock society members (Blevins et al, 2005). I hypothesised that altruism would be involved in decisions made to join a right to die society due to concerns for self and others Ideas about hastening death as an act of altruism were being expressed at the beginning of the UK right to die movement. Evidence for apparently altruistic reasons for joining FATE is shown through people's expressed desires not to place burden on others, to avoid dependence on others and to spare family members and other significant others from adverse effects during a hypothetical dying process. It would appear that people's expressions of concern for others are made in the context of their intended altruistic action to prevent harm to others through hastening death. But the concept of altruism relating to concern for others appears infrequently in studies of patient desire for hastened death.

Broad similarities between the results of this and previous studies show a marked trend toward atheism or agnosticism amongst right to die society members. But this study also demonstrates how some religious individuals see little conflict between their religious beliefs and their membership of FATE, supporting the hypothesis that

religious belief can co-exist with commitment to join a right to die society, although this has only been established here as a possibility in relation to Christianity and Buddhism.

Some answers to the initial research questions have emerged and the initial hypotheses are generally supported by the results of this thematic analysis. Right to die membership is shown to be culturally resonant with the contemporary emphasis on risk and vulnerability in UK society. But as FATE members represent only a small proportion of members of the UK-wide right to die movement, it may be that other UK right to die societies attract members from a wider range of socio-economic backgrounds, who join other societies for more wide-ranging beliefs, fears and personal agendas.

# **Chapter 6: Results (Part B):**

## **Interviews with thirty members of Friends at the End A quantitative and qualitative analysis**

The main objectives of the interview study were to explore peoples' responses to the initial survey in greater depth, in the context of why they joined FATE. Part B presents an analysis of data drawn from interviews with 30 FATE members (26 face-to-face and 4 phone interviews). Section 1 contains quantitative information about the 30 interviewees and a count of broad topic headings drawn from the interview data. Section 2 gives an overview of peoples' reasons for joining FATE in order to address the primary research question underlying this investigation. Section 3 reports on a detailed qualitative analysis of the interview data to elicit information about participant motives and beliefs. These are drawn from accounts of matters of importance to participants raised by them in the context of having joined FATE. Results of the qualitative analysis are presented under seven headings, each of which relate to higher level concepts and theories that offer an explanatory framework within which identified phenomena can be understood in relation to the society in which they occur.

### **1. Quantitative data: age, gender, professional status, social classification of interviewees and interview topics**

#### **1.1 Age and gender**

Of the 26 interviewees who disclosed their age, 22 (84.6%) were over 60 years of age with 11 aged between 71 - 80 years (Table 1). Two thirds of the interviewees were female [M = 10: F = 20]

Table 1: Age

<b>Under 50</b>	<b>51-60</b>	<b>61-70</b>	<b>71-80</b>	<b>81-90</b>	<b>Over 90</b>	<b>Age not disclosed</b>
1 (3.3%)	3 (10%)	6 (20%)	11 (36.6%)	4 (13.3%)	1(3.3%)	4 (13.3%)

## 1.2 Professional status and social class

Half of those interviewed had health/social care professional backgrounds (Table 2). Only one person did not meet criteria for socio-economic class I. Professional status by gender is shown in Table 3.

Table 2: Professional status and social class (from SEC three point scale)

<b>Professional status (n = 30)</b>	<b>Social class I (n = 15)</b>	<b>Social class II (n = 15)</b>
Health/social care professionals 15 (50%)	15 (100%)	0
Other 15 (50%)	14 (93%)	1 (7%)

Table 3: professional status and gender

<b>Professional status (n = 30)</b>	<b>Male (n = 15)</b>	<b>Female (n = 15)</b>
Health/social care professionals 15 (50%)	2 (13%)	13 (87%)
Other 15 (50%)	8 (53%)	7 (47%)

Interview participants are thus predominantly female, of social class 1 and over 60 years old.

Amongst those with a health/social care background, a majority (87%) are female.

## 1.3 Overview of interview topics

Topics discussed during interviews vary in subject matter between interviewees. Table 4 shows the main categories of topics drawn from the interview data.

Table 4: Key topics arising during interviews

<b>Interview topics</b>	<b>Number (%) HSCP** (N = 15)</b>	<b>Number (%) Others (N=15)</b>	<b>Number (%) All (N=30)</b>
Account of reasons for joining FATE	15 (100%)	15 (100%)	30 (100%)
Storytelling about others' dying and deaths	12 (80%)	12 (80%)	24 (80%)
Anticipatory fears discussed	15 (100%)	15 (100%)	30 (100%)
Evidence of activism	6 (40%)	5 (33%)	11 (37%)
Membership of other organisations (RTD societies, Dignitas)	5 (33%)	8 (53%)	13 (43%)
Religious views discussed	9 (60%)	8 (53%)	17 (57%)
Positive accounts of health care professions/services	6 (40%)	2 (13%)	8 (27%)
Negative views expressed about health care professions/services	9 (60%)	5 (33%)	14 (47%)
Professional experience in end-of-life care	12 (80%)		
Personal experiences of end-of-life care	13 (87%)	14 (93%)	27 (90%)
Evidence of planning for eventual death	9 (60%)	9 (60%)	18 (60%)
Fiscal matters discussed	4 (27%)	3 (20%)	7 (23%)
Concerns for others	8 (53%)	3 (20%)	11 (37%)

\*\*HSCP = health/social care professional

## 2. Reasons given for joining FATE

Why do people join a right-to-die society? Section 2 presents quantitative data about reasons people gave for joining FATE and qualitative data about personal experiences implicated in their decisions to do so.

All 30 interviewees talked about their reasons for joining FATE and the factors that influenced them to do so. All cited more than one influencing factor. Data relating to reasons for joining FATE drawn from the interview transcripts are presented under the fourteen overarching topic headings shown in Table 5.

Table 5: Reasons given for joining FATE (n = 30)

<b>Reason/category</b>	<b>Number (%) HSCP** (N = 15)</b>	<b>Number (%) Others (N=15)</b>	<b>Number (%) All (N=30)</b>
Professional experiences of ill and/or dying patients	12 (80%)		12 (40%)
Personal experiences of ill and/or dying persons	8 (53%)	11 (73%)	19 (63%)
Perceived quality of life/quality of dying-related issues	2 (13%)	0	2 (7%)
Rights-based beliefs	2 (13%)	5 (33%)	7 (23%)
Fears for self	14 (93%)	14 (93%)	28 (93%)
Deteriorating health/ terminal illnesses self or others	2 (13%)	3 (20%)	5 (17%)
'Tired of life'	0	2 (13%)	2 (7%)
Concerns about palliative care services	1 (7%)	1 (7%)	2 (7%)
Lack of confidence in quality of future end-of-life care	4 (27%)	1 (7%)	5 (17%)
Perceived ethical issues associated with current care ethos	4 (27%)	2 (13%)	6 (20%)
Desire to support the right-to-die movement	3 (20%)	1 (7%)	4 (13%)
Seen as logical action arising from professional background	2 (13%)	0	2 (7%)
Transfer from another right-to-die society	2 (13%)	2 (13%)	4 (13%)

\*\*HSCP = health/social care professional

In peoples' talk about their reasons for joining FATE, the numbers of reasons cited varied between individual participants and between those with a health/social care background and others. The former cite a greater number of reasons for joining FATE than the non-health/social care professionals as shown in Table 6.



Table 6: Frequency of reasons given for joining FATE

<b>Reasons given</b> (frequency):	<b>HSCP**</b>	<b>Other</b>
7 reasons (1)	1	0
5 reasons (6)	6	0
4 reasons (6)	5	1
3 reasons (12)	3	9
2 reasons (5)	0	5

\*\*HSCP = health/social care professional

## 2.1 Origin of beliefs

Interview participants were asked in the initial postal survey (Results: section A) to describe why they joined FATE. Subsequently in the face-to-face or phone interviews people were asked to expand further on why, how and when their pro-right to die beliefs had been formed, that led them to become members of FATE. Most talk about origin of beliefs is inextricably conflated with talk about reasons for joining FATE, especially in relation to professional and personal experience of ageing/dying/death and fears for self. Thirteen people (43%) indicated their beliefs had been long-standing but most did not elaborate greatly on reasons for this.

Participants who stated their beliefs were of long standing attributed their genesis to:

- Long term belief in (the right to) personal autonomy/ rights-based personal philosophy (3)
- Long-standing “horror of being a cabbage” (1)
- Childhood experience of working with farm animals; compassion for animal suffering
- Working with old people (1)
- Experiences as a student nurse (1)
- Stories heard from professional (medical) parent (1)
- Evolving over years (1)
- Reasons for beliefs were multiple and cumulative over time(1)
- Arising from a newspaper report about a ‘mercy killing’ (1)
- Unspecified (4)

Talk about the origin of pro-right to die beliefs reveals they were often formed through the impact of specific events. Here, for example, media reports about the case of Dr John Bodkin Adams, who was tried and subsequently acquitted for the murder of a patient, were implicated:

*“I’ve been ethically in tune with the idea since the Bodkin Adams case...I was a teenager at the time...and ever since it’s been sort of maturing in my mind that this was the right sort of thing to think about.” (P71, male, 60s)*

Specific events involving death of parents, partners and friends were also named as primary reasons for acquiring pro-right to die belief. In some instances, pro-right to die beliefs were generated through professional experiences with dying patients. Amongst those who talked about their experiences of dying and death, health/social care professionals were likely to have had more experience of dying and death than others due to the nature of their work. In 2.2 below, health/social care professional talk shows that working with patients is strongly implicated in the formation of positive attitudes toward having a right to die and as a reason for joining FATE. It can also be implied from the age profile of this interview sample that ageing is likely to have encouraged peoples’ focus on possibilities surrounding any future terminal illnesses, and how well or badly end-stage decline, dying and eventual death might eventually be experienced. “Horror stories” recounted during the interviews sought to present a positive image of self (positive personal qualities such as humaneness and moral integrity), to persuade the listener that pro-right to die attitudes were justified, to create empathy with the listener, and to assert an intellectual and moral basis for such belief.

The following quotes illustrate how past experiences of dying and death are closely linked with peoples’ decisions to join the right to die movement:

*“Parent died of cancer...did not die with dignity... didn’t want to be attached to some machine and life prolonged when there was really no life...(commitment to right to die movement) generated by...(x’s) diagnosis...that started it all off. (P34, male, 50s)*

*“Joined FATE because [I] had to think about it in relation to husband’s long illness. [belief] grew and grew because I wouldn’t like to die the way my husband died... Well possibly [before] because I’d been [a health professional]. You see people dying in*

*awful circumstances. I guess that was the reason. People being kept alive for what, for what?" (P153, HSCP, female, 70s)*

## **2.2 Stories about health or social care professional experiences of ill and/or dying patients**

Of the 15 people with a health or social care background, 10 attributed their pro-right to die attitudes, beliefs and decisions to join a right to die society to be influenced by professional experiences.

*"I joined Fate because in my working life I was a social worker. I came across a lot of elderly people whose lives were really turned upside down and they had to go into retirement homes. A lot of people turned their faces to the wall." (P163, HSCP, female, age not disclosed)*

Drawn from experience of patient care, some professionals commented on negative aspects of health care provision and ethical issues associated with topics such as "keeping alive" versus "letting go", cruelty and patient suffering, the contrast between the management of suffering animals and humans, carer stress, covert assistance to die and fear of colleagues. Among those who indicated their professional experiences were implicated in their pro-right to die beliefs, "horror stories" recounted about patient and family suffering were told in justification of their beliefs and actions in joining FATE. In describing a case of terminal cancer for example, patient and family suffering were cited:

*"....husband's suffering, child's suffering and (the patient's) suffering was really intense....it was prolonged...almost torture..." (P31, HSCP, female, 80s)*

In the next quote, a health professional challenges the way in which lives can be technologically extended. She suggests that doctors do not, or cannot, take time to think about the consequences for patients and their families of life saving treatments, nor to determine what patient and families might want; suggesting they may be frightened to discuss these matters with their peers, in particular nurses, implying they fear scrutiny of their practice if life-saving technologies are not applied. Her final critique accuses health professionals of unkindness in "keeping alive" "unhappy" patients with dementia:

*“All this technology is nowadays to keep people alive in conditions which are not particularly pleasant and often very painful....a lot more consideration needs to be given to what kind of patient you are treating and what the patients themselves and their families want...they’re so busy applying the immediate life saving technology they haven’t even got time to think about it and even if they did have time to think ... they are frightened of discussing it... don’t think it is so much the patients they are frightened of but their own peers and particularly the nurses...I’ve seen many many demented people who were exquisitely unhappy even though they don’t know what’s going on or where they are....they’re excessively unhappy and the idea of keeping such people alive by applying the latest technology, it’s disgusting actually and certainly very unkind.” (P83, HSCP, female, 70s)*

Comments about differing moral and ethical standards as applied to suffering humans and animals arose in interviews with professionals. This individual equated ‘keeping people alive’ when quality of life was poor with cruelty, contrasting perceptions of cruelty to humans with kindness in treatment of animals:

*“I think it’s cruel for people to be kept alive when their quality of life is really not worth being kept alive.....sometimes we’re kinder to animals than we are to humans...” (P86, HSCP, female, 70s)*

A ‘tired of life’ theme was raised in talk about the past. It was suggested that when doctors worked in small communities they knew their patients both professionally and socially and in this past milieu they were more sympathetic toward people who had “had enough” in those days, than doctors are in the present:

*“... it wasn’t that people discounted the elderly or the sick but [in the past doctors]...had an understanding that people had got tired and they had had enough...” (P88, HSCP, female, 60s)*

The importance of privacy in dying for this interviewee was reinforced through an account of a dying patient seen in the past, with husband alongside, exposed to full view in a hospital ward. Staff were reportedly indifferent to the situation and had to be asked by this health professional to close the curtains. This left a lasting impression and the importance of maintaining her own privacy when dying was one of the factors this person identified as influencing her decision to join the right-to-die movement:

*"...there was a woman dying in the middle of the ward...and sitting next to her was her husband....I suggested perhaps they ought to draw the curtains..." (P130, HSCP, female, 80s,)*

Two aspects of carer stress were raised here; suffering experienced by carers involved with end-of-life care and the wish to avoid burdening family members when terminally ill individuals require more intensive family input:

*"...it's bad enough for the patient - terrible for the carer who's looking after them". (P153, HSCP, female, 70s); and:*

*" the thought that they might have to do something like that on a long term basis - they're all terribly busy, they've got families, and the thought of them feeling that they've got to go and see [parent]...I would feel absolutely appalled by it..." (P89, HSCP, female, 80s)*

Some health/social care professionals held the view that in the past the medical profession was more open toward easing the passing of dying persons, as reflected in these references to covert assistance to hasten deaths:

*" [in the past] they would make it easier for the old folk rather than having them lie about in care of the elderly homes as they do now, or isolated on their own". (P88, HSCP, female, 60s); and:*

*"...the consultant would come in on a Friday and say "I don't think Mrs Smith is going to be with us on Monday Sister", and Mrs Smith was dying and Sister would say "No, I don't think she will be" and Mrs Smith was never there on Monday....they were being given an overdose of morphine usually and I didn't enormously object to that because very often they were dying and in pain and it seemed the most sensible thing to do to hurry it up a little". (P157, HSCP, female, 60s); and:*

*"I was aware that the passage of time, you know, when a good old fashioned family doctor who came to the house and helped somebody on their way had long gone...our GP in those days just used to leave the drugs on top of the wardrobe, and then a friend of the nurse, a friend of the doctor would come in and give the injection when it got too much". (P163, HSCP, female, age not disclosed)*

In the context of hastening dying patients' deaths, fear of colleagues was twice mentioned during this interview. In which themes about whistle blowing, fear of prosecution and the impact of staff religious beliefs were raised:

*"unless that fear of prosecution...they just look over their shoulders and see if the person is listening and going to report them.....I don't think its so much the patients they're frightened of, but their own peers and particularly the nurses as well...it often comes from a religious background where all this sort of thing is drummed into you, the sanctity of life and all that kind of thing." (P83, HSCP, female, 70s)*

### **2.3 Personal experiences of illness and/or dying persons (all)**

All 30 interviewees used stories to give meaning to their beliefs, to influence the listener toward perceptions of their beliefs as rational and to present themselves as people with positive personal qualities such as moral integrity. Stories were used to justify pro-right to die attitudes and joining the right to die movement.

Stories about "good deaths" were contrasted with "horror stories" about personal experiences of ill and dying partners, parents and friends; "horror stories" being told in the context of conveying the reasons for their death anxiety and fears about future decline that informed their decisions to join FATE. "Good death" stories were not cited in justification of membership of FATE, but rather to acknowledge that not everyone "dies badly" within the system. As noted previously, the telling of good and bad death stories sought to invoke empathy in the listener and to emphasise qualities of self such as authority, personal objectivity and ability to take a balanced view about care of dying people within the system.

Examples of "good death" stories served to emphasise the desirability of peacefulness, speed and ease in dying:

*"[Parent] had a peaceful last illness and a peaceful death". (P36, female, 70s); and:*

*“my parents were so fortunate, they both just lay down and died.” (P161, female, age not disclosed).*

“Horror stories” recounted to give meaning to personal fears and concerns about the possibility of an eventual “bad death”, were also used to offer a reasoned basis for desire to control timing and manner of future deaths. Fears about adverse effects of the use of technologies in managing future dying and death were grounded in past experiences:

*“...have no wish to die unpleasantly; I’ve seen people stuffed up with tubes in hospital and it’s not how I want to die”. (P148, male, 80s)*

An account of an elderly sibling’s terminal decline detailed the adverse effects of repeated medical and surgical interventions drawn out over several years, in which the patient was said to passively and indiscriminately acquiesce to every treatment offered. The resultant prolonged suffering perceived by family members was said to cause distress to both patient and relatives. The story emphasises participant’s fears about experiencing similar technologically prolonged life in the future:

*“ to see the medical profession giving her operations, giving her treatment year after year and knowing it was hopeless and they weren’t going to cure her ever...this chemotherapy was enormously painful for her...and if they said, “ Oh, we’ll take away your kidneys along with the top of your stomach” she’d go along with all of this, time after time...we are concerned with what they feel is their medical duty which is to prolong your life as long as possible even if that life is painful and intolerable.” (P131, male, 70s)*

The “tired of life” theme arose in the context of concerns about the potential for diminished quality of lives in people’s declining years, as illustrated in accounts of circumstances in which parents were said to have wished for death:

*“It was basically seeing my mother for the last two years of her life....she couldn’t read, she couldn’t get about, her mobility was poor, she was lonely and she would even say “I’m done”. She said “I don’t really want to go on, isn’t there a pill they can give me?” (P24, female, 60s); and:*

*"[parent] herself wearied dreadfully of life. Her legs were covered in sores. She was bedridden. She was very unhappy. She was of course depressed – very, very depressed. And she kept saying when we were calling, "Oh... still alive". She was willing death". (P160, male, age not disclosed)*

Concerns about future suffering and whether it could always be relieved were reflected in an account of a death that was said to involve suffering so intense that eventually covert euthanasia was practiced by a doctor responsible for the patient's care:

*"...looked after ... had all the palliative care in the world... was in a hospice ... it didn't make it any less ghastly... they pumped more and more drugs into her and that basically robbed her of everything, her mind and her confidence and everything and it was so awful to see... she had a very sympathetic GP... normally he would come in with the district nurse in tow but...this particular time he bowled in quite unexpectedly and rushed out again within about five minutes and in about 20 minutes she was dead ... the doctor described it as torture... it crucifies the people who have to look after you..." (P27, female, 70s)*

Informed by personal experiences, desire to avoid replicating the manner of others' dying and deaths was a recurrent feature in the interviews:

*"...it was absolutely ghastly... she wouldn't talk, occasionally she would scream ...it was just horrendous to visit and I thought, "Well I don't want to end my life in that kind of way with being thoroughly miserable physically and mentally." (P143, female, 70s)*

*"...after seeing what my husband has been through in the last 10 years... I tell you I would not want to go through any of that". (P153, female, 70s)*

In addition to a previous comment referring to cruelty versus kindness in the context of animal and human deaths, animal/human themes were cited in other interviews. Views expressed indicate peoples' beliefs that humane methods of addressing animal suffering would be equally desirable for humans.

*"...the vet gave him an injection and he was at peace. Now if you can do that for your dogs why on earth can't you do it for your loved ones? ...nobody objects to it happening with dogs." (P157, female, 60s); and:*



*“My oldest son’s dog was in such a perilous state and they weren’t doing anything about it. I said, “I don’t want to be like the dog...And I just feel we are more humane to animals than we are to humans which seems to me to be a bit of a paradox - the word ‘humane’. And yet we wouldn’t let animals suffer the way that we allow people.” (P143, female, 70s)*

A humane killing of a suffering farm animal was described to illustrate differences in the legal status of animals and humans relating to relief of suffering through hastening death, and to justify pro-right to die beliefs:

*“ It was a young piglet and he had to euthanase it because it had broken a leg and it was in terrible pain, it was upsetting the sow and all its siblings... (this was) to reduce carnage among other pigs and to put the pig at peace....we were all taught pragmatically about life and death... (parent said) ‘If the vet came out and saw the state of that animal and we had done nothing I would have been prosecuted’”. (P88, female, 60s)*

### **3. A thematic and conceptual analysis of interview data**

The theory-based hierarchical model of thematic categorisation previously described in Methods (Chapter 3) is reproduced here for reference. Ordered by underlying explanatory concepts, results of interview data analysis are presented under the seven level 1 thematic headings (Table 7), in turn divided into related sub-themes.

Table 7: Thematic hierarchy model

Higher level concepts, debates and theories: background						
Theories of self	New social movement theory	Medicalisation theory	Theory of altruism	Ethics/morality	Socio-economic theory	Risk theory
Level 1 themes						
Feared threats to self	Activism	Good/bad professionals	Concern for others	Personal philosophy	Resource-related themes	Pre-empting future risk to self
Level 2: sub-themes						
<p>Anticipatory fears of threats to self:</p> <ul style="list-style-type: none"> <li>• Pain</li> <li>• Serious disease</li> <li>• Loss of self through cognitive decline</li> <li>• Residential/hospital care</li> <li>• Burden</li> <li>• Disfigurement</li> <li>• Loss of control</li> <li>• Loss of dignity</li> <li>• Loss of autonomy</li> <li>• Loss of bodily integrity</li> <li>• Loss of independence</li> <li>• Loss of quality of life</li> </ul>	<ul style="list-style-type: none"> <li>• Membership of organisations</li> <li>• Active involvement in media and politics</li> <li>• Active involvement in FATE functions</li> </ul>	<ul style="list-style-type: none"> <li>• Keeping alive v letting go</li> <li>• Perceived systemic issues in health and social care</li> <li>• Technology/overuse of technologies</li> <li>• Positive/negative accounts of care</li> <li>• Relevant experiences (professional/non-professional)</li> <li>• Covert/overt assisted death</li> </ul>	<ul style="list-style-type: none"> <li>• Avoidance of harm to others</li> <li>• Avoidance of burden on others</li> <li>• Compassion for others</li> <li>• Desire to benefit others</li> </ul>	<ul style="list-style-type: none"> <li>• Religion</li> <li>• Harm/</li> <li>• Cruelty</li> <li>• Kindness</li> <li>• Rights/autonomy</li> <li>• Choice</li> </ul>	<ul style="list-style-type: none"> <li>• Desire to conserve personal and national resources</li> <li>• Fear of resource limitations</li> </ul>	<ul style="list-style-type: none"> <li>• Risk avoidance strategy</li> <li>• Contingency planning for end of life</li> </ul>

### 3.1 Anticipatory fears of threats to self

Fears about hypothetical self-compromising threats to integrity of body and mind at a future time (Table 7, column 1) were outstanding in talk about reasons for joining FATE and stories were recounted to offer persuasive justifications for doing so. People presented themselves in a positive light in order to promote and emphasise the validity of their fears for self. Self presentation tended to be executed through story-telling, sometimes via stories about past life, careers and other roles, along with stories about other activities and incidents that created a picture of self-efficacy.

Potential threats to self manifested in talk about forms of suffering. Here, a non-specific aversion to suffering in general was expressed:

*"I have always hated to see suffering...I can't watch it on the telly, I hated it with my own children, I hated it with my pets and just don't like suffering. Can't be doing with it."  
(P161, female, age not disclosed)*

Perceived threats to self varied between individuals. In Table 8, frequency of threats to self, with health/social care professional background of participants identified, indicate that loss of control, loss of dignity, loss of bodily integrity and loss of quality of life were most frequently feared. Little variance in frequency is shown between health/social care professionals and others for pain, cognitive decline, loss of control, loss of dignity and loss of body integrity, but health/ social care professionals appeared to fear serious disease, residential/hospital care, burden on others and loss of quality of life more frequently than others:

Table 8: Anticipatory fears about potential threats to self

<b>Fears:</b>	<b>HSCP**</b>	<b>Other</b>
Pain [10]	5	5
Serious disease [5]	5	0
Loss of self through cognitive decline (e.g. Alzheimer's)[12]	7	5
Residential/hospital care [9]	6	3
Burden on others [8]	5	3
Disfigurement[5]	3	2
Loss of control [20]	9	11
Loss of dignity [21]	11	10
Loss of autonomy [3]	1	2
Loss of bodily integrity (ability to manage bowel/bladder functions/personal hygiene) [20]	11	9
Loss of independence [14]	6	8
Loss of quality of life [17]	10	7
<b>'Other' related fears mentioned:</b>		
Boredom [1]	1	0
That views will be ignored [1]	0	1
A lingering slow death [1]	0	1
Being 'kept alive' [3]	0	3
Fear of resuscitation before DNR statement found [1]	0	1
Failure of future suicide attempt [2]	1	1
Being patronised; subject to paternalism [1]	0	1
Not being eligible for Dignitas [1]	1	0
Difficulty becoming a member of Dignitas [1]	0	1
Being thwarted in attempt to go to Dignitas [1]	0	1
Loss of access to care from own GP [1]	0	1
Unsure about family support for views/family opposition [2]	1	1
Shame and self-disgust	0	1
Fear of very advanced age and its consequences [1]	0	1

\*\*HSCP = health/social care professional

### 3.1.1 Self-construction: the independent autonomous self

In conveying a sense of positive self-attributes such as habitual control of life, independence and rationality, stories about fears for self and other people serve to

illustrate and emphasise the rationality of respondents' fears and concerns. People talked about themselves in terms that served to emphasise these qualities.

A long term belief in personal autonomy was cited to justify the pro-right to die stance:

*"I believe in autonomy, personal autonomy...I've been brought up to say 'you do what you want to do'....I want to be able to end my life if I want to." (P141, female, 80s)*

The following quote pictures an independently minded person habitually accustomed to retaining control of life. Based on this premise, threats to self perceived by this individual lie in surrendering control to mistrusted others:

*"...had a complex and very varied life. And it depended on my taking charge of what I'm doing and seeing it through. And that means that the very notion of surrendering to myself to the mercy of doctors ...to do with me what they like is absolutely, you know, alien to me." (P47, male, 90s)*

High value placed on independence was repeatedly emphasised by these next two people during their interviews:

*"I'm a very independent person. I live on my own and I'm very independent. I love my family...but I'm very independent..." (P36, female, 70s); and:*

*"I've always been very independent. I don't have any brothers and sister and....I've always had to look after (parent) from quite and early age...so I've always been very independent." (P143, female, 70s)*

The right to exercise autonomy without regard to family members' views was asserted through speaking of determination to pre-empt any family opposition to future end-of-life decision-making:

*"I've spoken to my children and said, you know, "It's my decision, not yours." (P143, female, 70s)*

This next narrative about a hypothetical future cancer diagnosis creates a picture of someone accustomed to making their own decisions about dealing with challenging life

experiences. Refusal of invasive treatments allowing a “natural” death is seen to be a fitting culmination to a good life:

*“I think if I was told tomorrow that I had cancer of the stomach I don’t think I’d even want to go ahead and have an operation or even chemotherapy. I’d rather nature just takes its course and when it got to the point where I felt that I’d had enough of this and was changing too much in my physique then take my trip to Dignitas. I just don’t like the idea of being cut open and various IV drips put up and all the other things that are involved. I just don’t want that now. I’ve had a wonderful life...” (P94, HSCP, male, 70s)*

### 3.1.2 Fear of pain as a threat to self:

With half of the 30 interviewees having spoken about pain and ten individuals having expressed concern about suffering caused through pain, pain emerges as a major concern.

Pain was of concern to this interviewee who was terminally ill:

*“I’m extremely concerned about severe pain.” (P157, female, 60s)*

A major concern about pain, related to cowardice by at least one respondent, was justified through having acquired more knowledge about death. Also, fear was expressed that professional caution might prevent adequate pain relief being given when it was needed:

*“I’m a terrible coward about pain...the more I know about death the more concerned I am because the more I realise how incredibly difficult it is to have a comfortable death...the more I learn [about death] the more I get to understand how frightened the medical profession are about giving enough pain killers”. (P93, HSCP, female, 80s)*

A low pain threshold made pain a major concern for this individual:

*“Pain is the main thing, yes. I have a very low pain threshold.” (P141, female, 80s)*

Previously experienced morphine-induced nausea and vomiting was said to be responsible for fear of future pain; but there was no talk about other options provided by alternative pain-relieving drugs:

*[fears pain because] "I get nauseous with morphine; if I take morphine I just vomit it up and feel terrible...so morphine's not going to help me very much if I'm in a lot of pain....I suppose I'm scared of pain."(P143, female, 70s)*

But five people acknowledged that pain was not a primary concern for them and this was attributed to pain relief having become more effective over time. One doctor spoke of being impressed by the way a dying relative's pain relief had worked, and as a consequence believed severe pain could be quite well dealt with. Others said:

*"I think the majority of pain that can be relieved probably will be...." (P71, male, 60s);*  
and

*"I think that pain certainly can be controlled a lot better than it was in the past..." (P24, female, 60s);*

### 3.1.3 Fear of future suffering in terminal disease as a threat to self:

People who were already suffering from terminal or potentially terminal diseases and associated disabilities voiced concerns about risks of future suffering. One person already experiencing an increasingly disabling medical condition feared finding herself in a care home and illustrated this fear through stories about friends in care homes whose quality of life was judged by her to be poor:

*[friend's] "quality of life is very poor...can't do much for himself and doesn't have much control over anything apart from whether to eat food or not to eat it..." (P86, HSCP, female, 70s)*

In describing an uncertain future in terms of survival, due to recurring episodes of acute illness, a conditional possibility of suicide was a feature of this person's talk:

*"... I do not want my life prolonged because the chances of me surviving if I take a really serious [exacerbation of existing condition] are not going to be very great...I want to live but I don't want to live if I'm going to be wheeled into hospital and get drips and bits and pieces and all the rest of it...and come out more weakened...I don't want it*

*and I think rather than argue with...I think the razor blade in the right direction will sort me out.” (P88, female, 60s)*

Persons who were terminally ill at the time of the interviews commented on future concerns about impact on others involved:

*“I’ve got cancer, but I’m not on my deathbed. My prognosis is very bad...I’m an outdoor person...if I was stuck in bed and unable to do anything much, people had to wash me and all that, my husband... wouldn’t cope with that...and that’s an added burden on me.” (P39, female, 50s)*

Support from the family for going to Switzerland was affirmed in this case although at the time family members were saying “not yet...”:

*“I have advanced cancer...if I could die in the hospice painlessly and easily, I think that would be my preference. But at the moment my quality of life is not good...I am now seriously thinking of going to Switzerland. I don’t know when...” (P157, HSCP, female, 60s)*

Disability associated with loss of self is suggested here through an account of personal experience of others’ behaviours when the participant was using a wheelchair; the implication being that others’ negative perceptions of wheelchair uses include perceptions that they are mentally incompetent. Also, talk about being abandoned in a wheelchair shows how wheelchair occupants can be treated as commodities rather than people:

*“[used]...a wheelchair sometimes at the airport...and people talk over you and talk like ‘what would she like or what do you think’, and you get abandoned, I’ve been abandoned in a wheelchair a couple of times...That puts me off being in a wheelchair or being dependent...” (P143, female, 70s)*

#### 3.1.4. Fears of cognitive decline (Alzheimer’s, dementias) as a threat to self:

Risk of loss of self through dementia/loss of mental capacity (often referred to by participants as Alzheimer’s) was one of the most frequently expressed fears for the future, occurring in almost 50% of the interviews. To emphasise points made, people



recounted personal experiences of the consequences of loss of self in cognitive decline among close family members and friends in support of their desire to avoid a similar fate.

Stories about loss of self through others' cognitive decline highlight the negative impact of dementia on behaviour, on quality of life and on other people involved:

*"...a friend who has moved into almost a vegetative state...now he's totally unaware of any anti-social angle (to behaviour), he would never have done that sort of thing when he was himself...a loss of impression one has on other people." (P58, male, 80s); and:*

*"They're like sightless human beings sitting there. Unresponsive. We don't know what drug regimes they're on of course, why they're like that, but what's the point of that existence?" (P139, HSCP, female, 70s); and:*

*"...her stories of coping with it were pretty horrific... he was a nuisance to other people (in the past) because when he was going into Alzheimer's he was driving ...because everyone knows each other they said 'x is a menace...well he came up to that junction and...he had the right of way but he wouldn't take it and the other drivers did not know what he was going to do. And eventually he did something which almost crashed. And I thought that was crazy...the police did nothing....so eventually I had to write to my MP... [to have x's licence revoked]." (P100, male, 70s)*

This next story concerns difficult behaviour associated with mental decline in someone who was concomitantly physically fit. That this illness could be of long duration with ongoing difficulties for family members are suggested by the story:

*"[relative] at the moment who is suffering from Alzheimer's and I feel so sorry for them, I really do. This woman is fit as a fiddle. She's not aggressive, she's quite pleasant but she's so difficult." (P161, female, age not disclosed)*

In talk about already-diagnosed vascular dementia, the reported loss of accustomed high level of intellectual functioning caused distress in addition to other health-related quality of life issues:

*"I am losing everything I ever had up here...[on being asked whether (person) sensed some change in intellectual ability] I don't sense, I know [it]. Yes, it's dementia but also I have a thing called vascular disease in the brain. And it means I am losing my*

*equilibrium; I forget everything obviously and so on. And between that and [other diseases] ....I really don't want to be around." (P47, male, 90s)*

Describing a parent's mental decline, fear of similar loss of self and loss of quality of life was attributed to this experience:

*"...little by little losing yourself and everything that made life worth living long before you die, that's the horrifying thing." (P27, female, 70s)*

Anxieties about risk of future dementias were raised here due to a family history of Alzheimer's:

*"So often there is a genetic connection so I would be very worried [story of parent with Alzheimer's 'unsettled, nervy, not a happy person'] and I wouldn't like that to happen...[to me]" (P24, female, 60s)*

Risk of dementia-associated loss of self was seen to be unacceptable; loss of self and negative impact on family were mentioned:

*"...and the thought that in my eighties I might be one of the... twenty per cent that have dementia would be so horrendous to me that I would not wish to accept that." (P31, HSCP, female, 70s); and:*

*If I didn't recognise my nearest and dearest I would not want to live any longer. Fear of loss of mental capacity - wouldn't want to live once personality gone.( P58,male,80s); and:*

*"If I were away with the fairies I suppose it doesn't matter so much but I would hate it for my children or my husband...that I was not the person that had once been... would not wish to go through whole process. No. I would hate it. Hate it and hate it for others too." (P161, female, age not disclosed); and:*

*"I'm frightened that I might suffer from Alzheimer's and be a completely empty shell of a human being that my wife would have to look after...and I would not wish to be like that...I don't want her to look after this thing that's no longer me." (P160, male, age not disclosed)*

Distress associated with awareness of the onset of dementia was also raised. This interviewee expressed strongly held views about being kept alive against her will, not to be “cluttering up the earth” should she become demented, in emphasising her positive attitude toward hastening death:

*“I’m concerned in case I get demented...but especially, there’s a terrible stage when you’re aware that you’re dementing...I just think it’s terrible to keep somebody alive when they’re not really there at all. I think when somebody really has bad dementia they’re not the person, they’re not that person any more. And I think to clutter up the earth, to be kept alive when nobody wants you to be alive and you don’t want to be alive yourself, just appalling that, it’s dreadful.” (P89, HSCP, female, 80s)*

Again, death was felt to be preferable to loss of mental capacity:

[if participant got Alzheimer’s] *“I would wish I had the pill in my pocket so that I could take it when I felt that today was the day.”(P161, female, age not disclosed)*

### 3.1.5 Fears of entering residential care as a threat to self

Talk about residential care was associated with of loss of autonomy, control, dignity and quality of life. People who expressed negative views about residential care illustrated them through describing visits to family members and friends in residential care.

*“I certainly would not like the curtailment of going into a multiple residential facility...I would just not accept that curtailment to my life...[parent] handed me something and said ‘what is that?’ and I said ‘Oh I think it is a stone’. She said, ‘No, it’s a chicken nugget and that’s what we were given for dinner the other night. And it was as hard as a stone and nobody could eat it’. So the food was appalling...but you see, I would never like to be in the control of a care home, never. ” (P31, HSCP, female, 70s)*

In support of her stance on care homes, this same person made reference to a study having identified humiliation of, and unkindness toward residents in care homes and a media story in which a journalist wrote about people in care homes having been humiliated, burned with cigarettes and where some workers were said to have had criminal records.

Social isolation and constant television without respite allowed were associated here with loss of dignity:

*"...the isolation of nursing homes where you are sitting round a room with the television blaring and that to me is hell on earth...every time I went in to see [parent] the television was blaring, they were all sitting looking at it, some were deaf so they had to have quite loud but there didn't seem to be any escape from that and if you said, "Oh she wants to go and sit in her room", "Oh well there's nobody to keep an eye on her there". That is a loss of dignity.... if you just want to sit quietly and do your knitting or your sewing or radio... there's an awful lot of loss of dignity just in that." (P24, female, 60s)*

Negative views held about care homes were justified by this interviewee through recounting a parent's loss of glasses, teeth and own clothing in residential homes:

*"...one home lost her glasses, another lost her teeth and her clothes, she kept getting other people's clothes which is very depersonalising...It was horrendous to visit and I thought 'well I don't want to end my life in that kind of way with being thoroughly miserable physically and mentally.'" (P143, female, 70s)*

Another theme that emerged about care homes concerned fear of losing a valued GP if they were no longer able to visit a care home outside the local area. This was a source of anxiety and apprehension for one participant who feared that the very successful treatment received at the time of the interview through their own trusted GP could be compromised through transfer of care to another doctor.

### 3.1.6 Fear of becoming a burden on others as a threat to self

Placing burden on others was another recurring theme, with hastened death being preferable for some participants:

*"I would also hate to be a burden to anybody else. I mean I'd rather die." (P153, HSCP, female, 70s)*

*"I've always...just not wanting to be a cabbage and be a burden on other people". (P39, female, 50s)*

*"I have no wish to be a burden on others...that terrifies me." (P157, HSCP, female, 60s)*

### 3.1.7 Fear of disfigurement as a threat to self

Of the five people who spoke about fear of disfigurement, reasons given for their concerns varied between the seemingly superficial and the more reflective.

Appearance was particularly important to this participant:

*"I suppose I just don't fancy looking horrible and so I think I would probably rather be dead than look awful" (P86, HSCP, female, 70s );and:*

But disfigurement as a threat to self was also acknowledged to be conditional on its severity:

*"I would find disfigurement, it depends how severe, I would find severe disfigurement very hard to bear, like the woman in France who appealed to Sarkozy and Ségolène Royale..." (P164, HSCP, male, age not disclosed)*

### 3.1.8 Fear of loss of control as a threat to self

Retaining control of life while still living stands out as one of the major concerns raised. Themes drawn from talk about control and its loss emphasise its importance to interviewees:

*"I like to be in control, indeed I do...that means a great deal to me". (P36, female, 70s)*

Fears about losses of control and autonomy are given meaning in the comments below. Fear of future compulsion that would override this person's wishes was raised in this context:

*"[loss of control].....means having to do things that I don't want to do." (P141, female, 80s)*

'Not being listened to' is seen as one aspect of loss of autonomy and control:

*"That I should not have the autonomy of being listened to when life was unbearable...I've always stood on my own feet, I've never been dependent, I'm independent and I like to control my way of life...and my decisions on where I will go". (P31, HSCP, female, 70s)*

As also reflected in the excerpt above, the meaning of losing control over life, dying and death differs in focus between participants. Here, loss of control is seen as both loss of dignity and loss of ability to control behaviour in the face of severe pain:

*"What I mean by dignity is if I was, again that's sort of loss of control really, that's loss of control if I was shouting and screaming, uncontrollable, again that severe pain as well. That all comes into the same package." (P157, HSCP, female, 60s)*

This suggestion that the 'niceness' experienced when under the care of palliative care services may not compensate for loss of personal control and autonomy relates to fear of becoming cared for by strangers:

*"...the actual care, the trappings are nice and the people are nice but you're still in their hands, they still do what they will with you." (P27, female, 70s)*

Fear of becoming dependent on strangers for care and losing control over life through becoming dependent in these circumstances was feared. But an established personal relationship with carers was a valued ideal that could perhaps make loss of control less unacceptable;

*"the loss of control... where the control of your life is in somebody else's hands and in some cases the people you don't really know...they may be caring people... but you don't really know them."(P34, male, 50s); and:*

*"...to think of being totally dependent on medical staff who don't know me or anything about me..." (P27, female, 70s)*

Uncertainty about future ability to retain control was a frightening prospect:

*“What might happen. You don’t know what’s round the corner. That’s what’s frightening isn’t it for people who like to be in control. To actually not know what will happen”.*  
(P139, HSCP, female, 70s)

### 3.1.9 Fear of losing control of bodily functions and personal hygiene

Loss of habitual control over the management of excretion and personal hygiene is another major theme recurrent throughout the interview data. Some participants referred to loss of control of bodily functions euphemistically (“calls of nature”) while others spoke bluntly, using both medical and lay terms (incontinence or “double incontinence”, defaecate, genital, vulva). Abhorrence of exposure of habitually private body care to others is evident in people’s talk.

Self-loss was associated with both depersonalisation and loss of independence in attending to personal hygiene:

*“everything that makes you a person rather than an object or an animal you know... you become something else...you know, a creature lying in a bed. Being kept clean.”*  
(P27, female, 70s)

Loss of ability to manage incontinence, and abhorrence of smelling badly was a further theme. Few participants spoke openly about fear of smelling unpleasantly; but three persons openly associated body malodour with no longer being able to deal with their own body hygiene with consequential loss of control over presentation of self.

*“... But it’s loss of control, the idea of lying in a reeking bed or somebody having to come and change the bed is awful. That is really bad.”*(P130, HSCP, female).

A nurse referred to habitual fastidiousness when providing patient care and in maintaining her own personal hygiene. It was assumed that in order to keep clean and sweet smelling, other people could not be relied on to maintain accustomed standards of cleanliness and freedom from genital malodour if care from others became a necessity:

*“I don’t ever want anyone to do my vulval hygiene unless I’m in control. I was meticulous when I did vulval hygiene or genital hygiene [for patients]... because I hate*

*smelling there... It may not bother other people and that's OK but it bothers me. I don't like to be smelly. I don't like to be sticky. I like to be lovely and fresh and clean and I will wash my vulva as often as I would wash my face. But that's just me...." (P88, HSCP, female, 60s)*

Similar fears were reflected in this statement, although acknowledging that decisions made in advance may change with circumstances:

*"there are diseases which make you ashamed of yourself... you might be very smelly or even as far as I'm concerned I should hate to think that I had to abandon cleaning myself after I evacuated my bowels to somebody else. But I'd have to think about that at the time - it would be my decision then whether I'm putting up with it or not." (P160, male, age not disclosed)*

Being able to manage her own colostomy was particularly important; inability to manage it being seen as a cut-off point for tolerable quality of life:

*"I wouldn't want anyone else to empty my colostomy bag thank you very much. If I can't do that myself, I don't want to do it. And yes, no, I definitely don't want anyone dealing with my bowels."(P157, HSCP, female, 60s)*

Here, loss of ability to use the toilet independently was anticipated to reach or possibly exceed limits of tolerability:

*"[if] I'm not able to get myself to a loo to defaecate, having to be carried or commoded...I think that is right on the borderline....(164,male, HSCP, age not disclosed)*

Inability to wipe one's own bottom, representing loss of control over normal life, was raised in the context of talk about determination to die at a chosen time:

*"at some point I'm not going to be able to wipe my own bottom and I don't want to be in that state..." (P100, male, 70s)*

Previous negative experience as a hospital in-patient of dependence on others involving asking for, waiting for and being left on bedpans caused fear of losing control of life in this manner:



*“I hated that, I hated it. You know, having to ask for a bedpan. Well OK, I’m not embarrassed or anything, it’s just that they don’t bring it. And then they leave you on it you know...it’s just the thought of not being able to control my life. I think that’s a horrible feeling if you’re not in control of your life”. (P143, female, 70s).*

### 3.1.10 Fear of loss of dignity as a threat to self

People were asked to expand upon the meaning of dignity to them. From their responses the meaning of dignity was clearly a personalised concept, evident in the different ways in which people described what they would see as violating their sense of dignity.

Losses of dignity were associated with the body, bodily deterioration and failures of bodily functions. As in section 3.1.9 (talk about loss of control of body wastes and body hygiene), fears about loss of control of body functions and their management were also closely associated with fears about loss of dignity. For people previously quoted in 3.1.9, retaining control was dependent on retaining control of body wastes and body hygiene. Loss of accustomed independence and privacy through needing help with personal care was equated with loss of control, and felt by some to be unacceptable to them. Similarly, loss of dignity was strongly associated with exposure of hitherto privately managed bodily functions to others and need for help in maintaining body hygiene, as shown in the following quotes:

*“when I think that someone else is going to have to take you to the toilet and wash your bum...I think it’s a complete loss of dignity...”(P24, female ,60s), and similarly:*

*“[dignity means]...not having your bottom wiped by someone else...and not getting stuck in the bath.” (P93, HSCP, female, 80s) and:*

*“What I fear [is] indignity more than suffering...if somebody had to blow my nose for me and that kind of thing I would think ‘well, I shouldn’t be here’”. (P100, male, 70s); and:*

Inability to dress and feed independently plus inability to manage body functions meant a loss of dignity for this individual:

*“not to be able to look after your personal needs or bodily functions...dressing , feeding...all those kind of things that you take for granted and you can no longer do.”(P131, female, 70s)*

Lack of confidence was expressed that dignity would be maintained if it became necessary to have others providing bodily care:

*“...you are no longer properly looked after, kept clean...” (P27, female, 70s)*

Loss of dignity was also associated with loss of self and stereotyping. Distinct from perceived loss of self and dignity due to cognitive decline, other meanings given to loss of self related to loss of dignity through depersonalisation. Being treated as an object rather than a person was a theme that arose in talk in which views about loss of dignity focused on diminution of personhood through others' attitudes and behaviour:

*“[Dignity means] ...being treated as a human being and not...a case.” (P148, male, 80s) and:*

*“I would not like to be treated as a cipher...I would hate to be treated like a package and be picked up and moved. I would hate not to be treated as a person. I don't care if they have to up-end me and clean my backside and all that kind of thing. I don't mind about that but if I'm not respected and talked to while it's being done...I would not like that. I would like to be a person, not a cabbage.” (P161, female, age not disclosed)*

Stereotyping and lack of respect regardless of age, appearance or physical ability as cited by this participant, was based on personal experience that to her equated with loss of dignity:

*“I think sometimes as you get older sometimes you find you get treated, you get written off, and people make assumptions about you based on “the elderly” and then they put you into that pigeon hole and treat you like that. You're not being given any respect for who you are. Assumptions are made because you've got grey hair and a certain age and certain disabilities that come with age....and they stereotype you. This has happened to me.” (P143, female, 70s)*

Becoming perceived as “someone else” if suffering from a terminal illness was equated here with loss of dignity:

*“For me dignity means that I would not want anyone to see me as someone else... it wouldn’t be me, it would be ‘me who’s extremely ill’, ‘me who can’t communicate, who can’t feed himself’... to remain myself as a person as I’ve been for the past x years...and that’s what I would want, that’s what it means to me.” (P34, male, 50s)*

In a very few instances, dignity was associated with appearance. In addition to talk linking appearance and dignity, appearance also was raised in the context of fear of disfigurement previously covered in section 3.1.7. While loss of dignity associated with appearance was one of the least common concerns raised, it is apparent that appearance has particular meaning for those individuals who specifically spoke about it; appearance was said to be important to them in retaining their dignity. One male who saw retaining his dignity as remaining ‘himself’, considered unchanged appearance as part of this ideal. To a female participant, dignity meant, among other things:

*“looking reasonably nice.”(P93, HSCP, female, 80s)*

Another female talked about her feelings of lost dignity through having been without her front teeth for a time, which she hated:

*“You know, I didn’t want anybody to see me like that.” (P143, female, 70s)*

Four other dignity themes were mentioned concerning loss of role in life; death with dignity through ending suffering; ability to maintain dignity in a care home being dependent on care from gender-specific staff; and behaviour in the company of other people as a condition for maintaining dignity.

*“[loss of dignity means] loss of a role.”(P93, HSCP, female, 80s), and:*

*“Death with dignity means that you decide the point [at] which you do not have to suffer any more. That’s dignity for me.” (P139, female, 70s, HSCP)*

Retaining dignity in a nursing home was felt to be conditional on being able to receive personal care from gender-specific staff:

*“For me the loss of dignity would be if I had to be in a nursing home and I didn’t have any say in who was dealing with me and I had male nurses dealing with my calls of nature, etc., you know. I’d hate that.” (P163, female, age not disclosed)*

Dignity was also associated with ability to behave in a group situation without causing embarrassment to others; this sense of dignity would be compromised by bodily unboundedness:

*“...dribbling from the nose or mouth...being unable to control my urinating or defaecating or farting... effectively inhibiting normal social intercourse.” (P164, HSCP, male, age not disclosed)*

### 3.1.11 Fear of loss of autonomy and independence as threats to self

A recurring factor relating to fear of self-diminishment through loss of autonomy and independence was associated with having to enter residential care. Overall, residential care represented losses of control, of self, of autonomy, of independence and of quality of life to participants in this study.

The circumstances surrounding a serious injury sustained by a parent in a nursing home were cited as a background to aversion held toward nursing homes in general, and quoted here, the perceived unacceptable nature of entering residential care due to envisaged loss of freedom and removal of control over life:

*“I certainly would not like the curtailment of going into a multiple residential facility. I would just not accept that curtailment to my life... I would never like to be in the control of a care home, never” (P31, HSCP, female, 70s)*

Aversion to care homes was based here on experience of working with older people in care homes in the past:

*“the idea of going into old peoples homes is worse, far worse than death...the loss of autonomy, the smell, conditions were awful”. (P93, HSCP, female, 80s)*

A previous experience of being a patient in a nursing home was recounted to justify determination to avoid future helplessness and dependence on others through ending life at Dignitas:

*"I don't want to spend any time where I've got to ring a bell and say, "Please do this for me or that" because I'm lying in bed helpless – that's not on... To be in that room by myself almost at the mercy of people... the buzzer didn't work when I wanted a commode"... So things like that and I thought, "God, I don't want to end my life like this and I don't want to be dependent on people like this". (P94, HSCP, male, 70s)*

### 3.1.12 Fear of loss of quality of life as a threat to self

Acceptable quality of life was seen as an important factor that would bear on peoples' desire to live or die and it was observed that the acceptability of quality of life can only be individually determined. In referring to a deceased partner, talk was about the individually determined and multifactorial nature of quality of life:

*"I wouldn't like to die like [x]... died...ghastly, just a vegetable for the last few years. Who wants to live like that in that nightmare? To me, I can't understand why anybody wants to live if they've lost all quality of life...the main thing I still think is total lack of quality of life...loss of control...social isolation... and loss of dignity. All are really bundled together isn't it? It all comes under the quality of life." (P153, female, 70s)*

In describing their reasons for joining FATE, seventeen people (10 with a health/social care background) talked about quality of life:

*"You weigh the pros and cons of being alive, a quality of life question." (P94, HSCP, male, 70s)*

Being already ill, one individual said their will to continue living was dependent on their quality of life, and in a similar vein yet another said that if the quality of life became too poor they would go to Dignitas. A cut-off point would be reached for an individual for whom curtailment of his ability to engage in accustomed social activities was seen to be unacceptable. A very elderly person noted that her looks belied how she felt; she'd "had enough" but her family members did not perceive any valid reason for this

viewpoint. The rationale for extending life of diminished quality through use of life-extending technology was questioned:

*“You can tube feed somebody, have them on an IV drip, you can breathe for them, there’s so much that can be done artificially to keep people alive, and I think there’s a real risk of extending life in cases where the quality is so poor and, you know, we’re just doing it because there’s life”. (P144, HSCP, female, 40s)*

Talk about residential care was a source of themes about loss of autonomy, independence and quality of life; all being seen as a significant threats to the self. Talk about quality of life and residential care homes was predominantly concerned with how quality of life might be compromised through loss of liberty, autonomy and control, isolation, lack of choice and quality of care. Some people did recount anecdotes of a more positive nature. For example, one person acknowledged that their partner had been treated with courtesy and consideration in a care home. However, others cited experiences of visiting friends and family members that had informed their views about the negative impact on quality of life imposed through entering residential care. This example includes comments on quality of care and staff behaviour toward a parent:

*“There were things that I didn’t like. [Parent] didn’t have proper care, people were neglecting her and actually being quite positively unkind to her.” (P160, male, age not disclosed)*

Isolation in an environment where escape from imposed and unwanted entertainment and escape from heightened noise levels was feared to be impossible was seen as an unacceptable feature of residential care:

*“The isolation of nursing homes where you are sitting round a room with the TV blaring and that to me is like hell on earth....every time I went to see [parent] they were all sitting looking at it, some were deaf of course so they had to have it quite loud but there did not seem to be any escape from that...” (P24, female, 60s)*

Again, television in residential care was mentioned in association with loss of independence and diminished control, in combination being equated with poor quality of life:

*“You don’t have much control over your life at all particularly in a home where you see people all sitting round the wall half asleep and the television’s on and nothing much is happening...his quality of life is very poor....[describes friend’s condition] which in itself wouldn’t be so bad I suppose if he had any independence or any control over his environment or what happens to him.(re another friend in a home)...Her quality of life is very poor too in a home”. (P86, HSCP, female, 70s)*

One couple both spoke about their experiences of a relative with dementia resident in a care home; citing loss of self (“a vegetable”) and diminished quality of life likely to be prolonged through longevity:

*“Visiting these homes where [relative] is now, suffering from Alzheimer’s...he’s just like a vegetable...he doesn’t recognize us...seeing the rest of the people in the room with him...it’s a typical situation, it’s appalling...no quality of life...they’re like sightless human beings sitting there, unresponsive...what’s the point of that existence?” (P131, male, 70s); and:*

*“ he has no short term memory at all...he can’t remember his wife has died...doesn’t recognise us...no quality of life - terrible...and he looks as if he could go on for another ten, twenty years...just a vegetable....living so long now you just end up in one of these things (referring to nursing homes)”. (P139, HSCP, female, 70s)*

Quality of life issues observed throughout the duration of a partner’s Alzheimer’s disease prompted the view that:

*“After seeing what [x] has been through in the last ten years, I tell you I would not want to go through any of that”. (P153, HSCP, female, 70s)*

Being ‘tired of life’ as another aspect of quality of life was raised by two people, in their late 80s/90s. One of these who had been a long term member of Dignitas and more latterly a FATE member, talked about a long and complex life. At the time of the interview this reportedly high-functioning intellectual had reached the decision that life was no longer tolerable on the grounds of the severity of his lived physical and intellectual deterioration and, in his view, the loss of a useful role in life. This person has since gone to Dignitas where his life ended; intention to take this course of action and reasons for this decision were discussed during the interview; being ‘tired of life’ due to mental and physical deterioration and advanced age was implied:

*“I spent my life trying to do things which are useful and so that has been my motivation in all of my jobs and in my work. And I feel I’ve got to the stage when there isn’t much I can do...I am losing everything I had up here...[on being asked whether (person) sensed some change in intellectual ability]...not sense, I know...it’s dementia...also I have...vascular disease in the brain...and it means I am losing my equilibrium, I forget everything obviously...and between that and [gives details of cancer surgery]...I really don’t want to be around.” (P47, male, 90s)*

To this older interviewee, feeling tired of life in advanced age and fearing the impact of extreme old age was said to be due to past experience with parental longevity:

*“I’m not happy to be alive but what can I do? I can’t do anything. I would love to go but I dare not ... I’m very frightened [about] what can happen to me still. [parent] was a hundred and five and a half...until she was one hundred she was 100% all right... So you can imagine what a long time I have to wait still. It’s a terrible idea.” (P146, female, 90s)*

Conditionality was a feature of talk about continuing life of diminished quality. Differing ideas were expressed about at what point life might become intolerable. But it was recognised that ideas about a pre-defined end-point to tolerable living might change:

*“...if the bowels and bladder go I do not want to go on living unless...the quality of life is actually better than I thought it would be...” (P24, female, 60s); and:*

*“when it comes to the bottom line and if one has a terminal condition unacceptable to the individual concerned that has to be a purely personal judgement ... if I didn’t recognise my nearest and dearest I would not want to live any longer. Every individual would tend to have their own notion of an acceptable quality of life...that staircase is critical for my continued existence. When I can’t get down those steps any longer and I can’t up them again well I should think it’s time to sign off... If I can’t play bridge, if I can’t sit in a circle and read a play and if I can’t go to the theatre, well life isn’t worth living”. (P100, male, 70s); and:*

*“If I went under a bus...well I don’t want to go through all the pain and struggle with a very reduced quality of life; I would want to die then and there...” (P93, HSCP, female, 80s); and:*



*“...I'd have to think about it at the time...it would be my decision then whether I'm putting up with it or not...obviously in consultation with [partner]...or [other]”. (P160, male, age not disclosed); and:*

*“...it's difficult to be definite...X often said to me, 'well the ability to endure goes on increasing'”. (P164, HSCP, male, age not disclosed)*

## **3.2 Activism**

Joining a right-to-die society implies activism and as an activist organisation, FATE is involved in initiatives that include meetings, production and distribution of a newsletter, maintaining a website, providing information to the public, lobbying MPs, publicising the cause through media appearances and other campaigning activities. A befriending service is also offered for people in need of support. Drawn from the talk of the 30 interviewees, aside from the implicit activism of joining FATE, explicit evidence given for activism is grounded in playing an active role in supporting FATE's affairs, membership of Dignitas, involvement in lobbying activities, and active contingency planning for eventual dying and death.

While membership alone of FATE and any other right-to-die organisations including Dignitas and EXIT can be viewed as activism, not every FATE member interviewed spoke about taking an active role in supporting the movement. Some members are known to be active in other right to die organisations. Twelve of the interviews contained evidence of activism over and above membership alone. Members who do not necessarily take part in other activities, do, from time to time, write to their MPs at FATE's request in support of matters of interest to the society. In a letter to their MP, for example, one member wrote:

*“it's absolutely monstrous that one's not allowed to do it and one of the political things that I'm happy to say is that I've had some dialogue with [MP]... I wrote to him afterwards saying that I had two main concerns about my personal life of the future...the other is that if I wanted to die and can't I won't be able to get help.” (P164, HSCP, male, age not disclosed)*

Evidence of responses to letters sent to SMPs at FATE's request show evidence of campaigning activity:

*"Fate asked us to write to all the SMPs...I had at least two almost positive responses, some are very very clearly anti..." (P58, male, 80s)*

Active involvement with Dignitas was evident in peoples' talk. One of FATE's functions is to offer members information and advice about Dignitas and how to join and access its services if desired. One or more members are known to have accompanied people to Dignitas whose lives were ended there.

Ten individuals talked about Dignitas during the course of their interviews. Four said they were already members, one of these four spoke of accompanying people to Dignitas. A fifth person discussed perceived inappropriate use of Dignitas as seen in a film, a sixth criticised the procedures required in order to use Dignitas, a seventh person wanted to join but spoke about problems with documentation, an eighth indicated interest in Dignitas in specified circumstances, a ninth person was seeking information about Dignitas and a tenth had contacted Dignitas in the past on behalf of a friend.

### **3.3 Good/bad professionals**

Opinions and beliefs expressed about medical and nursing professionals were based on past personal experience (professional and lay), more contemporary personal experience, media stories and hearsay.

#### 3.3.1 Doctors in the past

Instances in which active or passive hastening of deaths were facilitated by doctors (and nurses) in the past were recounted in the context of perceptions that in the present lives are liable to be prolonged more indiscriminately than happened in the past. Doctors in the past were believed to be less concerned with preserving lives in circumstances which interviewees felt it desirable for patients to be "let go". It was also

suggested that doctors might now be afraid not to actively prolong lives in contrast to a greater willingness to “let go” in the past. Past practices in which patients were believed to be allowed to die, or even helped to die were seen as a “good thing”, as illustrated in the following three quotes from professionals.

It was suggested that some doctors in the past would tacitly collude with family members by leaving drugs in the home for hastening death:

*“I was aware that that with the passage of time, where a good old fashioned family doctor who came to the house and helped somebody on their way, had long gone.....our GP in those days just used to leave the drugs on top of the wardrobe, and then a friend of the nurse, a friend of the doctor, would come in and give the injection when it got too much.” (P163, HSCP, female, age not disclosed)*

“Letting a patient go” was seen as a courageous act in circumstances in which others may have attempted resuscitation:

*“...there was a very brave senior registrar... and some people had a tendency “Quick, what can we do? Do this, do that.” ...he prevented anyone from attempting to resuscitate her. He said, “Just let her go” and literally within ten minutes or less she had gone but it was because he had the courage to say, “We must let her go because we can do heroic things and five minutes later we’ll be back in square one”. So I was very impressed with that... ”. (P130, HSCP, female, 80s)*

This next interviewee believed that in the past, doctors’ communication with patients and relatives was based on mutually (tacitly) shared and more accepting attitudes toward medical management of dying and death, in contrast to her perceptions of present-day public and professional attitudes inhibiting communication between doctors, patients and family members. She also believed that public attitudes toward timely death have been transformed into overriding expectations of extending life, changing the dynamics in the relationship between doctors and relatives in ways that place doctors in a more defensive position than in the past:

*“when I was young or a youngish doctor...you could say things to patients and relatives. Like when somebody comes in with a bad stroke you ask the relatives about what they were like and what the patient might have wanted, and then I used to say things like, well “I quite often feel that it’s best to wait a day before putting in a tube, to*

*see if they show signs of recovery or not, because if they don't I find that the quality of recovery from stroke is very poor and they're likely to end up in a nursing home in a very sort of poorly position, and it might be better to let nature take its course". And you could say that to people and they would understand what you were saying you know. And they would after say "that sounds quite sensible, shall we see how things go". But now you know it wouldn't be worth the doctor's livelihood to say something like that to relatives who would be likely to dislike us and the doctors themselves would be likely to find themselves up before the GMC...they're [the public] always being told doctors will do everything to keep everybody alive and therefore when anybody passes away it's always somebody's fault... when somebody gets pneumonia in a nursing home and they didn't send them to the hospital quickly enough... ...in the past, they'd never send someone with pneumonia [to hospital], in the past you would treat it in some way or another as best you could and if it didn't work, well that was the end of life. And if it did work they just soldiered on. But now, if you don't try to keep people alive or manage to keep them alive you're likely to be criticised". (P83, HSCP, female, 70s)*

### 3.3.2 Doctors now

Some people believed that the current medical ethos now is to keep people alive at all costs regardless of individual wishes or the degree of suffering caused by life-prolonging measures, although hearsay serves to perpetuate the view that covert help to die is still practiced by some members of the medical profession. Members of the medical profession are feared by many FATE members because, although perceptions that doctors in the past might have been inclined to help suffering patients to die, they believe doctors now would be more likely to prolong lives in the face of extreme suffering, and being subject to such treatment in the future is particularly feared.

Two people suggested that members of the medical profession now are frightened of providing adequate pain relief to patients; one of whom also believed doctors are frightened of their colleagues and frightened to discuss end-of-life issues in clinical settings.

*"People are frightened of supplying any kind of drug which might possibly go against this pro-life ethic and shorten life, whether it does or not and hence the number of prohibitions about using analgesia as we feel we need to in certain cases both from the*

*doctors point of view and the patients point of view... But now, if you don't try to keep people alive or manage to keep them alive you're likely to be criticised...* (P83, HSCP, female, 70s)

The belief that medicine now is engaged in prolonging life indiscriminately despite patient suffering was revealed during the course of the interviews:

*"...everything seems to be concentrated on giving you that little bit longer however miserable it is. I don't see why..."* (P27, female, 70s)

*(at the mercy of people) "...who are concerned with what they feel is their medical duty which is to prolong your life as long as possible even if that life is painful and intolerable..."*  
(P139, female, 70s)

*"... medical science is actually brilliant...in keeping you alive...it just won't allow you to let go, it won't allow you to go peacefully...the thing that worries me particularly is...certain (people) who have really serious diseases, they really want at the end of their life...when they feel "Right, I've had enough"...they want to say goodbye rather than being forced to say "don't put any more tubes into ...don't any more" "(P24, female, 60s)*

In the context of indiscriminate prolongation of life, members of the medical profession were criticised over perceived infantilisation of a terminally ill relative over the course of an illness during which life-prolonging procedures were repeatedly undertaken, believed by close family members to have caused unnecessarily prolonged suffering:

*"I would want to know things and I would want to make decisions for myself rather than this kind of ...the child who was told by the medical profession what she should do, who are concerned with what they feel is their medical duty which is to prolong your life as long as possible even if that life is painful and intolerable."* (P139, HSCP, female, 70s)

It was suggested that the medical profession now has failed to enter into a debate about timing and circumstances in which death might be allowed, or in this instance, hastened:

*“The individual goals for each part of the profession is to keep them alive as long as possible it seems because there’s been no other debatable choice really within the medical profession, there’s no debate ‘when shall we help this person to die’”. (P131, HSCP, male, age not disclosed)*

Young doctors now were believed to lack sensitivity toward individual wishes. But whether this might have been perceived as a consequence of the training received by young doctors (or not) or whether it might have been a critique of individuals currently recruited into medicine was not explored.

*“I think young doctors and so on they just haven’t got that sort of breadth of vision. They are concentrating on there’s the patient, you treat them, you get rid of their disease, you help their symptoms. You don’t think about the broader picture of what the individual, what they would really want themselves.” (P89, HSCP, female, 80s)*

Use of medical technology was believed in some instances to take precedence over patient wellbeing:

*“...all this technology is nowadays to keep people alive in conditions that are not particularly pleasant and often very painful ...I think a lot more consideration needs to be given to what kind of patient you are treating and what the patients themselves and their families want and somehow or other we’re going to have to get doctors to be able to relinquish the technological side and think more about the patient.” (P83, HSCP, female, 70s)*

### 3.3.3 Nurses in the past

A critique of the present system of delivering nursing care was voiced by a nurse, whose concerns were about lack of continuity of staff when looking after patients on wards. Use of agency staff was believed to have diminished stability and leadership of nursing teams resulting in less effective information sharing and patient care becoming more impersonal. Having previously taught and practiced high standards of patient care in the past, this person’s particular concerns were about perceived deterioration in standards of patient care and hygiene between past and present.

### 3.3.4 Concerns about access to adequate pain control

Two people spoke of their lack of faith in the effectiveness or availability (not specified which, or both,) of universal pain control:

*"I think most of us do die a miserable death especially if you are in great pain." (P24, female, 60s); and similarly:*

*"...but there remains a significant small proportion of pain which is I understand, not (possible to relieve)...and that's partly I suspect exacerbated by the fact that a number of practitioners are timid in their approach and don't in fact do all that can be done..." (P71, male, 60s)*

### 3.3.5 Positive/negative accounts of end-of-life care

Three persons spoke of their concerns about palliative care services. One was concerned that there would never be enough hospice resources for all who need it, another talked about the variable quality of patient care in hospices and a third criticised the public image of palliative care services of providing "nice peaceful death" due to personal experience of a particularly distressing death of someone under hospice care. The next comment is based on personal knowledge about the experiences of dying patients and their families during receipt of care from health and social services:

*I hear all the horror stories about how people die, I certainly hear things about how old people die and about lack of care and lack of dignity, lack of everything. It's not what it's cracked up to be...the actual care, the trappings are nice and the people are nice but you're still in their hands, they still do what they will with you." (P27, female, 70s)*

Restricted visiting hours in a hospice were criticised:

*[friend in hospice]"...it was a really strange place and there were very restricted visiting hours...absolutely crazy for someone with a terminal condition..." (P144, HSCP, female, 40s)*

In an account of a relative's last illness, the absence of interdisciplinary care planning was criticised:

*"There's somebody who does the surgery and then there's somebody else who does the chemotherapy. You never have a meeting of everybody concerned in order to discuss the patient's well-being... It's this departmentalising of a patient so there's no case conference...where you think about the whole patient and everybody contributes and you get to some opinion about it and how to achieve this sort of goal." (P139, HSCP, female, 70s)*

Palliative care services were also praised by professionals:

*"[parent] had wonderful care in the hospice ward...it was really wonderful..." (P144, HSCP, female, 40s)*

*"I've been into some palliative care places...palliative care is great for those that want it and accept it and do not want to die...the only hospices I've been into, they have been very very good..." (P24, HSCP, female, 60s)*

*"([hospice]...patient was in an environment where this was instantly coped with. They were able to put [patient] in a separate room so that the smell did not affect anyone else...I don't think she was too distressed because everything was copable with and they did it in an entirely professional way...makes a lot of difference." (P130, HSCP, female, 80s)*

### 3.3.6 Personal interventions made to stop active treatment

The following instances in which family members and friends felt compelled to persuade hospital staff to cease treatment were all recounted by professionals:

This doctor felt that taking steps to secure the withdrawal of life-prolonging technology from a dying parent was a deeply loving act:

*"...spent one day going through the hierarchy of the staff of the hospital getting somebody who was prepared to take a drip out...felt it was the most loving things we'd done in our lives..." (P164, HSCP, male, age not disclosed)*



A wife recounted how she acted to prevent her husband's life, described by her as having little quality, from being repeatedly prolonged:

*[life was] only prolonged... four times. Well three times. I stopped it at four. (P153, HSCP, female, 70s)*

One older doctor described an interchange with a young doctor whom she believed had failed to take account of her friend's circumstances in determining his treatment when he was very ill; this was cited in the context of a previous critique of young doctors and also in the belief that this was the right thing to have done for her friend:

*"...when I came out of the room there was the young registrar there and I said, "Well I hope you're not treating him?" And he said, "What do you mean?" And I said, "Well he's eighty seven, he lost his wife three months ago, he can't live alone in his house any longer, his only son lives in [x]. He's got to go and live in a care home in [y] with nobody that he knows. He's beginning to lose the place. Do you think that his life is worth saving? He wouldn't want it."(P89, HSCP, female, 80s)*

Another doctor also intervened on behalf of a relative to gain withdrawal of what she saw to be inappropriate use of technology:

*"I had a [relative] who was in the [X hospital] and he was unconscious but he still had oxygen tubes up his nose... and I said to the doctors, "Why are you giving him oxygen?" And they said, "Oh but otherwise his brain will swell" and I said, "Well so what". At least he would be out of the misery and the family would be out of misery and he said, "Oh well. If that's what you want". So they took the oxygen out and in about half an hour he died. So to my mind that was the right thing to do". (P86, HSCP, female, 70s)*

### 3.3.7 Covert assistance to die

Stories about doctors giving covert assistance to help people to die were based on both direct experience and hearsay. Professionals also held the view that covert assistance was given more readily in the past (Section 3.3: Doctors in the past).

Covert assistance to die was witnessed by this individual both in the past and in recent times:

*"...present at two home deathbeds...and both times euthanasia was practiced...[the first] in the days when there wasn't any palliative care so the pain I watched was dreadful...it was such a relief...it was a blessed relief to everyone.. but of course it had to be so secretive...(the second) had all the palliative care in the world... it didn't make it less ghastly...it was so awful to see... this particular time, he bowled in quite unexpectedly.....and rushed out again within about 5 minutes and in about 20 minutes she was dead..." (P27, female, 70s)*

A case was cited in which the means to hasten a patient's death was provided for family members use; tacit understanding between doctor and patient's relative(s) facilitating this action:

*"...had a living will on which...stated that...did not wish to be kept alive unnecessarily and...doctor knew this and discussed it with....was dying at home in great comfort and about 10 days before...died, the pharmacist delivered a large bottle of strong morphine [together with anti-vomit and anti-panic pills]. Nothing was said about this, no reason given, no instructions. But both....and I knew what it was for, but neither of us spoke about it". (P141, female, 80s)*

Unconfirmed accounts of covert assistance to die also circulate through word of mouth:

*"One talks to other people who say, "Oh we know she or he were helped out by the doctor with the agreement of the relatives", but we haven't had that experience." (P131, male, 70s)*

One professional believed that doctors' (past) willingness to help patients die had been compromised by the 'Shipman effect' and another implied that "pro-life ethics" dominate medical practice:

*"...since Doctor Shipman I think there's much less of that isn't there?" (P139, HSCP, female, 70s)*

*"People are frightened of supplying any kind of drug which might possibly go against this pro-life ethic and shorten life, whether it does or not and hence the number of*

*prohibitions about using analgesia as we feel we need to in certain cases both from the doctors point of view and the patients point of view and therefore there needs to be much more consideration of this situation and efforts to improve it". (P83, HSCP, female, 70s)*

### **3.4 Altruistic concern for others**

Concern for others in the context of this study appear to be altruistic in origin, as FATE members have cited these concerns to justify in part their intent to hasten their deaths in order to avoid causing burden and distress on others. Feelings of concern for others were conveyed through talk of desire to avoid causing burden and distress to family members. People were concerned for their children, that they should not be burdened or inconvenienced in their busy lives by parental dependency, nor should avoidable burden be placed on them by dependent parents, given children's' own responsibilities for work and families. Both practical and emotional issues for children arising from dependent parents were cited.

Avoiding distress to her children through their finding the body in the event of suicide was of great concern to this interviewee who had made arrangements in advance to try and prevent this from happening:

*"my concern is to avoid distress to the children so that if I die when I'm on my own or if I choose at that moment that enough is enough and I shall commit suicide my worry is who's going to find the body and that's what I don't want to distress the children with. They are so good. They do whatever they can for me and allowing for the fact that they're busy, they've got lives of their own, they've got jobs of their own... But that distress that I refer to is the finding, who's going to find me if I commit suicide". (P130, HSCP, female, 80s)*

Causing misery to family members while dying and wishing to avoid burdening them should she lose mental capacity was a particular concern here:

*"I'm more concerned about other people than I am with myself actually. I think I'm concerned that I don't want to put other people through misery while I am dying.....it's for others that I'm concerned really. [then later, with reference to 'being away with the*

fairies'] I would hate it for my children or my husband...that I was not the person that had once been... I suppose for myself I wouldn't, I suppose, particularly no. I don't want them to have to deal with it. My son has a mother in law at the moment who is suffering from Alzheimer's and I feel so sorry for them all. I really do. This woman is as fit as a fiddle. She's not aggressive. She's quite pleasant but she's so difficult". (P161, female, age not disclosed)

In this case, hastening death would be preferable in order to avoiding distress to family members through disease-induced changes to the accustomed self in order to preserve the 'normal self' in family members' memories. It is unclear whether this concern refers to bodily changes, loss of mental capacity or both:

*"I've seen too many families suffer when someone's been dying, especially of cancer, and they just waste away before your eyes and the family for six months is wrapped up in this, a person they see die is not the person that they remembered...So I frankly don't want to have an end of life like that. I don't want them to see me too different, [not] as they should probably remember me."*(P94, HSCP, male, 70s)

Avoidance of burdening family members was due to a wish to avoid adding further burden to people with demanding professional lives:

*"I would not wish to really join my family because although I love them very much they both work, they're in very, very demanding and busy professions... and I just wouldn't want to join them, I'd rather be in my own house."* (P31,HSCP, female,70s)

Again the concern was to avoid adding to a child's existing burdens:

*"wouldn't like to be a burden on [child] in any way...certainly wouldn't be the right sort of thing to happen at all. I'm concerned [child] wouldn't be able to cope with that as well. I don't know whether your mental state changes at that point and... do you become complacent and willing to put up with a state of being dependent on someone? And getting to the state where you couldn't decide, it seems quite appalling to me. So...we don't want a dependent life whatsoever".* (P139, HSCP, female, 70s)

Positive action had been taken to provide resources for home and residential care in order to prevent any future burden of care falling on this individual's family members:

*“The thought that they might have to do something like that on a long term basis, they’re all terribly busy, they’ve all got families and the thought of them feeling that they’ve got to go and see [me]..., I just would feel absolutely appalled by it. And if they didn’t do it they’d feel guilty and that’s even worse. So I feel that very strongly.[Own parent] ...it was an absolute nightmare actually. I didn’t want my children to have to face the same sort of problems... but if I was really disabled and they had to come more frequently that’s what worries me.”(P89, HSCP, female, 80s).*

### **3.5 Personal philosophy**

Evidence for concordance between religiosity or non-religious-based personal moral principles and support for the right to die movement was repeatedly illustrated through accounts of personal experiences of suffering, dying and death. Those with religious beliefs framed them in ways that, for them, justified no conflict. Moral agency of self was evidenced through talk about religion, religious legacy, and beneficence.

Religious faith was confirmed to co-exist with pro-right to die attitudes through differing moral justifications. In talk about whether conflict between the two existed, for example, this practicing Christian spoke of kindness as a Christian virtue versus cruelty (by default as un-Christian behaviour), followed by talk about a friend’s circumstances where it was felt that being allowed to die following a catastrophic illness would have been a blessing:

*“I do believe...and I go to church...No [conflict], not at all. I think it’s a kindness to let people die sometimes rather than...I think it’s cruel sometimes to keep people alive.”  
(P86, female, 70s)*

Others made cases for co-existing beliefs based on concepts of God-given skills, a God-determined time to die (although through human agency), no conflict between religious belief and choosing time of death and a God that could not intervene, implying that humans were free to act as they choose:

*“I think if God hadn’t given us the skills to do the things that we do to save life, to prevent the start of life, then he wouldn’t have wanted us to be able to take our lives and so that’s how I view it.” (P163, female, age not disclosed)*

This form of justification placed responsibility for ending life with God, regardless of its cause:

*"...no, [no conflict] at all because you are dying...If you believe in a God, God has decided this is the time to die..."(P27, female, 70s)*

No conflict was seen here between religious belief and ending one's own life:

*"I'm a member of a church...I don't see a conflict... ....I don't think your soul is going to be harmed if you take your own life because you've reached a stage in your life where you've thought 'Well that's it, I'm done, I've completed the life that I want to live. I do not want to carry on in this moment'. So I don't see any conflict there at all." (P24, female, 60s)*

While the existence of a God was not denied, belief appears to be oriented toward a non-divinely directed human prerogative to make one's own decisions about how to do one's best for others:

*I've gone through a journey...I went (to church) at least every Sunday...but I worked things out for myself in the sense that I felt there wasn't a God that could intervene...I'm firmly convinced in doing the very best through life...giving everyone care, listening to them and trying my best to do good job. Caring and doing something worthwhile that can make the world a better place..." (P31, HSCP, female, 70s)*

Two Buddhists voiced critical views of Christian attitudes; one suggesting a self-serving basis for Christian opposition to assisted dying and the other suggested some Christian doctors lack compassion toward human suffering:

*"It seems very un-Christian...to not allow people to die when their time really has come and they've become helpless or useless or in misery. Un-Christian in my opinion....So to keep them alive, who are they keeping them alive for? For themselves? Rather than for helping the person?" (P143, female, 70s)*

*"I was brought up [a Christian]... and then I've looked into the basic Buddhist philosophy of not taking life and I've had lots of discussions about what if there's kind of suffering which cannot be alleviated in any other way and come to the conclusion that if*

*it's done with the correct motives and true motives of alleviating suffering and looking at all the options, that ending life is the right thing to do. I do believe in a force, a living force and energies that we can tap into and be inspired or connect with in some way but if there's a God as such to me he's a God of compassion... and I find it difficult because I was speaking to...[some doctors], their religious belief is such that life is sacred and you never would do anything to end it... the Catholic was speaking against it and believing that suffering can be good for us as it can bring us closer to God and honestly if I hadn't heard it with my own ears, some of the stuff he was coming out with, I just wouldn't have believed it." (P144, HSCP, female, 40s)*

Morality-related themes were present in talk by people who had been religious in the past but who had eschewed religious belief altogether. Personal morality was seen as a legacy of past adherence to the Christian faith:

*"...I'm not religious now...I would hope and think we lead a pretty Christian life without being in attendance...[belief in pro-right to die principles] doesn't conflict at all."(P39, female, 50s); and:*

*"Well my beliefs are, I'm not religious any more. So I am an atheist I suppose if you want to put a label on it. I feel that I've spent my life trying to do things that are useful and so that has been the motivation in all of my jobs and my work... (P47, male, 90s); and:*

*"I've always felt very strongly that people should have a right to personal choice as long as it doesn't impinge on other people...I've always thought about ethics and the morality of different things...I was brought up as a Christian and I suppose in a way that's a Christian legacy that it makes you think in those terms." (P89, HSCP, female, 80s); and:*

*"It was round about the time I had freed myself from what I consider the bonds of religion...and I thought 'well I do believe in ameliorating the position of my fellow man and as I look about me I can see this and that that ought to happen and that's just one of those things I began to feel, this [legalisation of assisted dying] ought to be done.'" (P160, male, age not disclosed)*

These next quotes omit any mention of previous adherence to religious faith but talk about beliefs and values held that justify hastening death:

*"...I think assisted suicide is really ending the pain rather than ending life. Life would end anyway if you have a terminal illness...it's just cutting short the period at the end where you suffer unnecessarily...we're not religious at all so we don't have any feeling of having to suffer pain because of one's Christian beliefs."(P139, female, 70s)*

*"I think that the humanist position regarding life is that there are no external supernatural entities so therefore human beings are responsible to each other and to themselves. I believe at the end of the day people own their own lives...so when it comes to the bottom line and if one has a terminal condition unacceptable to the individual concerned that has to be a purely personal judgement..." (P58, male, 80s)*

*"...a philosophical approach to say you've had a good life, you don't know what the hell it's all about but you've done what little you think you should be able to do. And if there's an afterlife - fine. Taking these pills will take you to the afterlife which if it exists would be more curious that life on this earth. And yet if there's no afterlife then fine...our presence in this world has been a bit of an accident."(P94, HSCP, male, 70s)*

Unfavourable opinions expressed about religion and politics show disapproval of religion and religious bodies in terms of the power accorded to them to influence governmental decision-making:

*"I consider (religion) a great evil. I really do. And I consider it an encumbrance to government in this country..." (P164, HSCP, male, age not disclosed)*

*"...the Catholic Church has the strongest and most determined opposition to this and they have quite a lot of influence, particularly in the Scottish Parliament." (P58, male, 80s)*

### 3.5.1 Belief in rights-based morality

Talk about rights, autonomy and choice features prominently in right-to-die movement rhetoric. Talk about rights and human rights are primarily centred on the right to self-determination in ending life should this be deemed necessary. Although the belief that



the right to hasten death is a human right is not supported by human rights legislation, rights to autonomy and choice in deciding one's time of death, and access to legally sanctioned assistance to die was framed as a "human right" and a "civil right" in talk about why people joined FATE.

*"...the bottom line for me is I regard it as one of a human being's rights to decide that he's had enough" (male, P58)*

Autonomy is seen to be vital to maintain and be retained. In this quote, the question of being trusted and respected by others is also raised:

*"From my teenage years I've believed in the right of the individual to do almost anything as long as it's not harmful to other people...loss of personal autonomy is very vital to me. It's always been vital...I've got to be trusted and I've got to have my autonomy. Autonomy, personal respect is the most important thing a human being can have. To be trusted as a human being is really important. My autonomy is more important to me than anything else." (P100, male, 70s)*

Having a right to an assisted death was framed as 'justice' on the grounds of its ability to help dying people:

*"I think there's a justice to giving people the right to do it and it undoubtedly helps people". (P164, HSCP, male, age not disclosed)*

A case was made suggesting a right for an assisted death should be viewed in the same way as rights to make other autonomous decisions. In the context of serious diseases and suicide it was also inferred that legalised assistance to die would be preferable to covert ways of hastening death:

*"And also for those who are seriously in pain or seriously afflicted by things like Parkinsons or Motor Neurone disease which I think people ought to have the right, you can decide where you live, you can decide if you want to send your son to private school, you can decide if you want to pay for medical care, you can decide if you're going to vote, and this is the one thing, well people do commit suicide anyway – it's just that they happen to do it in horrible ways like jumping off bridges and putting the car hose pipe, and things like that. I mean people do commit suicide, we're never going to*

*stop that. But it's just got to be done in an under the carpet, you know, rather hole in the wall kind of way". (P24, HSCP, female, 60s)*

An individual with a legal background frames "human right" as a "civil right" to be able to decide whether or not to seek a hastened death. Disgust with life was raised in the context of being free to exercise this discretion:

*"I considered it undemocratic and enormously pretentious to control what a responsible person may do with his or her life. I actually feel that discretion about ending one's life should be the civil right of every responsible person...we should accept that people can feel completely disgusted with their lives. And it's not for us to judge whether if we were in the same position would be similarly disgusted...I think it's a human right...I can see no substantial justification for protecting you from yourself or from your nearest relatives...I think that is a pretty tissue thin objection" (P160, male, age not disclosed)*

Past experience of a violent suicide by a terminally ill person was disclosed after this interview was over; the circumstances and the means of effecting this suicide clearly had a profound effect on the individual concerned and possibly explains their reference during the interview to "delayed and dreadful death":

*"I think a reasonable death is a human right, it's the last and most important of human rights. I've always felt strongly about this [human rights and civil liberties]. I believe there are human rights we must have. Delayed and dreadful death is such a horrible thing that it's our human right to do anything to avoid it." (P36, female, 70s)*

Power imbalance between patients and doctors was challenged due to the belief that an individual should have a right to decide how to their end life:

*"I can't see why doctors should have the right to dictate how you should end your life. I know it's simplistic, but if the time has come when you feel you've had enough then it's your right, your life." (P39, female, 50s)*

### **3.6 Resource issues at the end of life**

Talk about resources arose during eight interviews. Consideration was given to a number of resource issues associated with dying and death that were seen to bear on

national, personal, patient and family resources. Themes drawn from resource-related talk concern limits to resources for end-of-life care, desire to conserve personal resources, assisting death for material gain and the potential resource-related negative consequences an assisted death could result in for family members.

### 3.6.1 Resources for end-of-life care:

Doubts were raised by three health/social care professionals about sufficient resources being available to meet the residential care needs of an increasingly ageing society:

*“we live in an ageing society...you’d have to be building care homes and palliative nursing homes day in and day out just to cope with the numbers of people...[in the UK] an awful lot of people still die pretty miserable, lonely and painful deaths and I just don’t think there’s ever going to be enough for hospice care... at the end of the day I do not see even in the foreseeable future...really serious money being spent on palliative care”.*(P24, HSCP, female,60s); and:

*“it’s going to get worse because they’re not going to have the money for...the number of elderly and also the frailty and dependency is going to increase”.* (P31, HSCP, female, 70s)

*“I think most of us as we get older also see our own parents and their generation suffering the results of this situation...there are so many old people that everybody’s frightened and health services all round the world are having to cope with...and they like to think it can be avoided by us all living a healthy lifestyle but that’s rubbish, it can’t be, they will always have severe disease at the end of life...they’re a bit older when it starts...if we didn’t die then probably the whole of humanity would just collapse, it’s essential people die, life is organised that way. No one is exempt either”.*(P83, HSCP, female,70s)

Experience of a friend’s life having been extended by artificial means resulting in residence in a nursing home was recounted in conjunction with a desire not to consume resources for care in similar circumstances:

*...“and I really don’t want that. I really don’t want to be like that. Also you’re using up all the resources you know...”* (P143, female, 70s)

### 3.6.2 Rationing resources for end-of-life care

It was acknowledged that lives cannot be maintained at all costs, life-saving resources are limited and allocation of life-saving technology must necessarily be prioritised. Desire to avoid futile consumption of medical resources that prolongs an unwanted life while depriving others of treatment was expressed:

*"...in practice doctors make judgements all the time which involve ending a patient's life, they switch off the support machine and they're doing that very often for the best of reasons, that the machine is better employed on another patient who has a chance and actually says 'thank you' for that; the argument arises should we use this very expensive drug to give somebody another 3 - 4 weeks of life, but not of very high quality...that's rationing of medical resources, it happens all the time...The argument arises, should we use this very expensive drug to give somebody another 3 - 4 weeks of life, but not of very high quality - that's rationing of medical resources - it happens all the time... [I] would not like to think that I was using medical resources and medical time which was largely to no effect which could be better used elsewhere" (P58, male, 80s)*

Rationing and prioritisation of access to life-saving technologies were raised again in the context of treatment of a terminally ill relative who was believed to be suffering greatly. Inferences drawn from this story about being "kept alive" suggest that use of life-saving technology was inappropriate in this case; criticism of doctors was implied for having used these resources to prolong the patient's life:

*"...she was on a life-support machine...now if somebody else had needed that life support machine who was younger or need (it) more they would have terminated her and that would have been..." P139, HSCP, female, 70s)*

This health professional bemoaned the powerlessness of patients to effect the diversion of resources from themselves to others through cheaply ending an unwanted life. This was expressed in terms of lack of personal control over clinical resource expenditure despite 40 years of contributions to health service resources:

*"For over 40 years I've paid vast amounts in insurance and tax into the health service and I have literally never used it because I've never been ill...so I feel at the end of my*

*life for a prescription that would just be a few pounds, people aren't listening to me and...I'm not getting my money's worth.[laugh]" (P31, HSCP, female, 70s)*

### 3.6.3 Desire to conserve personal resources for the benefit of family members

A desire to benefit family members through avoiding the expense of residential care was expressed in terms of altruism:

*"I think that an aspect that is frequently overlooked, only a few people dare mention it, is the fact that using up all your resources so there's nothing left for your children and a lot of people would far rather forego some of that such as nursing home care, having to give up their home and so on so that their children can benefit. I believe that it's an utterly wicked idea and anybody who might be thought to be utterly at the mercy of their children or something or rapacious families or whatever, whereas to me I think it's a very important human attribute that you should consider your family and your children and the idea of downgrading it and saying that unselfish attitude is sort of foolish and selfish..." (P83, HSCP, female, 70s)*

### 3.6.4 Personal costs of prolonged care

Several people voiced concerns about the cost of future care. Expenses associated with a long-extended life pose a serious concern for this nonagenarian:

*"It's very difficult and expensive to have someone in to come and help you...[concerned that] I will get too old and won't be able to look after myself and with have to have someone here or go to a Home which is both very bad and very expensive. Expense worries me a lot. I am very very careful with my money... I don't spend anything unnecessary. And you know how expensive everything is? And if you have to have somebody for quite a few years it's just unbelievable". (P146, female, 90s)*

The possibility of funds running out were explored although suicide to conserve resources was not being contemplated:

*"if I live a very long time my money will run out...If you have the money to run up care in a residential home or the cost of a hotel one's finances will run out after a few*

*years...you'll be wondering which happens first - whether you would die first or run out of money first...it would be ideal to know...but in terms of management it would be ideal to know exactly what you're...then you could plan it like any other business...It is conceivable that if you live a very long life you would run out...you'd sell your house and so on and then it would all run out...eventually the state would pick you up ...it would be rather unpleasant".(P71,male,60s)*

### 3.6.5 Assisting death for material gain

Issues arising through helping someone to die if they were seen to be gaining financially from the death were discussed by someone who said they would have seriously considered helping their parent if the parent had asked for help to die. As the parent had no money it was noted that the child could not have been accused of profiting from the death in this case, but it was felt to be dangerous for people who stand to inherit, who may be accused of assisting death for profit rather than compassion. A case was cited where friends were asked for help rather than family members so that:

*"family aren't put in the position of 'I helped parent to die and now I've got £60,000 richer'....but the way society can twist things or interpret things, that is a serious consideration". ...but..."If parent had had a moment of clarity and said to me, "Get a pill or put a pillow over my face, I've had enough. I can't stand this". I would seriously have considered it – I would have. I was lucky inasmuch that she had nothing to leave, she didn't have a house, she had no savings. When she died her funeral cost more than she actually had in the bank. So there was no question of, 'Oh well you would have profited from this woman's death". So that is a difficulty where you know a loved one has asked you to help [them] to commit suicide and then they inherit the house or your savings or your stocks and shares and it can be argued she or he profited by two hundred thousand pounds by the death of his wife or spouse. I was very lucky in that sense that there was no question that I would profit by (parent's) death other than the peace of mind that I would have been able to give her".(P24, HSCP, female, 60s)*

A personal view about perceived futile expenditure on resources for end-of-life care was expressed in the belief that if such care was unwanted, resources should be directed toward others. This suggests a utilitarian viewpoint toward resource allocation in health care.

*“I would not like to think I was using medical resources and medical time which was largely to no effect... which could be used better elsewhere...” (P58, male, 80s)*

This health professional noted that access to an assisted death in Switzerland for UK residents is dependent on available personal resources in order to purchase services provided by Dignitas, therefore excluding people without sufficient means. This observation was made in the context of a critique of the UK legal system surrounding assisted dying and the legal status of persons accompanying others to Dignitas:

*“...but as long as you have £5000 and someone to help you go to Dignitas you can go and that’s the solution...”(P94, HSCP, male, 70s)*

### **3.7 Contingency planning for dying and death**

Talk about preparation for later stages of life and eventual death shows evidence of contingency planning to pre-empt future risk to self and others of the adverse effects of future diseases, dying and death. Contingency planning was evident in talk about advance directives, DNR statements, membership of Dignitas and preparations made for suicide if deemed desirable at a future time. In this group of people where control of their lives is an accustomed and highly valued attribute of self, it is unsurprising to find that in anticipating future risks seen to threaten control over life and/or death contingency planning is undertaken. Perceived needs to do this are grounded in mistrust of health professionals and health services, in whom ability to ensure people experience a “good death” is doubted, doubt being largely grounded in lived experiences of the deaths of others. Contingency planning through advance directives aimed to avoid life being prolonged in circumstances perceived as undesirable. It was suggested by one professional that end-of-life care was cheaper in cases where advance directives had been made.

Evidence for end-of-life contingency planning can be framed in terms of risk management in that risks of suffering are balanced against the benefits of dying, individual risk avoidance strategies are formulated and contingency plans set in place. Death was clearly seen by interviewees to be a benefit to self and others in given circumstances, should future suffering prove to be too great. Experiences of bodily

deterioration associated with ageing helped focus attention on possible risks to self that may arise. As one participant said:

*“Yes, it is a contingency. You see it coming nearer and nearer. You look at your own disintegration...we’re all saying to each other ‘I can’t do the things I used to do’...and we’re all recognising that there is physical deterioration about which we can do nothing.” (P130, HSCP, female, 70s)*

In addition to joining FATE, anticipation of future need to end life prematurely, should that need occur in the future, gave rise to three main forms of contingency planning; membership of Dignitas, preparing advance statements and procurement of lethal drugs.

Determination to bypass UK-based end of life care through joining Dignitas as a contingency plan reflects a lack of trust that UK end of life care services would necessarily provide adequate care and relief from suffering.

*“My choice would be to end my life in a dignified way and that would be through Dignitas, and as I’m a member of Dignitas that is what I would want to do.” (P34, male, 50s)*

*“I want (Dignitas) there as a possible exit for myself”. (P36, female, 70s)*

Although information and advice about joining Dignitas is available from FATE which has only existed since the year 2000, some members had joined Dignitas prior to FATE’s inception. Long term plans for death as shown below reflect long-term commitment to the right to die movement:

*“I joined Dignitas about 25 years ago...that was my contingency plan”. (P47, male, 90s)*

*“I joined Dignitas for myself years ago so it was my own kind of quick exit if I want one myself”. (P94, male, 70s)*

Despite contingency plans being in place, people acknowledged that their ability to retain control over dying or the manner of their death could not be fully assured:



*“To some extent you can’t be in total control of the actual process of dying but [in control of] circumstances, yes”. (P130, HSCP, female, 70s)*

The consequences of becoming incapable of carrying out plans, or of failure of chosen methods to succeed in achieving death, particularly concerned these people:

*“I may be incapable to carry out my wishes into effect when the time comes”. (P71, male, 60s); and:*

*“... And people say to me “but why do you have to belong to an organisation, you just have to take a couple of bottles of pills and a bottle of vodka and you’ll be alright if you want out at any time”...but that terrifies me, the thought that I might be brain damaged but not dead.” (P36, female, 70s)*

Implacable belief in individual rights to self-determination, and determination to ensure these rights would be respected was indicated through action being taken to legally challenge failure to respect a DNR statement should this occur in the future:

*“I carry a ‘do not resuscitate’ statement...if the paramedics refuse to follow [the DNR statement] and they resuscitate me could they be sued afterwards for not carrying out my instructions...have a lawyer looking into that.” (P141, female, 80s).*

Living wills, advance statements or advance directives place legal obligations on clinicians, providing they fulfil criteria for validity and applicability laid down in the Mental Capacity Act (2005) and Adults with Incapacity (Scotland) Act (2000)<sup>28</sup>. Advance statements are a further manifestation of risk management strategy in that they potentially provide some insurance against prolonged suffering at the end of life.

*“Well I quite often hear people talking about they wish they just had the little pill that they could pop in and end their life but they don’t actually actively do much about it like making a statement that they leave with their lawyer and their doctor and so forth. So I thought I would do that so that hopefully I’m not resuscitated for instance or kept unnecessarily alive.”(P86, female, 70s)*

Reported actions taken to end life if deemed necessary included advance procurement of lethal drugs. Difficulties associated with this course of action were acknowledged:

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<sup>28</sup> GMC, 2010

*“I’ve got a bottle of [drug] upstairs which I could use but there are quite considerable difficulties in the way of using that as you probably would realise. It’s not straightforward so you can’t just swig it down, probably be sick. You have to make all the arrangements for the body and people who find you and it’s really complicated”.*  
(P93, female, 80s)

Future activation of this contingency plan is subject to stated conditions, conferring a sense of reassurance through its existence:

*“I do have the medicine...as a safety precaution...somebody got it for me. So I do know that if life becomes really intolerable and nobody can help me I can help myself. It’s a great relief to know that whatever happens I don’t have to go through it...I don’t want to die, not that I’m depressed or anything but I just know that it’s there.”* (P141, female, 80s)

One other form of contingency planning emerged; this plan was made with the aim of preventing distress to a family member caused by finding the body following suicide:

*“I’ve got [named person] down actually as my next of kin so that if I’m found [named person] will be the person to be informed first of all. Not [family member].”* (P130, HSCP, female, 70s)

### **3.8 Social isolation**

Concerns about social isolation were mentioned by only two people; social isolation did not arise as an issue for the majority of interviewees. Social isolation was regretted rather than feared in the context of receiving fewer visitors should mental capacity deteriorate in the first quote but was felt to be a more serious concern in the second quote:

*“If I became delusional then I’m afraid my friends might just not come and see me quite so often and I really wouldn’t blame them and that would be a shame.”* (P157, HSCP, female, 60s); and:

*“ I couldn't bear to be socially isolated...I don't mean I want to go to a club or something...I don't want to go to these things just for the sake of going to a group of people.... but I suspect I would never be because I've got a telephone. If I could use the telephone...maybe I won't be able to use the telephone...but social isolation - that would be bad - tough.” (P141, female, 80s)*

#### **4. Discussion**

The interview sample differs substantially from the survey sample reported on in Chapter 4 because it was identified through purposive sampling. Whereas in the survey responses were random and opportunistic, apart from convenience sampling method employed, members within the interview sample were selected on the basis of their capacity to offer high quality data as shown in their survey responses. Because so many health/social care professional members had emerged from the survey, their views were of particular interest because of their experiences as practicing professionals and therefore the interview study aimed to seek as many of their views as practicable.

Older age and higher social class emerge as key predictors of membership of FATE and the thirty interviewees identified through convenience sampling conform to this trend, reported in both the previous chapter and previous studies of right to die society membership. In Chapter 4 it was shown that 22% of FATE members had health/social care professional backgrounds and 7% of the membership were medical doctors, albeit all retired. The interview group includes 50% of people with health/social care professional backgrounds, affording a unique insight into how professional experiences influence pro-right to die beliefs which have not previously been explored in right to die society studies.

Predominance of older persons in the survey sample and in previous studies of right to die society members (Wilson et al, 1998; Fox et al, 1999; Cossman et al, 2002) suggests older age may encourage people's focus on their mortality. This notion is echoed by Richards (2011) who suggests the older age of FATE members may be responsible for their starting to think pragmatically about their eventual dying and deaths. Among older interviewees who discussed future age-related possibilities for

lengthy and unpleasant ways of dying, it appears their decisions to join FATE were made on philosophical, pragmatic and altruistic grounds.

The results of these interviews show that FATE members are primarily concerned with assuring themselves of a “good death”, through avoiding dying in ways that would induce variants of suffering deemed to be intolerable. Perceptions of this need are frequently based on personal experiences of dying and deaths of family members and friends within the UK healthcare system. In order to achieve a good death for themselves, a need to retain control of their dying is seen as paramount, as relinquishing the management of their dying to others, in their eyes, cannot be trusted. Data from these interviews suggest a “bad death” is seen as one which is technologically prolonged, featuring inadequately relieved suffering with potential loss of control, de-personalisation, poor quality of life and loss of personal dignity. Desire to avoid loss of self in dying in a society in which “compulsory and obligatory self-determination” is endemic (Higgs and Rees Jones, 2009), is not altogether surprising. Joining FATE in order to retain control and manage risk in dying appears to be, as Richards (2011) concludes, a pragmatic act. Actions taken to insure against perceived future risks in dying include membership of Dignitas, living wills, and storing lethal drugs in order to end life if deemed necessary in the future.

How likely might it be that people’s fears about a bad death would be realised in the future cannot be predicted but if the possibility exists, joining a movement that campaigns for legalisation of hastened death might be seen as a rational act for persons who desire to establish some certainties about the manner of their eventual deaths. The probability of experiencing a bad death (as defined by interviewees) in the UK today is unknown, and based on the anecdotes recounted by interviewees, it is impossible to determine to what extent the fears they cite as grounds for joining FATE could become a future reality. With reference to the aims of the palliative care movement, recipients of palliative care at the end of life can anticipate experiencing the best death possible, yet access to palliative care services is not guaranteed for all dying people. Also, some FATE members believe that people can still die badly within palliative care services and Lawton’s (2000) findings support this view. It has already been established that desire for hastened death can be present concurrently with palliative care service provision (Kelly et al, 2003; Ganzini and Back.2003; Jansen-van der Weide et al, 2006; Terry et al, 2006; Gill, 2009). It is clear that the possibility of a

bad death, and desire to seek a practical solution, are the main reasons why people join FATE.

The 15 predominantly female health/social care professionals cited a greater number of reasons for joining the society than the lay interviewees. Why this should be is unclear but could possibly be related to professional knowledge and familiarity with circumstances surrounding patient deaths. Professional and personal experiences of dying and death, and fears for the integrity of, and control over the self are the dominant reasons for their joining FATE. Lay interviewees place similar emphasis on fears for self, followed by personal experiences of dying and death and rights-based beliefs as the most frequently occurring reasons for joining FATE. As reported in the preceding chapter, many individuals who join FATE have personal experiences of caring for terminally ill others and most interviewees elaborated on this theme. The main findings emerging from the interview study emphasise how personal and professional experiences of dying and death have influenced people to embrace the concept of having a right to die and to become members of FATE, echoing Holden's (1992) findings in which Hemlock society members' "death-proximate experiences" were said to be implicated in forming pro-euthanasia attitudes. These findings reinforce other's findings that witnessing the dying/deaths of others have the power to generate a desire for hastened death (Verpoort et al, 2004; Hallowell, 2006; Chapple, et al, 2006). Haworth (2007) also notes that pro-right to die attitudes can result from reaction against "bad death" through medicalised prolongation of lives.

Desire to manage perceived risks associated with a future dying process is reflected in talk about desire to protect integrity of self, to retain dignity, bodily control and control of circumstances during dying trajectories as a product of experiences of unacceptable ways of dying. The numbers of years people spend in poor health and with disabilities later in life pre-death is increasing (Office for National Statistics; Social Trends 39, 2009). FATE members speak openly about what they see as the "painful social realities" of dying and death and their desire to manage the risks they anticipate. This behaviour is not surprising given western cultural attitudes toward risk in which risk and fear are reflexively created, endemic, generated by wealth and market economies, and affecting all levels of social hierarchies and individuals in their everyday lives (Furedi, 1997). The risk of dementias, increasingly prevalent in an ageing population (Alzheimer's Society, 2010) is recognised by interviewees and fear of losing self

through dementia is a significant factor informing both pro-right to die beliefs and personal planning for death. Study participants' concerns about dementia imply perceptions of mind/body as separate entities in terms of a living body without a functioning mind or self being unacceptable to them as agentic beings. Dualism is represented in their talk about people with dementia in terms of being in a vegetative state or a vegetable, exhibiting anti-social behaviour, being without accustomed intellectual capacity, being unable to recognise close others or people not really there at all. All these mind-related factors attributed to dementias implied a dualistic picture of mind becoming increasingly absent while the body remained present. While the relationship between the body and self-identity have been subject to a variety of sociological insights (Shilling, 1993), these perceptions of mind/body dualism in dementia identify themselves more closely with dualism in the Cartesian tradition. Csordas (1994) also suggests that objectification of the body (as FATE members do in the case of dementia) emphasises individuality of the psychological self, implying a dualistic approach toward conceptualising human beings. From this perspective, the body as a governed object becomes ungovernable when governing mechanisms become degraded as in dementia. Dementia from this theoretical stance robs the body of governance through progressive loss of the self, with both body and reflexive self as separate 'sites' also suggestive of a dualistic approach as the self site diminishes leaving the body site ungovernable. In the instance of dementia this reciprocal relationship between body and mind is one in which assaults upon either have adverse effects upon the other. Frank (1991) describes a form of dissociation between body and self originating from Gnostic concepts of the body as a garment. Frank terms the disciplined body as one dissociated from self yet governed by self. Similarly to Foucault (Fox, 1997), this concept of the ungoverned body through loss of self in dementia mirrors concepts of dementia's impact on the body/self relationship as FATE members perceive them.

The hypothesis that reflexive self-identity is implicated in pro-right to die attitudes is supported by both the survey and the interview data. With autonomy and control as attributes of self-emancipation and reflexivity (Giddens, 1991), their loss is seen as an important threat to future wellbeing. The bodily realities of dying (Lawton, 2002) exert a significant impact on peoples' loss of self, leaving in some instances, as Lawton contends, a body minus its personhood. Interviewees present themselves as habitually autonomous individuals, used to being in control of many aspects of their lives. It can be understood therefore that undesired deconstruction of a reflexively constructed

emancipated self through bodily and/or brain disintegration, imposing losses of valued attributes of personhood, can pose a major threat to this particular group of individuals. Loss of valued self-integrity is seen to be one of the threats associated with dying, to be actively avoided. As reported in the previous chapter, fears about loss of mental capacity are also a recurrent feature in interviewees' talk.

Four of the most prominent areas of concern to interview participants are losses of control, dignity, quality of life and ability to retain self-management of bowel, bladder and personal hygiene. Retaining dignity is closely associated with retaining body boundedness, and interviewees expanded on this theme. Loss of bodily integrity, especially of loss of independent management of bowel and bladder, is a significant finding associated with membership of FATE, strongly associated with feared losses of dignity and control. This finding supports the contention that the act of delegating one's intimate and personal bodily care to others may be abhorrent (Howarth and Jefferys, 1996) and, as quoted previously, maintaining a bounded body is central and fundamental to selfhood (Kirkham, 2007; quoting Lawton, 2000) and inability to maintain it can induce "dismay and distress" in dying people (Kellehear, 2009c).

With customary control over lives a norm associated with higher social class and professional status, it is unsurprising to find that the consequences of its potential loss are of such particular concern to so many participants in these interviews. People in late modernity are expected to exercise individual responsibility for their own health (Haworth, 2007); seeking to exercise responsibility through retaining control over their own dying and death extends this principle.

Belief that people can be arbitrarily kept alive under the care of contemporary health services, without sufficient regard for suffering and loss of quality of life caused for individuals features in both survey and interview data. Being kept alive despite advance directives, and fears that doctors might use life-prolonging technologies without regard to suffering, quality of life or individual wishes were expressed. Fears expressed about being subjected to techno-medicalised management of dying and death have arisen through personal involvement in dying and deaths of close others. Kemp (2002) referred to beliefs about indiscriminate life extension in quoting an essay by Gisborne (1928) who charged society of that time with "a tendency to prolong life for its own

sake, even when accompanied by intractable suffering". For participants in this study, personal experience-based perceptions about the quality of care of ageing and dying people in the UK has clearly fostered mistrust in the quality of care that might be received at the latter end of their lives, particularly with regard to the care they would wish for to help maintain an acceptable quality of life and which ultimately would minimise suffering at the end of life. Suffering as an individual experience is defined as distress "associated with events perceived as threatening to a person's integrity" (White, 1996). According to Richards (2011), slow dying is particularly feared by FATE members and In light of these fears, joining FATE is a manifestation of personal risk management through seeking to avoid what its members most fear; an insurance against intolerable suffering and an assurance that under personally defined circumstances, life can be ended should this be desired.

The percentage of deaths in care homes and nursing homes have risen, with older people having disproportionately less access to palliative care services than younger age groups (Holloway,2007). Expressed aversion to entering residential or nursing home care in principle was ascribed by interviewees to poor quality of life seen among family members and friends in care. Fears expressed by interviewees about residential care confirm Richards' (2011) view that some FATE members would rather hasten death than be institutionalised.

As previously stated, interview data confirms the hypothesis that it is possible for religiosity to co-exist with pro-right to die beliefs as none of the participants owing to religious belief saw any conflict between the two. One argument advanced for concordance between religious belief and positive attitudes toward having a right to die concerned kindness versus cruelty, resonating with Badham's (2009) notion of compassionate and humane responses to human suffering that might also include hastening death. Also, abandonment of previous Christian faith was acknowledged by interviewees to have left a legacy of moral standards that support a pro-right to die stance.

Although risk aversion and risk management is endemic in UK society, positive risk management of dying and death (as opposed to insuring life or suicide prevention strategies) appears to attract little public attention, although the incidence of old age



suicide tends to be high (Office for National Statistics. Suicide rates in the UK 2000-2009). But FATE members actively manage perceived risks associated with future dying and death through indirect and direct means. Advance directives or living wills specify end of life wishes about treatment but some members are afraid these might not be honoured when the time comes. Others have taken more direct action through acquiring lethal drugs or by joining Dignitas. As Richards (2011) suggests, fear of a 'bad death' drives FATE members toward risk management strategies and since this research was completed, two members whom I interviewed are known to have ended their lives at Dignitas.

Resource-related issues form part of some FATE member's rationale for joining the movement. Talk about resources revealed awareness of national economic issues surrounding the care of an increasingly elderly population. Resources for future care and palliative care provision were acknowledged to be finite and rationing of treatment resources already in place noted. It was argued that scarce resources should not be used on futile treatment when others could benefit and it was argued that death as a natural culmination of life should be allowed without unnecessarily prolonging the dying process. These views further illustrate the practical approach FATE members show toward dying and death, in a social climate in which an increasingly long-lived ageing population poses a resource-based challenge toward future care provision and public talk about the practicalities of dying and death and its meaning tends to be hidden (Walter, 2009).

Concern for others was evidenced by interviewees in talk about causing distress, placing burden, and causing financial disadvantage to close others. That this concern is altruistic in nature is evidenced in talk about burdening close family members whose lives are already full. Yet studies of patients and older people who express concerns about burdening others seldom acknowledge any factual basis for peoples' wish not to burden others. Warnock (2009) asks why a wish for death for the sake of one's children should not be viewed as altruistic in the same way as other acts widely accepted as altruistic. Hardwig (2000) sees shared interests as being integral to altruistic actions. This study confirms that altruism can be associated with pro-right to die attitudes because interest in hastening death, associated with with altruistic concerns for others with intent to act on these concerns, is evidenced by the data. Interview participant's reasons for desiring death at a given time are clearly both self benefiting and altruistic

toward others, self-benefit being achieved through death and benefit to others conferred through dying by relieving others' burden, distress and suffering.

## Chapter 7: Discussion

This study provides one of the first empirical accounts of reasons underlying decisions to join the right to die movement, in this instance, FATE. The thesis contributes to existing knowledge firstly through providing a detailed account of FATE member's personal concerns about end of life care having prompted their decisions to join, and secondly through an analysis of those social factors most likely to influence these decisions. The thesis draws on new social movement theory, theories of self and individualism, risk and altruism and examines the roles of medicine and religion toward creating a new conceptual framework for understanding the right to die society phenomenon in the 21<sup>st</sup> Century.

In the course of this work I have learned much about the value of cross-disciplinary knowledge and research and its capacity to enhance thinking about the how the social world shapes peoples' beliefs, behaviours and actions. I contend that the sociological interpretation of the right to die phenomenon presented in this thesis has been enriched through drawing from sociology and other academic disciplines to answer the research questions, creating a new theoretical basis on which the existence of right to die societies and choices made to join them can be understood.

People decided to join FATE for a variety of reasons, the most frequently occurring single reason being due to either past experiences of others' dying and deaths or less commonly, being already terminally ill. Movement between other right to die societies and FATE is shown to have occurred due to personal preferences relating to differing approaches taken by right to die societies. FATE is shown in some instances to be preferred over other UK right to die societies due to its unique function in advising and assisting members who either wish to join Dignitas as a contingency plan or who wish to arrange to terminate their lives at Dignitas. It is FATE's pragmatic approach toward hastened death that appeals to its members who can, through FATE, access a practical solution to ending unwanted lives.

This study shows how FATE members are characterised primarily by their socioeconomic background and age, with women outnumbering men, in line with previous studies of right to die members (Lam, 1982; Holden, 1992; Kamakahi et al, 2001; Cossman et al, 2002; Blevins et al, 2005). Like the US Hemlock society, there is a striking absence of FATE members from lower socio-economic class backgrounds. Reasons for the near absence of people from lower socio-economic backgrounds within FATE membership are likely to be associated with differences in educational level and cultural values, customs and beliefs. FATE members are not only characterised by higher socio-economic status but also present themselves as individualistic and autonomous individuals. Personal qualities such as these are consistent with Giddens'(1991) and Goffman's (1959) theories of individualism and self-emancipation. The Oregon experience also shows that persons requesting assisted suicide were of higher socio-economic status than the general Oregonian population (Ganzini and Back, 2003). Beliefs in rights and choice surrounding dying and death are shown to be consistent with the reflexive emancipated self are characteristic of FATE members. With reasons for joining FATE and for beliefs underlying decisions to join having arisen through past life experiences, almost two thirds of participants had had professional and/or lay experiences of others' dying and deaths. Over one third of FATE members have been shown to be religious yet able to reconcile their religious and pro-right to die beliefs. High levels of apprehension about future dying and death have been shown to form a basis for decisions to join FATE. Fears are shown to have their origins in perceptions of risks associated with the dying process. The study shows how risk management and contingency planning are fundamental to members of FATE having joined the movement, an action consistent with UK society's preoccupation with risk and risk prevention in later modernity. Interest in access to Dignitas is shown to be a distinctive characteristic of FATE membership. The study has also provided evidence that altruism can be involved in pro-right to die belief systems. It has also shown that concerns about being a financial burden to family members and/or society can also be implicated in the decision to join a right-to-die society.

The background to the right-to-die movement has been shown to rest in a long history of past societies and cultures in which a diversity of philosophical, moral and cultural attitudes were held toward suicide, death and ageing. Whereas in the pre-modern societies of ancient Greece and Rome suicide was considered to be an ideal death (Emanuel,1994), Christianity proved a turning point for western civilisations since when

attitudes toward suicide as a good death veered repeatedly between proscription and permissiveness over many centuries. From the 19<sup>th</sup> Century onwards, milestones in the history of the euthanasia debate preceding the right to die debate becoming part of a new social movement, include the publication in 1887 of physician William Munk's book "Euthanasia, or Medical Treatment in Aid of an Easy Death (Hughes and Clark, 2004). Following this publication, Emanuel (1994) contends that the meaning of euthanasia as doctors' deliberate ending of life did not become fully articulated until 1902. Following the eugenics movement in the earlier years of the 20<sup>th</sup> Century, it was not until 1935, however, that a formalised British right to die movement arose (Chapter 1: Kemp, 2002). In parallel with the history of religion and medicine, the current debate about legal hastening of death in the UK forms part of this continuum, arising in an age characterised by major social changes in UK and other western societies, influenced by globalisation, market economies and consumer cultures, with accelerating advances in communication, information and biomedical technologies (Featherstone and Hepworth, 1998). The history of the 20<sup>th</sup> Century UK right to die movement as outlined in Chapter 1 has become increasingly dynamic in 21<sup>st</sup> Century late modernity, having spawned four further new right-to-die organisations: FATE (2000), and affiliated to Dignity in Dying, Compassion in Dying<sup>29</sup>. Two other newer small groups now exist; one of which has extended its campaigning brief to include assisted dying for non-terminally ill older people (SOARS<sup>30</sup>).

The original objectives of the study were to develop an understanding of people's motives for joining FATE, of what factors might be involved in influencing FATE members' commitment toward FATE's aims and to identify social factors responsible for the continuing existence of the right to die movement. I originally hypothesised that the popularity of right to die societies is related to the particular characteristics of societies in which they exist. FATE, inaugurated in the year 2000, its aims, its activities and the reasons held by individuals for joining, clearly show this right to die society to be a product of contemporary UK society in which political, economic, biomedical and moral principles are open to challenge by campaigning organisations.

In modernity the status of religion is changing. Lambert (1999) proposes a first "threshold of secularisation" model in which religion's formerly dominant and

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<sup>29</sup> [www.dignityindying.org.uk](http://www.dignityindying.org.uk)

<sup>30</sup> [www.soars.org.uk](http://www.soars.org.uk)

authoritarian role has become relegated to one of less authority although at the same time personal religiosity may remain in individualised societies. The study findings showing religiosity among some FATE members support the original hypothesis that religiosity can coexist with pro-right to die attitudes in an individualised culture. This is confirmed through the finding that FATE members who claimed to hold religious beliefs were able to account for how they rationalised concordance between their religious beliefs and membership of FATE. Also, the idea that religious individuals are able to rationalise the co-existence of these beliefs is illustrated through evidence showing high levels of religiosity among general populations in jurisdictions such as Switzerland in which hastened death is already legalised (Spoerri et al, 2010). A minority of US right to die society members do own to religious affiliation; also churchmen both past and present have supported right-to-die campaigns (Kemp, 2002; Tullett, 2006; Badham, 2009) although in general, the teachings of the main world religions proscribe such beliefs. During the House of Lords debate of the 2<sup>nd</sup> reading of the Joffe Bill in 2005, two members of the House of Lords who spoke in favour of the Bill professed Christian faith. Subsequently, in submissions to the Commission on Assisted Dying<sup>31</sup>, some religious participants (Rabbi Danny Rich, Rev. Nicolas Stacey, Professor Robin Gill and members of The Bio-ethics Group of the Church in Wales) offered conditional support for the principle of a legal right to die.

As previously stated, it is not the purpose of this thesis to participate in ethical debates surrounding hastening death. However, the data highlight two main areas of conflict between moral ethics and religious beliefs. Approximately one third of participants own to religious beliefs while seeing no conflict between these and hastening death and cite perceived reasons for their stance. This serves to draw attention to a possible conflict between the religious imperative of sanctity of life and Kantian principles of beneficence and maleficence in respect of how dying and death are managed in 21<sup>st</sup> Century western societies. Some FATE members acknowledged their fear of severe pain in the belief that this may not happen when dying but if the principle of beneficence were to be always invoked in practice, severe pain should be relieved - as a basic kindness (The Lancet, 2012). Participant suggested that doctors in the past could be kinder when they hastened the death of a suffering patient than could be expected today with cruelty (maleficence) versus kindness (beneficence) being cited in relation to peoples' fears about how future end of life care might be experienced, The Hippocratic Oath (Sokol, 2008) bids physicians to do no harm and forbids them to kill

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<sup>31</sup> <http://commissiononassisteddying.co.uk/>

their patients, although Sokol notes that at time of writing this injunction may refer to politically driven assassination common at the time rather than easing the passage of dying patients. Religio-ethical debates surrounding requested hastening of deaths in suffering patients remain equivocal and widely polarised between authorities, organisations and individuals, but for FATE members and unknown numbers of members of religious establishments, religious and ethical attitudes can for some individuals, be reconciled morally with acceptance of hastened death in principle.

The study findings are presented at a time when an increasingly aged UK population is giving rise to major concerns nationally about resources for health and social care for this fast-growing population. In a social climate where negative societal attitudes toward ageing are associated with negative social identity (Hockey and James, 1993), and outward appearance defines self-identity (Lupton, 2003), I have shown that social constructions of ageing, death and dying born of post-modern global and national developments in western society cultures are strongly implicated in fostering the continuing existence of the UK right to die movement. The ageing body presents an antithesis to the contemporary western society youth culture in which culturally endemic age resistance stigmatises the ageing body (Lupton, 2003) and by association, the ageing self. I contend that, due to the individualistic and autonomous profile of FATE members, who tend to be older, joining this society and becoming involved in right to die activism poses a direct challenge to the ageist stereotyping of older people endemic in UK society.

This study has shown how new social movement theory offers a lens through which the self, ageing, the body, and medicalisation of dying can be understood in relation to reasons why the contemporary right to die phenomenon continues to exist, and why people choose to join the movement. The study provides evidence showing older age is a defining feature of both UK and US right to die society membership. The study confirms that some UK health/social care professionals do join the right to die movement despite the official stance taken by their professional bodies. It has shown how personal experience of others' death and dying, for both health/social care professionals and lay people, exerts an important influence on their beliefs and fears about future dying, and is a critical factor in acquiring positive attitudes toward pro-right to die legislation. The results of this study suggest, then, that four major cultural factors are implicated in decisions taken to join FATE: the cultural context in which ageing and

dying take place; the ageing and biodegrading body, its significance in culture as a symbol of loss of agency and its interdependence with self. The study has shown how the self defines who joins FATE, and how threats perceived by FATE members toward self and body are associated with present-day medicalised dying, playing an important role in the pro-right to die stance characteristic of members of FATE.

### FATE and new social movements

Since the industrial revolution, new social movements have arisen in modern societies in response to grievances relating to political, economic, cultural or organisational conditions (McAdam, 1994). They seek to challenge contradictions between socio-cultural values and conventional social practices, and have become part of culture (McAdam, 1994). New social movements are characterised by their actions in challenging social conditions and defined by their activities in raising public awareness of issues concerning peoples' lives and in seeking political solutions (Giddens, 1991). They engage in political activism to campaign for rationality and justice in solutions to perceived social problems (Ali et al, 1998) and latterly they have become increasingly involved with matters pertaining to more personal and intimate health-related areas of human existence (McInerney, 2000). New health-related social movements are often characterised by formal and institutionalised opposition toward the "medicalisation of social experience" (Furedi, 2004). Health social movements have also arisen due to the domination of science and technology in social policy and regulatory decision-making that serve to exclude the public from important policy debates (Brown and Zavetoski, 2004). Health-related social movements seek to challenge the professional authority of medicine, political power and belief systems concerned with disease and illness experience. Originally concerned with matters such as equitable and non-discriminatory access to healthcare, health social movements have become increasingly focused on personal experiences of illnesses such as HIV/AIDS and breast cancer. This is due in part to emergence of a more confrontational approach by patients towards doctors in general, the patient as someone who 'endures' having moved into a more knowledge-challenging activist role (Hess, 2004). How people die has become a personal health-related issue driving the right to die movement and McInerney (2000) shows how state-controlled medical decisions made at the end of life, and "domination of the human body by medicine" are central issues in the right to die debate. FATE is part of a trans-national new social movement operating in the oppositional tradition of other new social movements through seeking a new legal right (to die), in the face of politico-religious opposition, The right to die movement is both



oppositional and health oriented as shown by FATE members whose campaign is in part driven by perceived issues with health and social care service delivery in the context of terminal illnesses, ageing and dying. Campaigning for new rights is common to other new social movements such as the feminist movement that initially sought to equalise rights between both sexes and continues to aim toward freeing women from constraints that prevent them from participating in traditionally male-dominated social activities. (Giddens, 1991). New health social movements such as the pro-abortion and disability movements also sought new rights for their members. So although FATE is clearly a member of a social movement that fulfils many of the criteria for new social movements, it differs in other respects from many other health-related social movements due to the older age of its members and the focus of its activism on practical ways of dealing with dying and death at the end of life rather than on the health politics of living.

Apart from its campaigning activities, FATE also differs from other UK right to die societies, in particular Dignity in Dying, due to the older age of its organisers and members and the more pragmatic approach of its members toward managing their own deaths. This due, as Richards (2011) suggests, to members' fears that they may not have the time to wait until a legal right to die becomes, if ever, law in the UK. The perceived need for pragmatism in the face of limited time remaining has led to FATE having become associated with Dignitas, as it is through FATE that its members can obtain information and support on how they can access Dignitas. In fact, FATE acts as a gateway to Dignitas in cases of need with two participants in this research having subsequently ended their lives at Dignitas. At one point, the founder of FATE was arrested but subsequently discharged for providing verbal advice over the phone to someone who wished to end their life (Interview, 2009). FATE's association with Dignitas therefore appears to be a stopgap measure taken on pragmatic grounds. This area of activity exists in parallel with, and does not compromise, its status as a social movement whose aim to campaign for a legal right to die in Scotland remains paramount.

On the basis of my findings, the defining features of new social movements are commensurate with the ethos and actions of the right to die movement and its members. FATE meets criteria for classification as a member of this new social movement through its political activism in seeking to gain a new legal right for its

members via its ongoing campaign for legalisation of hastened death. FATE's activities seek to challenge UK social practice in this respect through challenging individuals, organisations and national authorities in seeking to effect a change in the legal status of hastened death.

FATE's activism is concerned with the timing of death in older age in relation to anticipated risks of life-extension in the face of heightened suffering. Risk of suffering in dying, pragmatism and altruism are shown to be involved in driving FATE's campaigning and other activities. As part of a new social movement, FATE's activities exist at a time in which potential hazards surrounding dying and death have changed radically, and continue to change, from those of preceding centuries. Whereas public opinion polls consistently show high levels of support for the idea of a legalised right to die, right to die societies and their members, their beliefs and their actions are open to challenges from organisations and individuals who actively oppose the principles on which the right to die movement exists. Despite public opinion, medical, nursing and religious bodies oppose pro-right to die legalisation although it has been shown that the views of some members of these bodies are not always in total accord with those of their professional organisations. FATE's activism therefore includes engagement with the ongoing power struggle between UK right to die and pro-life organisations, played out through media-based activities in which FATE members take an active role (Richards, 2011). FATE members, some of whom are concurrent members of other UK right to die societies and own to long-held pro-right to die attitudes and beliefs, have chosen to engage voluntarily in right to die activism that also involves a power struggle against current social constructs of older age, suggested by Featherstone and Hepworth (1998) to be in part a product of the desires of interest groups who claim specialised forms of knowledge that legitimate control over older members of the population. The results of this study show how this distinct group of individualistic older persons are engaged in challenging the UK healthcare and legal establishments over a fundamental imbalance perceived and feared, between the pervading social constructions of older age, dying and death, and older age, dying and death as they are ontologically experienced. Informed by personal experiences of dying and deaths in others, the study has shown how FATE members anticipate threats from a system in which they are obliged to negotiate older age in a medicalised culture in which the reflexive and emancipated self, and retaining it, while highly valued by them, may be unacknowledged or demeaned by others due to socially constructed perceptions of ageing being concomitant with social and psychological impairment (Featherstone and

Hepworth, 1998). They fear losing their ability to retain this accustomed self in the face of threats to body and mind characteristic of the fourth age, and the negative social constructs of ageing by society in general with consequential suffering they believe could follow. They also fear loss of self through objectification and commodification of the ageing body on becoming patients, through medicalised management of dying, through perceptions that suffering may be disregarded by healthcare professionals and through losses of control, autonomy, quality of life and dignity during dying processes which they fear may be extended against their wishes. To some FATE members, institutions such as hospitals and residential homes pose threats to their wellbeing in dying, because to them, these institutions symbolise control over their inmates. FATE members' activism represents desire to avoid being involuntarily placed in positions where they would be subject to unwanted levels of control by others. Aversions expressed toward residential care, unwanted extension of poor quality life under medical control, and through expressed desires to end their lives if deemed necessary illustrate their desire to avoid entry into power struggles when they are dying, with persons and organisations perceived as seeking to impose countervailing values. Therefore it is not unexpected to have found that FATE members wish, and plan, to manage dying and death themselves if possible, and engage with activism through the right to die movement in order to do so.

The study has shown that people from lower socioeconomic groups are markedly absent from FATE membership. Membership studies of US right to die societies, similarly to FATE, record a marked absence of members from lower socioeconomic groups, also showing that ethnicities other than white are also markedly absent (Cossman et al, 2002). Defining social characteristics of members of the public in favour of legalising assisted dying in the UK show variance between opinion poll findings in this respect. A 2009 Ipsos Mori Poll<sup>32</sup> for Dignity in Dying shows higher levels of support for non-prosecution of people who assist a terminally ill person to commit suicide being characteristic of higher social classes but a 2010 Yougov poll<sup>33</sup> found little difference between socioeconomic groupings in favour of assisted suicide being de-criminalised subject to certain conditions. But social exclusion theory suggests lower socio-economic classes experience barriers toward full participation in social and political citizenship (Payne, 2004). I suggest that social exclusion

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<sup>32</sup> <http://www.ipsos-mori.com/Assets/Docs/Polls/poll-public-opinions-on-assisted-suicide-tables.pdf>

<sup>33</sup> [http://www.yougov.co.uk/extranets/ygarchives/content/pdf/Euthanasia\\_28-Jan-2010.pdf](http://www.yougov.co.uk/extranets/ygarchives/content/pdf/Euthanasia_28-Jan-2010.pdf)

commensurate with lower socio-economic status could, despite the presence of positive attitudes toward legalising hastened death, therefore inhibit people from taking part in pro-right to die activism, given the predominantly higher socio-economic profile of pro-right to die activist members of FATE.

### The self: autonomy, choice and agency

The study has shown that FATE members, as older people, value and aspire to exercising personal autonomy and control over dying. The study has shown how threats toward integrity of the self, and to a degree, associated threats toward close others in terms of burden and distress, are important drivers of right to die activism by FATE members. The autonomous self is central to FATE members' desires to exert choice and control over the manner and timing of their deaths which they associate with ideas about bodily and existential suffering.

Embodiment is a necessity for defining social identity (Lupton, 2003) and as Shilling (1993) asserts, Descartes' theories about the duality of self and body have been questioned by other theorists; body and self being widely understood by many social theorists to be interdependent, with embodiment/the lived body and how it is managed being central to self (Nettleton and Watson, 1998). However, as previously noted, some FATE members understand the body as existing independently of self in dementias, reminiscent of Cartesian duality in action. The study has confirmed the value placed by FATE members on autonomy and control. The qualities of individualism and emancipation they demonstrate are characteristic of Giddens' (1991) reflexive, socially constructed self, mediated by life experiences including dying and deaths of others; these values being commensurate with FATE members' social class and professional status. Kellehear's (2007) ideas associating individualism with heightened anxieties about death resonate with fears about future dying and death being an important facet of FATE membership, as confirmed by the data. Desire to retain control and to maintain autonomy of self during dying emerges as one of FATE members' most distinguishing characteristics. This is a similar finding to those of studies of patients (Kelner, 1995; Hudson et al, 2006). But the principle of autonomy cannot be absolute, nor relied upon by dying patients to be honoured by others, as it lacks the capacity to reliably deliver according to its own rules (Foster, 2009). In the case of dying patients who seek pre-emptive hastening of death for example, there may be a duty to prevent suicide or to avoid intentionally bringing about the death of a

patient, which then trumps the requirement on doctors to respect the autonomy of competent patients (GMC, 2008). In medico-legal terms Article 2 of the Human Rights Act, takes precedence over Article 8 that could support, in principle, a person's right to make an autonomous decision to have their death hastened. Advance directives are also likely to fail in ensuring respect for peoples' autonomous decisions as these decisions can be questioned on grounds of whether they were sufficiently informed, whether present circumstances coincide with the directive or whether patients might have changed their minds given current situations (Foster, 2009). As Quill (1998) suggests, desires for anticipated control over the circumstances of future deaths may bear little relation to future desires and needs on entering the dying process. Fear of future disempowerment of self on becoming subject to biomedical control or on entering residential/nursing care is evident where power imbalance can be weighted against the service user (Rose, 2007). It has been shown how FATE members' are aware of, and apprehensive about, how the management of older dying people includes, in many instances, sequestration from their own communities and being hidden from public view in residential or nursing homes ("grey ghettos"), resulting in social exclusion (Gilleard and Higgs, 2000) and concomitant loss of accustomed control over their lives. The possibility of sequestration against their will has been shown in this study to be particularly feared by numbers of FATE members due to perceptions of its adverse effects upon the self. Also, abuse of older people in residential care was raised by one FATE member in this context and both Twigg (2006) and Neuberger (2009) confirm that grounds for concern exist, as elder abuse is widespread. Elder abuse may be physical, psychological, financial or sexual (Draper and Wood, 2004) and loss of agency associated with older age renders people vulnerable to elder abuse.

#### The self: potential loss through cognitive decline

Losing the self through cognitive decline and loss of mental capacity in dementia has been, for some FATE members, perceived to be an unacceptable way of existing in the future for practical, financial, existential and altruistic reasons. Talk about dementias highlights fears about the physical and behavioural consequences of dementia, loss of control, loss of capacity to express or act on a wish to die, and the negative impact of these upon close others. Living with dementia is seen as pointless, having negative consequences for the autonomous self, for close others and for society in general. Contingency planning by FATE members for dying and death is associated with, among other concerns, fears about future loss of mental capacity. To some FATE

members, future dementia and its consequences are seen to be worse than death and similar attitudes toward dementia have been noted in other studies (Teisseyre, Mullet and Sorum, 2005). These attitudes toward dementia reflect perceptions broadly analogous with Cartesian mind/body dualism in relation to dementias, emphasised by peoples' talk about bodily life without mind. Dualism is also reflected in biomedicine's culture and practices that emphasise the body rather than the person (Higgs, 2008). It is unsurprising to have found the extent to which FATE members fear losing control of their lives and selves in light of the potential threats they perceive toward their future wellbeing in ageing and dying. In joining FATE they seek to support its campaign for a legal right to hasten death in order to prevent suffering associated with threats toward retaining self-agency, autonomy and control that are particularly feared for the future.

### The self and the ageing body: stigma and body unboundedness

Contemporary consumer culture is preoccupied with negative constructs of ageing. As a consequence, the aged body attracts negative stereotyping that, according to Twigg (2006), defines older people in a category 'other' than the rest of society. Neuberger (2009) expands further on the ageism theme, observing how older people tend to be depicted by the media as figures of fun and ridicule. In consumer cultures such as the UK, youthful bodily appearance and lifestyle consumerism (Gilleard and Higgs, 2000), age-resistance (Twigg, 2006), "moral control, self discipline, and 'caring about yourself'" (Featherstone, 1991), and "heroic maintenance" of youthful bodily appearance (Higgs and Rees Jones, 2009) are endemic. Thus, the appearance of the ageing body in the eyes of wider society has become culturally stigmatised (Lupton, 2003). Despite this emphasis on youth and beauty however, this study has found disfigurement to be one of the least important bodily concerns for FATE members. Fears of threats to the self have been shown to be more concerned with the body in terms of personal consequences of pervasive social constructs of bodily ageing, lived experiences of bodily ageing in others and themselves, and the consequences of bodily biodegradation and how they might be dealt with in future by healthcare systems. The study demonstrates how heightened fears exist, in particular, about the adverse consequences for themselves and others of body unboundedness. FATE members' talk about leaking bodies illustrates how unboundedness is anticipated to demean the self through loss of dignity, shame and humiliation. Bodily unboundedness involving dependence on others for its management, and loss of mental capacity, have both been shown to be conditions in which hastening death would be considered by FATE members should they transpire at a future time. This study has shown that FATE

members who anticipate a future in which their bodies leak, or who become dependent on others for dealing with body wastes are repelled by the thought of exposing private body functions hitherto managed in privacy to outsiders, and in doing so transgress habitual socially acceptable behaviour (Elias, 1978, Douglas, 1996). Comparison made between independent self-management of body functions and how this might be compromised in the future can be shocking (Charmaz, 2000). Thus body unboundedness is associated by FATE members with negative feelings about loss of dignity, suffering, repugnance, shame, mistrust of others' upholding hygiene standards, feeling dirty. These findings resonate with Elias' (1978) account of how body unboundedness breaches accepted norms of behaviour and Douglas' (1966) work on dirt and pollution, suggesting that negative attitudes held toward poor hygiene and unpleasant smells from body emissions within society in general may also extend to peoples' feeling repulsed by their own bodies if placed in a situation where body unboundedness is exposed to others. Body unboundedness is contemplated by FATE members to become a potential source of intense suffering involving losses of control and dignity and potentially, causing disgust in others. Studies of patients report similar sentiments (Bogner et al, 2002; Bordeianou et al, 2007; Kellehear, 2009b) and Twigg shows how some care workers are disgusted and repelled by dealing with body wastes. To FATE members therefore, clearly dependence in bodily unboundedness is both a major transgression in socially accepted behaviour and a potential source for future suffering.

### Suffering and vulnerability

In current risk societies, everyone is deemed vulnerable to a plethora of risks, material, physical and mental. Persons who fail to act to minimise risks in their life-world are likely to be seen "as lacking self-control and therefore not fulfilling their duties as fully autonomous, responsible citizens (Petersen, 1997). Furedi takes the view that the dominant culture is obsessed with risk and collective vulnerability. Perceptions of human vulnerability, according to Furedi (2004), are increasingly prevalent, informed by a cultural climate that fosters doubts about the capacity of the self to cope with adversity. Furedi ascribes this to the pervasive therapeutic cultural orientation in which people are encouraged to resign themselves to becoming helpless, thus rendering them powerless. In ageing and dying, Furedi claims that vulnerability, and the collectivisation of vulnerability directed toward particular social groups has been created and fostered through medical social control and reinforced by the palliative care ethos.

Suffering experienced in dying has been shown to pose diverse threats toward rendering self, body and mind vulnerable to loss of agency. Ageing, disabilities and illnesses are commonly associated in professional and public minds with vulnerability. But while older people tend to be collectively viewed as vulnerable, Higgs and Rees Jones (2009) anticipate a growing conflict between older people acting as agentic consumer citizens and those services and agencies that would seek to reduce their agentic status to one of vulnerability and helplessness. The ability to retain agency as a preventive strategy against imposed vulnerability is one reason for FATE members being fearful about, for example, the consequences of entering residential care homes. The study shows how certain groups of older people typified by FATE members have entered into a fight against socio-medical controls imposed on older and ill citizens, in particular with reference to the vulnerability and risk culture surrounding ageing, terminal illnesses and dying. This newer area of conflict helps locate FATE as part of a new social movement that exists to help its members pre-empt some of the newer forms of suffering typical of western societies in the 21<sup>st</sup> Century, including the status as vulnerable which is associated with ageing, with becoming a patient and with dying.

Body-related fears (including degenerative brain diseases) informing FATE members' commitment toward having a right to die relate frequently to suffering and vulnerability caused by dementias and loss of body boundedness. Studies of terminally ill patients also identify similar themes (Kellehear, 2009b), but the subjectivity of existential suffering experienced by patients through dementias and loss of body boundedness poses difficulties for healthcare professionals in making objective assessments of the lived severity of existential forms of suffering due to the "lack of terminological and conceptual precision" in defining them (Monforte-Royo, 2011). Subjective existential forms of suffering exemplified by losses of self, dignity, control, independence, body boundedness and becoming a burden on others appear to be collectively feared more frequently than physical suffering (pain) in informing FATE members' attitudes and beliefs (Chapter 4, 1.9). Studies of patients' wish to hasten death suggests that existential suffering rather than pain, plays a key role in their distress (Monforte-Royo et al, 2011), although it is acknowledged by authors of this study that requests for hastened death do not necessarily signal a genuine desire to die. Although pain is feared by some FATE members, existential suffering is shown to be a greater issue for them. Suffering in dying can clearly encourage some individuals to contemplate a hastened death, although without intention to act. In light of this, active steps taken to



hasten death might be seen either as resulting from vulnerability to suffering, or from determination to retain and affirm agency in acting to pre-empt increasing levels of suffering through end life prematurely. In the case of FATE members, intention to bring about death under anticipated circumstances of great suffering might also not necessarily be acted upon, but exists primarily as a contingency plan. This suggests that medico-social labelling of individuals as vulnerable may not always accord with individuals' perceptions of their own vulnerability. This is because FATE members' fear of becoming vulnerable during dying and death is due to imposed forms of suffering they believe could be experienced in the hands of health and social care services. In anticipation of this possibility, they believe that retaining the power to exert intellectual control over their dying would afford them some immunity from vulnerability imposed by outsiders. The results of the study have shown how contemplating possibilities surrounding the nature and intensity of future suffering, and the point at which this might become intolerable gives rise to fears that it may not always be recognised by care professionals. In light of this, recent evidence (Bazalgette et al, 2011) shows that 10% of suicides in England involve people who are dying slowly with chronic and/or terminal illnesses and suggest that this figure is likely to represent a considerable understatement of the actual suicide rate among this category of individuals. However, data on the extent to which these individuals might have been suffering pre-suicide, or the intensity and duration of their suffering, is not available. Membership of FATE is clearly driven by the chances of extended and severe forms of suffering becoming a reality, inducing desire for a death-hastening option to be available in the future. I conclude that risk of a 'bad death' featuring prolonged and intolerable suffering is a fundamental driver among this right to die society's membership.

In general, the range of FATE members' fears relating to a future dying process identified in this study are expressed in terms of strong desire to avoid experiencing individualised versions of suffering believed to be intolerable. They value autonomy and agency, considering them important to retain in the interest of being able to choose not to experience these forms of suffering. They are pragmatic in contemplating how to achieve bodily death (Richards, 2011) as a suffering avoidance mechanism; characterised by a practical acceptance of inevitability of the biodegradable body and eventual death. The impact of bodily degradation upon themselves and others during the dying process is central to the fears and concerns informing peoples' anticipation of future suffering of body and self during dying. Perceptions of the need to avoid

unacceptable levels of suffering are met through the practical steps they take to prepare for this eventuality, should it arise.

### Extended dying and desire for hastening death

As previously noted in Chapter 1, for the purpose of this study 'dying' and 'terminal' have been defined as a process characterised by irreversible bodily disintegration, potentially extending over long periods of time (Brown, 2008; Ashby, 2009; Hester, 2010; Heath, 2010). But, as noted by Kendall et al (2007), the concept of "end of life" incorporating dying and terminal illnesses may be defined by health professionals by much shorter periods of time. However, as a longer dying trajectory can potentially involve extended periods of suffering, typifying FATE members' most feared forms of dying and deaths, I considered defining dying in this manner was appropriate in the context of this study.

Desire to avoid some of the more unpleasant consequences of protracted dying has led a number of UK citizens, including at least one member of the medical profession (Day, 2009), to seek assisted suicide in Switzerland. Death tourism has become an option for dying UK citizens. In the absence of a legal means of hastening death in the UK, advice about how to commit suicide toward the end of life is available through various publications and other avenues within the global right to die movement (Magnusson, 2002) and the World Wide Web. Alongside its core campaigning activities, FATE offers its members practical advice and help toward accessing assisted dying through the Swiss organisation, Dignitas. Reasons given for membership of FATE reveal considerable interest in accessing this particular service. This study has shown that interest in, and demand for this service is likely to be closely associated with intensity and duration of suffering, experienced and/or anticipated, during extended ageing and dying. It also shows that FATE members seek to challenge the accepted social construction of ageing, and vulnerability (Furedi, 1997) through refusal to conform to or collude with stereotypical assumptions about themselves as older persons, and are prepared to die in order to maintain self-integrity and agency, or to pre-empt losses which they see to be in their best interests to avoid. Some FATE members stated they would contemplate hastening death by suicide in situations in which loss of self would be a consequence of bodily and cognitive disintegration and since the study commenced, two participants have ended their lives at Dignitas in the absence of concurrent terminal illness diagnoses.

Bazalgette et al (2011) observe there may not always be a clear distinction between chronic and terminal illnesses, there are difficulties associated with defining terminal illness and difficulties in making an accurate prognosis for patients who are terminally ill. But it is the intensity and duration of individuals' suffering in dying from chronic and terminal illnesses that is fundamental to FATE members' decisions to join the right to die movement. As Bazalgette et al (2011) suggest, much academic research tends not to focus on the relationship between suicide and chronic or terminal illness in general. Presently, data on intensity and duration of suffering pre-deaths by suicide are neither measured, systematically collected or audited on a national basis, although much study data on patient suffering in terminal illnesses is available (Kellehear, 2009b). However, should attempts to audit duration and intensity of pre-death suffering in all dying persons ever be contemplated, it may be impossible to overcome the many difficulties associated with this task. Even so, Bazalgette et al (2006) do make recommendations for a more rigorous approach to suicide audit, locally and nationally, that would serve to uncover more facts about suicide in the context of chronic and terminal illnesses. Because heightened levels of suffering in lengthy dying forms a basis on which hastened death is conditionally desired and prepared for by members of FATE, my study suggests that audits should include information about intensity and duration of physical and existential suffering in dying should they ever be considered in determining peoples' reasons for, desire for, or completion of, assisted death or suicide in the presence of chronic or terminal illnesses.

### Medicalisation of dying

The importance of the part played by biomedical technology and contemporary medical practices in peoples' decisions to join FATE is illustrated by the many and diverse fears expressed by FATE members, frequently informed by their own experiences, about how their future dying might be managed within the UK healthcare system. Given that personal experiences of dying and death have been shown to be closely associated with pro-right to die beliefs, in the absence of data about pre-suicide suffering in the study by Bazalgette et al (2006) previously cited, questions arise about a mismatch between dying and death rhetoric from a health service provider perspective, and members of the public's lived experiences of dying and death in today's medicalised culture. Alongside advances in standards of living, health and wellbeing, medical technological advances facilitated through societal affluence have created new and

prolonged ways of dying in the presence of long-term chronic and terminal illnesses. This is evidenced by the growing numbers of older people in affluent western societies for whom living with irreversible deteriorating chronic illnesses towards the end of life can now be medically extended over many months or years (Munday et al, 2007: and Chapter 2 ,section 4.1). It is this form of “slow dying” and the potential suffering it can entail, that the study shows to be particularly feared by many of those who join FATE.

Some FATE members believed that medical advances were driven more by a desire to develop life saving technologies to stave off death rather than to relieve suffering. Whether this is actually the case is of course unknown, but FATE members I studied often believed that there were no guarantees that they could be assured of active treatment being withdrawn at a time of their choosing during the dying process. The uncertainties they expressed in the context of how future dying might play out included “being kept alive” in unpleasant circumstances, adding impetus to their pro-right to die beliefs. These fears echo Lupton’s (2003) accounts of negative illness experiences encountered by persons accustomed to being in control. Lupton also suggests that doctors who become ill “may have the most difficulty of all in accepting the helplessness of the patient’s role because they are so accustomed to approaching the medical encounter from the other side”. Professional backgrounds have clearly been influential among health/social care professional members of FATE in developing the intention to avoid future indignities and suffering as potentially vulnerable older patients. Some older health/social care professional FATE members believed they personally provided a more compassionate service to dying patients in the past than they themselves expected today.

The study reveals that those with health/social care backgrounds cited a greater number of reasons for joining FATE than the non-health/social care professionals. It is unclear why this may be but it is most likely that health/social professional familiarity with ageing and dying patients or clients affords more detailed insights into many and varied negative possibilities for future experience of the dying process, into the more technical aspects of quality of care and into any potential hazards and risks that could arise in the future. Health/social care professionals who took part in the study were clearly apprehensive about how they might die in the future and that the care they receive may not be adequate to prevent suffering.

Fears held about medicalised dying indicate that trust in the healthcare professions to afford FATE members a tolerable death in the future has become eroded, and reliance cannot be placed on healthcare systems and healthcare professionals to afford them any certainty about how future dying might be managed. Patients being unable to fully rely on medical compliance with living wills, or DNR tattoos (BBC news, 2011), exemplify how mutual mistrust between patients and professionals can be fostered. This study has shown how many older FATE members, including those from a health/social care professional background, mistrust and fear the very systems set up to care for them when terminally ill and that perceptions of the negative consequences of engaging with these systems induce determination to avoid them should circumstances dictate avoidance strategy implementation. Subjecting themselves to systems where the existing power imbalance between patient and professionals is seen to pose a direct threat to their sense of agency through rendering them vulnerable to the losses of self they fear most.

Trust in others, in particular in health professionals providing care in dying, helps patients retain self-identity while avoiding anxiety and feelings of powerlessness and personal impotence, as embodied in the aims of the hospice movement. It has been argued that patients may be less inclined to trust their doctors if assisted suicide were to be legalised in the UK (House of Lords, 2005), but this study suggests that FATE members may be less inclined to trust their doctors knowing they are not able to rely on them to hasten death if it should be needed. Mistrust of doctors, nurses and health and social care service provision is shown through stories of what was seen and experienced in the past, although some of the reported experiences that informed these views took place a considerable time ago. These views raise wider questions and concerns about the realities of dying and death in the UK today; the extent to which poorly relieved suffering may be experienced by patients without being adequately addressed within current health and social care systems, and numbers of “bad” deaths nationally, judged on length and intensity of suffering experienced during the dying process. The Healthcare Commission’s report on second-stage complaints (the first stage of the NHS complaints process being provided by local providers) between July 2004 - July 2006 shows 54% were related to end-of-life care (Ellershaw and Wilkinson, 2010). Badham (2009) refers to the bodily realities of dying today being shielded from public discourse and Lawton (2000) suggests a somewhat romanticised picture of dying patients is “all too prevalent in the literature”. A justifiable basis for

FATE members' fears and concerns is open to further question, because their witness accounts of deaths involving "slow and miserable death"; "daily indignities"; "too much pain and suffering"; "bad practice and lack of common humanity" often refer to deaths that occurred a considerable time ago. However, some members of the wider dying population, regardless of age, are currently unable to access specialist palliative end of life care, although efforts are being made nationally to address this situation (Department of Health,2009). The fact that optimum minimisation of suffering and active prevention of suffering reaching intolerable heights is not yet deliverable to all dying individuals clearly helps to foster the contemporary right to die movement's continuing growth. A capacity to achieve this more universally would surely allay many of the fears about future severe suffering that feed the right to die movement's campaign for legalising hastened death.

### The role of caring experiences

I originally hypothesised that individuals who join FATE would be likely to have personal experiences of caring for terminally ill others. This is confirmed both by the relatively high numbers of health/social care professional members of FATE who took part in the study and the numbers of FATE members who recounted experiences of providing care for family members and others. Being older, many had cared for their own parents prior to death. Some recounted stories about peaceful and quick deaths, cited as an ideal for the future. Conversely, accounts of deaths involving prolonged suffering were cited as a reason for joining FATE, as these experiences induced fears about possibilities for their future replication.

FATE members' caring experiences have also been shown to have heightened understanding about the consequences of placing care burdens on others, in the context of desire to avoid placing burden on others when dying. With regard to burden on others, unlike studies of patients in which burden on others has been identified only as a concern (Hudson et al,2006), some participants in this study explain the nature of burdens they could potentially place on family members based on their familiarity with their own family members' lifestyles and commitments.

### Caring experiences: dying humans versus dying animals

A member of the veterinary profession drew on her experiences in caring for dying animals and contrasted these with the experiences of a dying friend. Others also cited experiences of care received by dying animals in this context. These findings emphasise the significance of the role played by autobiographical experiences of dying and death of humans and animals in generating either reassurance, fear or envy of (in the case of pet animals) how they might die in the future, dependent on previous encounters with dying and death. Studies of patients approaching death similarly confirm how witnessing others' suffering can induce desire for hastened death (Verpoort et al, 2004;Hallowell, 2006; Chapple et al,2006). Patients also employ animal analogies in describing their suffering (Elliott and Olver, 2008: Chapter 2, section 4.2.9). References made to differences in end of life management of suffering humans and animals indicate this remains a live ethical debate among members of the public.

### Management of risk in dying

Although it was not initially planned to use grounded theory methodology, conceptualising FATE as a risk management organisation with its members campaigning and acting to pre-empt the risk of heightened suffering in dying emerged from the data, with literature on risk being read in depth only after the data had been analysed, and this is reminiscent of a grounded theoretical approach (McGhee et al, 2007). Risks associated with contemporary dying have changed from those of past centuries due to advances in medical technologies that have contributed toward rising populations and increasing longevity accompanied by dramatic increases in untreatable chronic illnesses (Beck, 1992, pp.204) that can accompany extended dying, especially in older age. Desire to insure against risks associated with dying and death through contingency planning to ensure that 'good or better death' options can be made available was an overarching aim pursued by study participants. Since the inception of the UK right to die movement in the 1930s, insurance against a bad death has always been a driver behind attempts to legalise hastened death, but since that time the way people die has changed radically with the advent of antibiotics, increasingly sophisticated methods of pain control and continually heightening technical ability to extend lives. The current pervasive UK risk culture including health and safety legislation and the insurance industry clearly has some bearing on FATE members' desires to manage risk surrounding their own future deaths. Between 2007/08 FATE received over 300 calls seeking information and advice (Bazalgette et al, 2011). This suggests that unknown numbers of individuals may be concerned about current or future suffering in dying. Avoidance of prolonged periods of unacceptable

levels of suffering through retaining self-integrity and cognition, dignity and control over the dying process that includes an option for hastening death if required defines the 'good death' for FATE members. Threats perceived toward eventually dying a 'good death' include fear of indiscriminately 'being kept alive'; fear that intensity of suffering might not be recognised and/or acted upon, and ideas about suffering an unacceptable quality of life while dying slowly, often informed by past experiences of dying and death. The most commonly reported end of life concerns reported by patients who obtained an assisted death under the Oregon Death with Dignity Act (Ganzini, 2004) are loss of autonomy, diminished quality of life, loss of dignity and loss of control of body functions. These are similar in nature to future risks perceived by interviewees. In reality, a basis for their fears has been shown to exist as cases still occur in which people die "in distress with uncontrolled symptoms" (Ellershaw and Ward, 2003) or are "inappropriately resuscitated or have futile interventions" (Lakhani, 2011).

Kendall et al (2007) suggest that research evidence that would support a "good death" definition in developing evidence-based end of life care, especially from patient and carer perspectives, is lacking due to difficulties in conducting end of life research. But this study has shown that FATE members, some of whom are patients, or have current or past experience as carers, have cited a range of variables that to them constitute a 'good death', although these vary in frequency and emphasis between study participants. Aspects of dying most feared (Chapter 4, section 1.9, Table 12) suggest a good death would be one in which variables such as retaining control and agency during the dying process, retaining dignity and mental capacity, avoidance of burden and distress to others and avoidance of symptoms such as severe pain that would cause intolerable suffering would all contribute toward a good death. Quality of life, control of body boundedness, a quick rather than a slow death, avoidance of residential care and having an "escape" option if dying became too unpleasant were all raised in this context. For some FATE members, in the absence of a legal option in the UK, omitting the final stages of terminal illnesses altogether through an assisted suicide at Dignitas or through other covert suicide methods could provide greater assurance that a good death would result and a preferred option rather than submitting themselves to dying under the care of healthcare services, although they may worry that a good death might be difficult to achieve by covert methods. For others, a good death is aimed at through treatment refusal via advance directives, although whether these would be ultimately honoured is uncertain and a matter of concern for some FATE members. The purpose and efficacy of advance directives have also been challenged by Malpas



(2011) on the grounds of their being open to undue influence by others, or based on insufficient information, or falsified by others. Malpas cites Perkins (2007) who argues that advance directives are conceptually flawed and promise more patient control than can actually be delivered. Nevertheless, preparing for dying and death in these ways afford FATE members some security in the hope that they may not have to suffer beyond their endurance when dying under the auspices of health and/or social care services.

Seymour (2012) states that supporters of assisted dying wish to exercise their autonomy in choosing timing of death “regardless of the quality and quantity of palliative care that may be available”. This study shows, however, that FATE members also believe that palliative care cannot always prevent or ameliorate the particular forms of suffering they fear most.

Although the probability of bad or good deaths is difficult to predict with any accuracy, the study has shown that FATE members do believe that sufficient risk exists to warrant the actions they are taking to pre-empt distressing deaths. They are aware of the risk that terminal illnesses and/or slow dying in older age can render them vulnerable to losses of self, autonomy, choice and control. The contemporary climate of risk aversion is likely to foster desire to minimise perceived risks associated with future dying and death; right to die society membership arguably being an example of risk minimisation because desire to avoid future suffering informs peoples’ need to retain control over the dying process and the time and manner of death. In situations where concerns about prospective suffering exist, individuals are said to derive comfort from having the means to end their lives if needed (Stern and DiFonzo, 2009; Chapple et al, 2006). Based on these premises, joining FATE is arguably a manifestation of risk management of future dying.

Actions taken to avert risk of severe suffering in dying, such as joining FATE, resonate with Giddens’s (1991) views about ontological security, that to be ontologically secure is “to possess answers to fundamental existential questions which all human life in some way addresses”. Ontological security in preparation for dying and death can also be associated with Beck’s (2009) concept of normativity of diversity within the wider community and communities concerned with risk such as FATE. Joining a right to die

society assists people by providing answers to questions about how to avoid risks of heightened suffering in dying, how to avoid placing burden on loved ones, how to control dying so as to retain the accustomed self, how to preserve dignity and how to live with reduced anxiety about future dying and death. While FATE members demonstrate a pragmatic acceptance of dying and death as inevitable, their need is to achieve optimum ontological security with regard to the process of dying in order to minimise anxiety as they live their lives. I contend that this is hardly surprising in light of the present-day risk-averse culture in UK society.

The role played by, and relative importance given to existential issues during the process of dying are viewed by some members of FATE to be a greater source of suffering and distress than physical pain. This raises questions about whether this emphasis placed on existential rather than physical suffering may be symptomatic of a contemporary trend in which desire for a good or good enough death is becoming a more general aspiration for the end of life. Should this be the case, and based on the findings of this study, the contemporary extended and highly medicalised conduct of dying and death now common in western societies is possibly implicated; other factors could be expectations of greater longevity, potentially accompanied by multiple pathologies and disabilities, poor quality of life, loss of agency, sequestration in care homes and loss of mental capacity. In light of these, if indeed the good death is becoming an increasingly common aspiration, and if ontological security in the face of such threats would be assured by introduction of right to die legislation, might not the absence of ontological security in anticipation of dying and death explain why a majority of public opinion is consistently in favour of right to die legislation? In these circumstances, whether assisted suicide should be made available, given the medico-cultural factors that influence imposition of either bad, good or good enough deaths across the UK, remains open to debate. It is the relative incidence of bad deaths and whether these could be significantly prevented that is key to determining a need for legislation.

Anticipated intense suffering in dying is shown to be an important informant of decisions made to join FATE. How great the risk of a death characterised by prolonged severe suffering might be in the UK today is not predictable although possibilities clearly exist. But reduction of this risk is likely to increase over time through continuing advances in the care of dying people, especially through the work of hospices and the

palliative care movement. In recent years the Liverpool Care Pathway (Department of Health, 2009) has been introduced into clinical practice with the aim of delivering quality dying to people at the end of life, and is recommended for use by the UK Department of Health. However this does not appear to be the answer in all cases (Edmonds et al, 2009), and it has not been universally adopted across services providing end of life care. The Department of Health is also working toward improving systems and practice for end of life care for people in residential and nursing homes<sup>34</sup>. However, currently access to specialist end of life care services remains variable across the UK with dying under the care of palliative care services not universally assured in the UK. Problems for older people in accessing palliative care services, for example, may be due to factors subjecting them to inequitable treatment including ageism and “debatable...cost-effectiveness ceilings set by economists’ studies” that can deny some medical treatments to older people (Coote, 2009). Other problems associated with access to palliative care services relate to socio-economic grouping (higher>lower) and availability (Lewis et al, 2011). FATE members are aware of the uncertainties created by this situation. It also remains uncertain whether palliative care services can ever fully alleviate suffering experienced through losses such as control over body functions, or of self through dementia. Questions remaining to be answered include whether right to die societies would continue to exist if most dying trajectories involved no more than tolerable levels of suffering and were followed by good deaths, whatever that means to diverse members of UK society, and could be guaranteed for all. But this utopian scenario must be impossible to deliver universally on the grounds of cost, and on the inherent unreliability and variability of healthcare service delivery and human error among those who populate them, both as professionals and as patients. Also, the subjective and existential elements of human suffering render its intolerability difficult to measure along with, at the same time the inability of doctors to fully trust patients’ self-assessments of their own levels of suffering, Conversely in such circumstances, suffering patients may feel they equally cannot trust their doctors to relieve suffering adequately if they feel that their accounts of suffering are not liable to be full believed or acted upon.

### Altruism

I originally hypothesised that altruism is implicated in decisions made to join a right to die society. Kantian ethics of beneficence toward others (Scott and Seglow, 2007) and avoidance of harm to others accords with the study’s findings having shown that FATE

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<sup>34</sup> [http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/DH\\_115469](http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/DH_115469)

members, in their desire for a hastened death option to be available, do so, I contend, in part because their concerns for others are more than empathic alone but are also altruistic when associated with desire to address these concerns through intent to act upon them by hastening death. Altruistic qualities displayed by FATE members appear to be reciprocal in that they are concerned with two main desires: avoiding harm to others (distress and burden) and to themselves (suffering). Only one FATE member expressed concern about the negative impact of suicide on close family members in terms of their finding the body, but others did not appear to consider the distress that their suicide could cause to close others, although some indicated their family members supported their pre-emptive decisions to hasten death. The Oxford dictionary defines altruism as 'selfless concern for the well-being of others' but this definition does not fully explain FATE members' altruistic concern for others, and consequent desire, or intention to hasten death as an altruistic act. Because their expressed concerns are simultaneously for themselves, their concern for others is a form of reciprocal altruism in which both parties are seen to benefit through a hastened death.

Studies of terminally ill and older patients also identify concerns about burden to others in the context of requests for earlier death (Hudson et al, 2006). FATE members describe how their family members could potentially be burdened by them in the context of their knowledge of family members' lives. Desire not to burden close family members rests on personal knowledge about those persons' lives, responsibilities and commitments. Altruistic desires to spare family members from added burden rest on this knowledge; avoidance of burden being seen a basis for pragmatic action. With consideration of others' wellbeing a feature of pro-social behaviour inculcated from infancy (Warneken and Tomasello, 2009), desire to avoid disadvantaging others at the end of life could be argued to be both altruistic and a socially responsible duty to avoid the risks they associate with dying (Peterson, 1997). However, contemporary medicalised culture surrounding dying and death seldom views suicide in terminal illness as a Durkheimian heroic or altruistic act, but rather as an aberrant act "while the balance of mind is disturbed". FATE members' attitudes toward hastening death suggest that altruistic motives underlying desire for hastened death could be present in the absence of mental distress, rather as a practical solution to preventing harm to close others.

Altruism is also implicated in FATE members' talk about socioeconomic factors relating to their membership of FATE. Financial advantages and disadvantages to themselves and others are contemplated in the context of desire to retain resources for their families and not to waste resources, both their own and those of the NHS through being kept alive in circumstances where they would prefer to be dead. Monroe's (1996) cost-benefits based model of altruism is applicable here; e.g. the benefit conferred through death by someone who considers themselves to be better off dead under given circumstances, in reducing physical, psychological or material cost of burden to family members, or in monetary terms, improving family members' financial circumstances. Pragmatism and altruism are shown in discussions about financial matters, including costs both financial and human, associated with maintaining lives that may no longer be wanted in future. Despite current concerns about the costs of future care for a burgeoning older population, as Epstein (2007) observes, UK law and medicine are silent on linking economic factors with end of life ethics, "an unspoken argument". But as Epstein states, death has important economic implications for society as a whole, and, as some FATE members have articulated, for dying individuals and their family members. FATE members' desire for autonomy and choice include desire to control how their financial assets may be used. This is commensurate with the agentic self as customarily responsible, controlling and prudent in personal financial management. Their concerns about use of national economic resources raise a different ethical debate about the economics of living versus dying in terms of their own and their family's best economic interests versus economic best interests of individuals and/or organisations providing care plus economic best interests of the State while people remain alive. With living necessarily associated with resource consumption, resource consumption escalates with older age. It can be argued that beneficiaries of extending lives include providers of goods and services that facilitate life extension, potentially to the detriment of dying persons and their family members.

In conclusion, following their study of Hemlock Society members, Kamakahi et al (2001) concluded that social scientists " must continue to examine the beliefs concerning a patients' right to die and associated beliefs on euthanasia and physician assisted suicide". I have aimed to build on the work of this and of other previous studies of right to die society members. My thesis uses new social movement theory, theories of self and risk theory to create an understanding of how peoples' pro-right to die beliefs and motives for joining FATE are grounded in contemporary UK society. I have identified a range of motives for becoming a member of FATE. Desires to avoid

intolerable suffering during the dying process are shown to arise through loss of trust in the healthcare professions, inducing fears about losses of self, dignity, control, and independence. The experience of witnessing dying and deaths of others is also shown to be important in this respect. Desires expressed to avoid perceived self-diminishing losses are shown to be in part a product of the professional status of FATE members. Particular fears about bodily and mental disintegration, desire to conserve financial and caring resources and altruistic desire to spare others from added burdens play a part in this group's *raison d'être* and campaigning activities. FATE's unique function among the three main UK right to die societies is shown to be its preparedness to offer practical solutions to members who seek to hasten their death. Although FATE and Dignity in Dying, the largest other UK right to die society, both campaign for legalisation of a hastened death option in the UK, differences in what they offer to their members in terms of the practical help to access Dignitas that is exclusive to FATE raises questions as to what extent the findings of this study might also be applicable to persons who join other UK right to die societies and this is as yet untested. Some FATE members do retain membership of more than one right to die society but reasons given for retaining concurrent membership were not adequately clarified in this study, although a number of questionnaire respondents provided identical reasons for joining FATE and other right to die societies prior to FATE's inception.

But studies of other right-to-die societies may reveal a different picture. This study confirms that health/social care professionals do join the right to die movement, suggests that exposure to dying patients can be an important factor in acquisition of pro-right to die attitudes, and provides some insight into professionals' motives for doing so. The study demonstrates how joining a right to die society, in this instance FATE, symbolises reaction against ageism and current medico-social constructs of, and practices in dying. The UK's ubiquitous risk management culture is suggested to bear some responsibility for reinforcing desires for self-managed hastened deaths in the future.

Although peoples' reasons for joining FATE are diverse and individually variable, this study offers an account of the varied reasons for FATE members having acquired pro-right to die moral/philosophical beliefs and reveals commonalities between participants in autobiographical experiences of dying and death, fears for self and body in contemplating future dying, and desire to managed perceived risks associated with

dying through pragmatic action. A theoretical basis is offered showing how specific aspects of social practice encourage acquisition of pro-right to die beliefs amongst a particular cohort of older individuals in contemporary UK society. Richards's (2011) ethnographic study was focused on exploring the activities and convictions of FATE members, through observation and participation in the group's activities, whereas my study, which also focused on beliefs and attitudes, sought primarily to discover more about underlying reasons for peoples' beliefs and attitudes that had induced them to join FATE. Although different methods were used to collect data, similarities are shown in the main findings of both studies. Richards also identifies FATE as part of a new social movement, driven by the social stigma of older age having shaped its members anticipation of death. The finding that achieving a "good death" is an aim for FATE members is common to both studies. Good death is described by Richards as "foreseen and controlled at a point where biological and social death converge", whereas my study explores concepts of the good death, noting how these concepts vary between individuals. The desire to avoid the indignities of institutional care, and the fact that many members come from professional-managerial backgrounds, is also a finding common to both studies. Although Richards refers to peoples' motives for joining FATE, differences between the two studies lie in my exclusive focus on the origins of FATE members' beliefs and my investigation into what FATE members particularly fear about dying in the UK today which provides more data about motives for joining the right to die movement than has previously emerged from the few past right to die society studies. My findings also show how personal experiences of dying and death play an important role in generating FATE members' fears about their future dying. In contrast, Richard's main focus is on the association between age and FATE's organisational arrangements and its members' activities in promoting their cause. In addition, analysis of organisational differences between FATE and Dignity in Dying forms an important part of her study. She shows how FATE differs substantially from Dignity in Dying in terms of its non-professionalisation and its focus on medically hastened death on the grounds of suffering in extended dying that may not necessarily include a terminal illness. She shows how Dignity in Dying focuses more exclusively on working for a legalised "choice" of hastened death in terminal illness alone being made available. FATE's pragmatic approach to information and advice about methods for hastening death and its organisational lead by older people are also shown to differ substantially from the information provided, and the age of organisational leaders of Dignity in Dying.

Because personal experience of terminal disease, death and dying is influential in decisions made to join FATE, a perceived need to manage future risks of unacceptable levels of suffering in dying is shown in this study to be a fundamental trait in persons taking part in this study. In view of the UK's endemic risk culture and the individualistic disposition of FATE members, this is not surprising. FATE members' fears about suffering in dying are often justified by them through references made to patchy provision of specialist end of life care, restricted access to it and their own experiences with dying patients and family members. Within the UK healthcare system, opportunities for experiencing extreme suffering during the process of dying still exist (Lawton, 2000), and studies of patients' lived experiences of dying, especially of prolonged dying, reveal that fears held about the dying process are similar to those held by FATE members. Although conducting research with dying persons poses a number of ethical problems and can be hindered by gatekeepers, many dying people would be willing to participate in research as it gives them opportunities to contribute toward service development and to the benefit of other patients (Hales et al, 2008). It is dying persons themselves who can directly account for their lived experiences of dying and it is dying persons themselves who can define the intensity and meaning of their suffering.

Currently, practical functions common to all three main UK right to die societies (Dignity in Dying, FATE and EXIT) include active campaigning for a legally sanctioned option for assisted dying and provision of living will (advance directive) forms. Dignity in Dying does not provide practical advice about hastening death, and is unique in that it has become professionalised, and unlike FATE, is run by younger people (Richards, 2011). FATE is also unique due to the older age of its members, its focus on practical ways to achieve pre-emptive suicide in the absence of right to die legislation with associated high levels of interest among its members in gaining access to Dignitas as the study has shown. FATE is also alone in providing procedural advice and information necessary for gaining access to Dignitas' services; its main activity according to Richards (2011). In this respect FATE differs from both Dignity in Dying and Exit. While members of all three societies are concerned about the risk of experiencing dying accompanied by suffering that potentially could be protracted, FATE is alone in supporting its members' active preparedness to take practical steps to plan and implement exit strategies if needed.



In light of the numbers of health /social care professional members of FATE, further exploration of their views would be of particular interest, especially in view of the recent formation of a new UK health professional right to die group. And in view of the increasing number of jurisdictions around the world who are adopting legislation permissive to assisted dying, research involving other UK right to die societies would further enhance understanding of the beliefs and experiences of people supporting this social movement, and the social factors influencing the movement. Seymour (2012) notes the long-term marginalisation of end of life care for older people, suggesting that 20<sup>th</sup> Century understanding of need for palliative care has been limited, requiring far greater integration between end of life care and chronic disease management in the 21<sup>st</sup> Century, especially in older age groups.

In late modernity in which contingency planning and risk management through insurance against risk is endemic in western societies, risks associated with accidental death and future costs of funerals are insurable but no form of insurance exists against the risks attendant on contemporary medicalised regimes of dying under the care of UK health and social care providers. Furthermore, the probability of dying badly is not calculable due to lack of data about the incidence of deaths preceded by severe and prolonged suffering occurring within the healthcare system. Conceptualising and measuring health outcomes in terms of the quality of individual dying and death, with systemic evaluation of outcomes derived from patient (pre-death), family and professional perspectives could help identify the incidence of bad dying nationally, and provide a learning tool for service improvement.

If right to die legalisation existed, providing ontological security against bad deaths for those who seek assurance of an escape route from intolerable suffering in dying, it remains uncertain whether subjecting services to a formalised system of ongoing evaluation and learning cycles would completely obviate all desire for hastened death. Although FATE members' desire for hastened death is premised upon both physical and non physical suffering during the dying process, it is the risk of, and intensity of suffering in the round that drives them to seek a legalised option. Also, the individualism and autonomous nature characteristic of FATE members renders them more likely to seek solutions to pre-empt future risks in terms of length and severity of suffering they might realistically endure preceding death. With the pervasive cultural emphasis on risk and vulnerability, the fact that so many health professionals have

joined FATE due to their familiarity with risks causing them to fear how their dying will be managed by professionals in the future suggests lack of confidence that care in terminal illnesses and of older persons approaching the end of life care will always minimise severe suffering. Komaromy (2009), for example, found “good death” rhetoric does not always reflect the reality of how older persons die in residential care homes. FATE members see themselves as vulnerable to risks when dying in the hands of care services. Mismatch between peoples’ experiences of suffering during extended dying and end of life care rhetoric from authorities on the aims and efficacy of end of life care draws attention to opportunities for improving end of life care services. Empirical information about people’s death experiences could help to encourage development of more evenly distributed specialist end of life care services, aiming to reduce current levels of adverse risk in dying and death in terminal illnesses and also for the rising numbers of older people in the UK. The Department of Health’s End-of-Life Care Strategy (2008) is currently being implemented to address discrepancies in current end of life care in the UK through encouraging a whole systems approach to death and dying (Seymour, 2012). The incidence of prolonged suffering in dying and bad deaths would benefit from more open acknowledgement and systematic requirements to audit, evaluate and learn from deaths in order to deliver, where indicated, humane care practices with the aim of minimising the incidence of bad dying and deaths in the UK from professional, patient and family members’ perspectives.

In relation to the issue of trust between doctors and their patients, health and social care service rhetoric could benefit from more open acknowledgment of the realities of how people die under current care systems, especially with regard to slow dying during the fourth age with its multiple opportunities for suffering. The GMC (2008) states, “Patients must be able to trust their doctors with their lives and health”. What FATE members are indicating is that they cannot fully trust their doctors and healthcare systems with their dying and deaths, based on personal experiences of others’ suffering during dying and death. In light of this, implications for practice suggest the public might benefit generally from becoming more openly and clearly informed about how advance decisions should be prepared in order to optimise the obligatory nature of directives to be followed by care staff to ensure as far as possible that unwanted lives are not extended against peoples’ expressed wishes. At the same time, a system to ensure health and social care services can access peoples’ advance decision statements at the point of need may help toward addressing the issue of mutual lack of

trust between FATE members and members of the medical profession, through knowing there was greater certainty that advance decisions would be respected.

The UK Department of Health's second Annual Report on the End-of-Life Care Strategy (2010) reports ongoing progress with initiatives aiming to improve the experiences of dying people in all care settings, including an audit and research programme. Despite minimising patient suffering being implicit in implementing this Strategy, suffering is only mentioned once in the report in a quote from a patients' partner and it is the prospect of suffering in dying that is the overriding issue driving people to join FATE. However, research into the quality of end of life care is now taking place under the auspices of the Strategy. More needs to be done to improve recognition of and effective action in cases where dying persons' suffering is severe. Prolongation of very poor quality of life accompanied by severe suffering in dying persons of all ages, and how fourth agers might better be managed across the board to help minimise suffering during the course of their sometimes slow dying needs consideration. Medicine and nursing might learn more from the experiences of dying persons of all ages and their family members through open discussion, and where indicated, after-death review of practices that in some cases have the capacity to impose severe suffering and distress on dying persons. Also, apart from palliative care services, public attitudes toward dying can, in some instances, lead people to call for successive heroic technological interventions to extend lives even further rather than accepting death as a natural end at the right time for the dying person. Promoting a cultural shift in attitudes toward more open awareness of the inevitability of death and the need to prepare dying persons and their close family members for its ultimate arrival is a further aim of the Department of Health's End-of-Life Care Strategy.

The findings of this study also serve to emphasise the importance of monitoring the standards of end of life care for dying residents of care homes. Given that specialist palliative care services are unlikely to ever be funded fully enough to make them available to all when dying, advance directives should perhaps become obligatory for all persons entering hospitals or care homes and greater open dialogue on planning for dying and death and dying encouraged more systematically and openly. Ethical principles of beneficence and non-maleficence are important principles to be invoked as part of service development for end of life care. The ethical principle of non-maleficence (do no harm) is generally applied to preserving life. But as Foster (2009)

notes, “one man’s harm might be another man’s wish” and for dying persons, being kept alive might either not be considered harmful by them, or might actively harm individuals and close family members. Similarly the obligation of beneficence, to do good overall, may be experienced differently according to personal identity and role. The obverse is that some people could be willing to suffer greatly in the hope that their lives could be extended, for whatever reasons and whatever the cost to themselves and to health services, whereas others such as FATE members are not. A greater cultural emphasis on openness about dying and death is supported by the Department of Health through both the Mental Capacity Act (2005) and the End-of-Life Care Strategy, but more could be done through all adult patients of primary care and inpatient services being required to complete advance directive to be held in their notes and updated at intervals, so encouraging open awareness, discussion and advance planning to a wider extent than exists today. On the basis of the study’s findings, determining the most humane ways to assist and care for people coming to the end of their lives is of the utmost importance. But FATE member’s recounted experiences of dying and death suggest that technologically driven medical imperatives to save life might, in some instances, be afforded greater priority than ethical considerations of avoiding harm in extending lives of very poor quality.

This study also has implications for the right to die social movement, in terms of their health and social care professional membership. As members of the public, health and social care professionals of all ages provide a valuable resource for research based on their professional knowledge as well as their personal values and experiences. More can be learned from them in order to encourage heightened awareness among health and social care practitioners about current practices likely to have adverse effects on the care and experiences of dying persons. The movement could also, for example, engage with organisations such as the Patients’ Association and Age England to add weight to their focus on shortcomings in end of life and older age care with the aim of promoting learning within services that would improve the dying experiences of those who suffer most within present care systems. The overall aim would be to achieve good enough dying and death for a majority, although this might never be good enough for everyone. FATE’s willingness to take part in this research has been valuable in enabling a greater understanding of the right to die movement in terms of how societal culture and practices promote pro-right to die activism among a discrete section of the population, and how the dying process can be experienced by dying patients and their families in ways that incentivise people to join FATE.

Finally, despite FATE members' efforts to pre-empt intolerable suffering in dying through seeking the legal option of hastening death, there is no certainty attached to how people will die in the future. As the Department of Health's End of Life Care Strategy states:

*“Some people with long term conditions remain in reasonably good health until shortly before their death, with a steep decline in the last few weeks or months of life. Others will experience a more gradual decline, interspersed with episodes of acute ill health from which they may, or may not, recover. A third group are very frail for months or years before death, with a steady progressive decline”.* (DOH 2009 End of Life care strategy)

It is clearly the prospect of terminal illnesses, protracted dying and becoming members of this third group (fourth age) which gives rise to most fears and concerns expressed by FATE members.

## Chapter 8: References

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# Appendix 1: Questionnaire for Members of Friends at the End (FATE)

My name is Marion Judd and I am a research student at the School of Sociology, Brunel University. This questionnaire is part of a research project for a doctoral dissertation. The purpose of the research is to gain insight into the complex reasons why people choose to join right to die societies.

Anything you tell me in answering this questionnaire will be treated with complete confidentiality. Your privacy and anonymity will be fully protected at all times. All information given by you will be kept securely. No one who responds will be identifiable at any time, either in the final dissertation or in any future publications.

Please mark the squares to indicate the answers of your choice.

Are you:                      Male                       Female

Year of birth:

What is (or was) your occupation? \_\_\_\_\_

1. In what year did you join FATE?

2. Are you, or were you previously, a member of VESS (now EXIT)?                      Yes  No

a) If yes, in what year did you join EXIT?

b) If you are no longer a member of EXIT, why did you leave?

c) Are you, or were you previously, a member of Dignity in Dying (formerly the Voluntary Euthanasia Society)?                      Yes  No

d) If yes, in what year did you join Dignity in Dying/VES?

e) If you are no longer a member of Dignity in Dying/VES, why did you leave?

3. Why did you join FATE?

4 (a) If you are also a member of Dignity in Dying, why did you join Dignity in Dying?

4(b) If you are also a member of EXIT, why did you join EXIT?

5. Have you ever been closely involved in caring for a person who was terminally ill? Yes  No

If yes, in what capacity? Please describe (*if necessary, please continue on a separate page*):

6. Have you ever been closely involved in caring for a person who was close to death? Yes  No

If yes, in what capacity? Please describe (*if necessary, please continue on a separate page*):

If yes to 5 & 6, did these experiences influence your decision to join FATE and/or Dignity in Dying/VES in any way? Yes  No

Please describe (*if necessary, please continue on a separate page*):

7. Are you religious?:  
Strongly religious   
Moderately religious   
A little religious   
No religious beliefs

8. If yes, which faith do you belong to? \_\_\_\_\_

9. If you are religious, do you see any conflict between your religious \_\_\_\_\_

beliefs and your belief in the legal right to die?

Yes  No

10. Do you have any particular concerns about your own eventual death? If so, please tick to indicate how concerned you are about the following:

	Not at all concerned	A little concerned	Somewhat concerned	Very concerned	Extremely concerned
Severe pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disfigurement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being dependent on others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being a burden to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Is there anything else that particularly concerns you about your own death? If so, please describe (*if necessary, please continue on a separate page*):

**Thank you very much for completing this questionnaire. Please return it in the stamped addressed envelope provided.**

Finally - I would like to have an opportunity to meet with some of the people who reply to this questionnaire to find out more about why they chose to join FATE.

If you would be willing to meet with me to talk about the answers in your response in more detail, please provide your contact details below. I may then contact you to discuss this further with you.

I am willing to meet with you to discuss my reasons for joining FATE

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Phone number: \_\_\_\_\_

e-mail address: \_\_\_\_\_

# Appendix 2: Information sheet and consent form

## INFORMATION SHEET FOR MEMBERS OF FATE

### TITLE OF PROJECT: Why do people join right to die societies?

This study has been approved by the School of Social Sciences Research Ethic Committee at Brunel University.

## INFORMATION SHEET - INTERVIEWS

Thank you for volunteering to participate in the second stage of this research project. Before we start, it is important that you read the following information carefully. Please ask me if there is anything that you are unsure about or if you would like more information.

The purpose of this phase of the research is to gain further insight into the complex reasons why people choose to join UK right to die societies. It is anticipated that one of the outcomes of the research will be to gain more knowledge about the reasons why right-to-die movements arise in society, what common themes can be drawn from the reasons why people join right-to-die societies and how these relate to social conditions in contemporary UK society. The results will form part of a doctoral dissertation. It is also intended to publish one or more papers based on the research findings.

This stage of the research involves taking part in an interview in which you will be asked more about the responses you made in your previously returned questionnaire. You are free to withdraw at any time from the interview if you so wish.

Interviews will be tape recorded and the contents transcribed and analysed. Recordings of interviews will be deleted once transcribed. All personal information will be kept securely in accordance with the Data Protection Act 1998. No personal information will be seen by anyone other than the researcher, and any personal information held will be deleted on completion of the project.

No one taking part in an interview will be identifiable at any time, either in the final dissertation or in any future publications.

## INFORMED CONSENT FORM FOR MEMBERS OF FATE

The School of Social Sciences at Brunel University requires that all persons who participate in research studies give their written consent to do so. Please read the following and sign it if you agree with what it says.

I freely and voluntarily consent to be a participant in the research project entitled "Why do people join right to die societies?" being conducted at Brunel University, by Marion Judd with Professor Clive Seale as supervisor or principal investigator.

I have been told that my responses will be kept strictly confidential. I also understand that if at any time during the interview I feel unable or unwilling to continue, I am free to withdraw from this study at any time, without consequence.

I understand that my name will not be linked in any way with the research materials, as the researcher is interested only in the sum of the total information gained from interviewees, not any particular individual's account of their experiences, beliefs or opinions.

I understand that my interview will be tape recorded and I am aware of, and consent to, the use of the recording for the purpose of this research.

I understand that all personal information will be treated with complete confidentiality and my privacy and anonymity will be fully protected at all times and handled in accordance with the provisions of the Data protection Act 1998. I also understand that my personal information will be deleted on completion of the study.

I understand that the results of this research will form part of a doctoral dissertation and may also be published in peer reviewed journals. I also understand that a report will be given to FATE on completion of the study.

### Participant's statement

I \_\_\_\_\_

Have read and understood the information above and consent to participate in this study. I understand that I will be given a copy of the informed consent form to keep for my records.

Signed \_\_\_\_\_ Date \_\_\_\_\_

### Researcher's statement

I \_\_\_\_\_

Confirm that I have fully explained the research procedure and purpose of the study in which the above-named has consented to participate. I will retain one copy of the informed consent form for my records.

Signed \_\_\_\_\_ Date \_\_\_\_\_

# Appendix 3: Interview Schedule

## Interview schedule for members of FATE June 2008

Introduce self, offer further explanation of what I'm trying to do  
Informed consent - verify  
Permission to record interview

I see from your answers to the questionnaire that.....

Can you tell me a bit more about how you became involved with FATE in the first place?  
(further questions prompted by what emerges from this response)

Why do you hold these beliefs?

Tell me a bit more about (interviewee generated topics).....

I see that you've had first hand experience with a terminally ill person close to you. Can you tell me more about how this experience affected you?.....

Were there any particular aspects of the illness you found particularly difficult to accept/cope with?

Was there anything you found particularly distressing during his/her illness?

How did the ill person feel about coping with their illness....

Were there any particular aspects of the illness they found particularly difficult to accept/cope with.....

- quality of life issues
- dignity - meaning
- suffering - meaning
- isolation and loss of community
- body changes
- humiliation
- disgust
- embarrassment
- appearance

If you were terminally ill, how do you feel about ..... (explore possible altruism)

How do you think this whole experience has influenced your feelings about assisted death?

[Where relevant]Tell me about your religious faith - why do you think that having assistance to die does not conflict with the teachings of your faith?

Is there anything else you think might have influenced you to join DiD/FATE?

Is there anything else you would like to ask or tell me?

Thank you very much for giving your time to talk about these things - I appreciate your help very much and hope that doing the interview has not been too distressing/stressful for you (according to circumstances).

If you wish, I can also send you a personal copy of the summary of the results

# Appendix 4: Mortality Paper

## Joining a right-to-die society: Motivation, beliefs and experiences

Marion Judd & Clive Seale  
Centre for Health Sciences, Queen Mary University of London,  
Barts & the London School of Medicine and Dentistry, London, UK

Marion Judd & Clive Seale (2011): Joining a right-to-die society: Motivation, beliefs and experiences. *Mortality*, 16:3, 223-241