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Euthanasia and Policy – Choosing When to Die

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Introduction

In medically advanced countries, voluntary euthanasia and assisted suicide are hotly debated issues across all strata of society. Legislation permitting the practice of hastening your own death with help from a third party has now been passed or is pending in a number of US states, Canada, Switzerland, Belgium, Luxembourg, and the Netherlands. Parliamentary bills which would legalise a form of assisted suicide were also debated by the UK and Scottish Parliaments in 2015. The beliefs that people hold about the practice are hugely influenced by their own first-hand experiences of illness and death (Hendry et al., 2013; Judd and Seale, 2011), as much as by any pre-existing moral code stemming from religious and cultural teachings or otherwise. The social and legal sanctioning of voluntary euthanasia and assisted suicide may divide opinion, but the fact that so many people appear to hold and are prepared to vocalize strong opinions about an issue relating to death and dying is unusual, given the social taboo which still operates to regulate discussions about the end of life more generally (Walter, 1991). In many ways, the high profile occupied by the voluntary euthanasia and assisted suicide debate has facilitated public discussion of broader issues to do with the ways in which people die in the twenty-first century.

In order to clarify just what mode of dying is being discussed in this chapter, it is important to understand the terms that commonly circulate in what is an intensely polarised and divisive political debate across the globe. Voluntary euthanasia involves a deliberate act to end a person's life by another (usually a medical professional) following a voluntary and competent request from that

individual (Lewis, 2007). This differs from assisted suicide where the means to end life, although provided by a third party, is *self*-administered (Lewis, 2007). This latter practice is considered by some advocates of legalisation to provide greater assurance that the final act is a self-determined one. A third term, ‘assisted dying’, has become prominent in the current UK debate, and is used either as a compendium term, incorporating both voluntary euthanasia and assisted suicide (Lewis, 2007), or in order to denote assistance which is offered only to those who are already dying of natural causes, that is, whose illness has already entered the terminal stage (Wootton, 2010). Whilst all three terms have different historical resonances, as this chapter will explain, and are often used strategically by campaigners in an effort to evoke particular associations in the public imagination, they all signify a form of deliberate, self-chosen death that is artificially induced, usually to bring an end to prolonged suffering due to incurable or terminal illness. I will use the terms voluntary euthanasia and assisted suicide throughout this chapter in order to avoid the controversy surrounding the term ‘assisted dying’¹ and also to keep in readers’ minds the defining aspect of this mode of death which is that it is artificially induced and self-chosen.

This chapter explores the current state of the UK’s ‘right-to-die’ or euthanasia debate, while reflecting on developments internationally. It begins with an examination of the history of the UK movement in order to place recent developments in a broader context. While those campaigning for a right to an assisted suicide in 2015 might want to put clear blue water between their proposed policies and the euthanasia policies of the Nazis, for example, or the eugenics movement more generally, these associations remain influential, particularly because they act as a motivation to the many factions which oppose legislative change. The chapter then moves on to discuss how older people specifically might be affected if any legislation were passed in the UK. Finally, the chapter discusses the policy developments following Debbie Purdy’s successful high profile legal challenge to force clarification from the Director of Public Prosecutions (DPP) about the circumstances under which a person might be prosecuted for assisting in a suicide. Mention is also made of the subsequent case of Tony Nicklinson, a man with locked-in syndrome who argued that a doctor should be allowed to assist in his suicide without risking prosecution on the grounds of respect for his human right to family and private life (Article 8 of the European Convention on Human Rights). Whilst Nicklinson’s case was ultimately unsuccessful, it revealed the growing influence the media has in defining the terms of this contentious debate. The ultimate aim of the chapter is to bring together a discussion of legal and policy

developments in the right-to-die debate with analysis of the broader sociocultural and historical changes which have influenced those developments.

Recent developments

For many years, UK policy on voluntary euthanasia/assisted suicide remained unchanged. The Suicide Act of 1961 was a defining piece of legislation, which, on the one hand, decriminalised suicide but, on the other, made assisting the suicide of another subject to prosecution. It specified that anyone in the UK who helped someone else to take their own life, whether a medical professional or a lay person, could be punished by up to 14 years in prison. Whilst, in principle, this remains the legal position, a House of Lords ruling in the case of Debbie Purdy in 2009 forced the publication of a policy which outlines the factors which are likely to be taken into account by the DPP when deciding whether or not to prosecute someone for their assistance (CPS, 2014[2010]). This policy enabled individuals to determine *in advance* whether their proposed assistance to someone wishing to take their own life would be likely to be deemed criminal. The explicit nature of the policy has changed the landscape with regard to what kinds of actions and motivations may be deemed legally (and perhaps morally) defensible. While the policy should not be interpreted as making the legalisation of assisted suicide more likely, its existence certainly contributes to a sense that there is a growing momentum behind the pro-euthanasia movement in the UK and that assisting someone to end their own life is becoming a criminally defensible, and even in some circumstances, a socially permissible act (Richards, 2015).

This growing momentum was also signalled by the introduction of two parliamentary bills to the English and Scottish parliaments in 2014: the Assisted Dying [HL] Bill and the Assisted Suicide (Scotland) Bill. The English bill seeks to legalise a form of doctor-facilitated assistance with suicide for people who have been diagnosed with a terminal illness and have a prognosis of less than six months.² The Scottish bill proposed a form of assisted suicide where a ‘licensed facilitator’ rather than a doctor would be permitted to offer assistance in the suicide of persons with a progressive or life-shortening illness and without a terminal prognosis.³ The debates surrounding both bills have generated a significant amount of media coverage, raising awareness of the issues and prompting responses from a wide range of interested parties and organisations across different sectors of society.⁴ The debate and publicity

which the introduction of the bills has generated serves to bolster the view (as with the publication of the CPS's policy in 2010) that assisting in another's self-chosen death is slowly gaining social legitimacy. The reasons for this are many, but include: the rise of the patient choice agenda within healthcare provision (Mol, 2008; O'Neill, 2002); the perception that medical technologies are being used inappropriately to sustain life against people's wishes (Ariès, 1974); and increasing focus on the individual as the ultimate arbiter of what is in their best interests, including how they want to die (Walter, 1994). All of these societal changes are linked to the rise of consumerism in the latter half of the twentieth century and rights-based discourses which grew out of the new social movements of the 1970s, prompting the reframing of the euthanasia debate as the 'right-to-die' debate.

Another aspect which is influencing the development of the requested death movement is the ageing of the so-called 'baby boomers'. Born in the aftermath of the Second World War, this was the first birth cohort to come of age in a consumerist culture, and as they and subsequent cohorts age they face an increasing risk of ill health, which acts as a motivation to create healthcare systems that allow choice and control over how they age and how they die (Seymour and Gott, 2010). The baby boomers represent the gateway generation for the rise of consumerist values, the privileging of individual rights and control, and the promotion of a certain neoliberal logic which promotes self-sufficiency and rejects dependency (Jones et al., 2008). It is these key cultural changes which have created the conditions where there is increasing political support for legislative change in many Euro-American societies.

History of the right-to-die movement

The British historian Nick Kemp (2002) traces the beginning of the modern euthanasia movement in the UK to the late nineteenth century when developments in analgesia and anaesthesia made physician assistance in suicide a realistic possibility for the first time. In the public debate at that time, the Christian principle of the sanctity of life – that life, as a gift from God, was sacred and thus ought to be protected at all costs – was always cited as the main impediment to any real prospects of winning mainstream support. It was not until the First World War and the scale of the loss of life in the trenches that this principle really came under attack. The war, which had received almost unanimous ecclesiastical backing, exposed Christian ethics to unprecedented scepticism and criticism (Kemp, 2002, pp. 76–8). A concurrent theme that

arose in response to the war was that of eugenics.⁵ The intensive war effort and the economic hardship that resulted called for a prioritisation of scarce resources. Crude eugenics proposals were advanced that people with mental disabilities or people lacking mental capacity should be non-voluntarily ‘euthanised’ in order to relieve an overburdened state (Thomson, 1998).

The Nazi euthanasia programme, code named Aktion T4, revealed at the end of the Second World War, marked a turning of the tide with regard to the public acceptability of eugenics principles. The T4 programme began with an enforced sterilisation measure in 1933, and extended to the medicalised killing of an estimated 200,000 people with physical and mental disabilities between 1939 and 1945 (Burleigh, 1994). Hitler’s targeting of Jews was similarly justified in terms of eugenics and of preserving the purity of the Aryan race. The post-war revelations of these mass killings tarnished the word ‘euthanasia’ and seriously hindered the possibility of any voluntary euthanasia legislation being passed in the immediate post-war period. Arguably, the persistent association between the Nazi euthanasia programme and contemporary proposals to legalise a form of medically-assisted suicide continues to impede the passing of legislation.⁶

The historical thesis advanced by Kemp (2002) is that the influence of the eugenics debate on the development of the British euthanasia movement is too often excised from histories of the debate. He emphasises that proposals for voluntary euthanasia for the terminally ill were distilled from the eugenics proposals ‘rather than the more common assumption that proposals for voluntary euthanasia lead to the advocacy of non-voluntary euthanasia’ (2002, p. 62). Analysis of the American euthanasia movement reveals a similar trend (Dowbiggin, 2003, p. 15).⁷ The most likely reason for the separation in much of the historical literature is to maintain the distinction that is currently emphasised between voluntary and non-voluntary euthanasia. Advocates of legalisation believe that assisted suicide is a fulfilment of what the political philosopher Isaiah Berlin (2006 [1958]) termed negative liberty – freedom from interference and control by others. In other words, the individual is viewed as the locus of all decision-making, including decisions about when to end their life. Non-voluntary or involuntary euthanasia, it is argued, would entail exactly the opposite of this – entitling others to control when you died in an act which would negate any sense of individual freedom. Given what is perceived as a clear difference in the thinking underlying the two types of euthanasia, one can understand why advocates (and perhaps historians as well) may wish to keep discussion of the two separate. However, in practice the

distinction can sometimes be difficult to maintain for two main reasons.

First, there are genuine fears that if the societal prohibition of intentional killing were lifted in order to allow a form of medically assisted suicide, it would open up the possibility of different forms of medicalised killing being authorised by the state; what is commonly referred to as the ‘slippery slope’ argument. In straitened economic times, in particular, when increasing expenditure on health and social care services for older people is a key political issue, there are fears about older individuals feeling pressure to foreshorten their lives in order to relieve an economic burden. The next step is a generalised fear of bureaucratised state-sponsored death where the lives of people who are disabled or suffering from incurable illness are not only devalued but are deemed to be *without* value – exposed as mere or ‘bare’ life (Agamben, 1998) – and are left beyond the protection of the law.

Secondly, even amongst their own ranks, right-to-die supporters sometimes, perhaps unintentionally, blur the distinction between voluntary and non-voluntary euthanasia. For example, in October 2008, the House of Lords life peer and vocal right-to-die advocate Mary Warnock publicly expressed the view that people living with dementia may have a ‘duty to die’ because they have become a ‘burden’ on the state and on their families:

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

(Macadam, 2008)

Warnock’s comments were widely interpreted in the press as endorsing a form of involuntary (non-consenting) euthanasia (see Doughty, 2008). Her views came under heavy criticism not only from right-to-die opponents and charities advocating for older people’s rights, but also from those trying to forward the case for legalisation of assisted suicide and voluntary euthanasia. For example, the Chief Executive of the main pro-campaigning organisation, *Dignity in Dying* (DID), wrote a letter to the *Guardian* newspaper firmly disagreeing with Baroness Warnock’s beliefs (Wootton, 2008). DID supports physician-assisted suicide only for fully mentally competent people, who have undergone a psychiatric assessment, and have only months left to live, that is, who are already considered to be dying. However, contained within the Chief

Executive's letter is a reference to the fact that some of DID's supporters will always regard its aims as not far reaching enough; and indeed the issue of assisting suicide in cases of individuals with dementia is a growing one (see Tomlinson and Stott, 2015).

After the 'extremely dark cloud' (Kemp, 2002, p. 118) which enveloped the voluntary euthanasia movement following the revelations of the Nazi euthanasia programme, by the 1960s and 1970s the moral climate for legalising assisted suicide in Europe and North America became more propitious. Like the American movement, the UK right-to-die movement benefited enormously from the rise of the women's movement with its celebration of 'our bodies, our lives' (Dowbiggin, 2003; McInerney, 2000). In the UK in the 1960s suicide was decriminalised, the death penalty suspended and then abolished, and, in 1967, David Steel's Abortion Law Reform Bill passed. All these changes in the law enhanced individuals' (negative) liberty. Life-prolonging medical technologies were also developing at this time, thus complicating medical ethics and decision-making.⁸ Pre-1960, discussion of voluntary euthanasia had been concerned almost exclusively with those patients whose end-of-life suffering medicine was unable to relieve. Post-1960, however, dying could not only be protracted but might need to be negotiated with medical professionals. This was because technological developments in biomedicine meant that death was often a matter of a decision: for example, turning off a ventilator, or deciding not to treat. Public attention focussed increasingly on cases where medical technology could maintain life, but with 'poor quality' (Kemp, 2002, p. 186). By the beginning of the twenty-first century, while concerns about experiencing extreme, poorly controlled or intractable pain in the terminal stages of a protracted illness continued to motivate demands for the legalisation of voluntary euthanasia, significant advances in palliative care and pain control had caused these concerns to recede somewhat, and a rival discourse concerned with defending patients' autonomy and promoting individual control over the manner and timing of death had taken hold.

To conclude this section, I return briefly to the influence of the patient choice agenda on how people anticipate and make plans for their own dying. In the early part of the twenty-first century, health and social care in the UK is being restructured to fit a personalised model of care (see Chapters 2 and 3 in this volume). It includes devolving budgets to individuals so that they can decide on the care services they want to enlist. This 'personalisation' (for which we can read individualisation) joins an already well-established rhetoric about patient choice. Crudely summarised, it is an agenda which asserts that patients

should be given sufficient information about the options available to them to enable them to make an informed choice about what they want for themselves, rather than having those choices made for them by healthcare professionals (see Department of Health, 2013). This new policy focus has created a political atmosphere in which *Dignity in Dying's* message about assisted suicide being simply an extension of patient choice can firmly take hold. However, as Mol (2008, p. 40) has argued, the idea that patients should be treated as consumers when in the consulting room assumes that they are autonomous, clear-thinking individuals capable of comprehending all the 'choices' open to them. This perspective, Mol argues, is unrealistic. Instead of perpetuating a logic of choice, she argues, a more pragmatic logic of care should prevail whereby people are enabled to live a pain-free, comfortable existence without being inundated with choices which they are not fully able to comprehend. Whilst a small minority of very determined strong-willed individuals may actively choose to determine the manner and timing of their death, there are many more who cannot be categorised as patient *choosers* or *consumers* who may be susceptible to suggestion or pressure from others and need to be protected. One of the groups of people identified as being vulnerable in the context of proposals to legalise assisted suicide are older people with chronic illnesses.

Assisted suicide and an ageing population

In February 2015 it was reported in the UK press that two Scottish cousins, aged 86 and 89, had been assisted in a lawful joint suicide at the Eternal Spirit right-to-die organisation in Basel, Switzerland (Templeton, 2015). The cousins, who had reportedly been living together for 40 years, were concerned that due to increasing age-related illness – poor eyesight, early stage dementia, hip injuries leading to mobility difficulties – they would be unable to continue to live independently and did not want to run the risk of being placed in separate care homes. Responding to the story, the director of Care Not Killing, the UK's main anti-euthanasia organisation, stated that 'assisted suicide in these circumstances is the ultimate abandonment'. He went on to argue that a change in the law to allow assisted suicide 'will have the effect of steering more vulnerable elderly people towards taking their lives'. Despite the cousins' voluntary decision to travel to Switzerland for an assisted suicide, the news story raises the question of whether their decision to die was prompted by 'unbearable suffering' as a result of their physical conditions, or whether it was

more a decision taken out of fears of: increasing dependency; lack of choice over living arrangements; and poor care in residential homes, a fear which has potentially been exacerbated by a series of high profile care home scandals (for example, at Orchard View care home in West Sussex [Milmo, 2013]).

The circumstances affecting these Scottish cousins, as reported in this news story, are likely to affect an increasing number of people in the UK. As the population ages, there is an increased prevalence of long-term, progressive conditions. A 2011 survey found that 4 million older people in the UK (36 per cent of people aged 65–74 and 47 per cent of those aged 75+) reported that they had a limiting longstanding illness (Age UK, 2015; ONS, 2013). Due to the changing epidemiology in the way we die, many older people do not ‘get sick and die’, but rather live for many years in a state of ‘long-term dwindling of function’ requiring years of personal care (Lynn, 2005). It is during the years of ‘prolonged dwindling’ that older people may contemplate the meaning and value of life, and its end (Seymour and Gott, 2010).

Some older people, in dealing with health-related issues at the end of life, may prefer to defer to others, whether they are family members or healthcare professionals. This has been termed an ‘other culture’ (Seymour et al., 2004). This group might be considered vulnerable to suggestion from others about making use of assisted suicide legislation. Other older people, however, want to make decisions themselves and indeed actively endorse the principles of the right-to-die movement. It is interesting that whilst most of the UK’s right-to-die ‘celebrities’ – individuals such as Debbie Purdy and Tony Nicklinson who have initiated high-profile legal challenges – have been middle aged (<60 years old), the majority of grassroots activists are over 60 years old (Judd and Seale, 2011; Richards, 2012). It has been argued elsewhere that one of the motivations for older people becoming active campaigners on this issue is that their anticipation of their own death and demise, and their desire to exert some control over it, is an increasing preoccupation for them as they advance in years.

When considering how far legalising voluntary euthanasia or assisted suicide would be likely to affect older people, two key questions of equality dominate. The first is whether older people’s ‘typical’ dying trajectory – the ‘prolonged dwindling’ identified by Lynn (2005) – would enable identification of a terminal phase (reasonably expected to die within six months) thereby allowing older people to make use of the legislation currently being proposed in England and Wales. Prognostication is much more difficult in cases of increasing co-morbidity (Lunney et al., 2003) and older people wishing to have

an assisted suicide may find that they do not fulfil the criteria. In a number of countries that have legalised the practice, the Netherlands and the US state of Oregon for example, the evidence suggests that older people are actually less likely than younger people to have an assisted suicide (Battin et al., 2007). Indeed, van der Geest and Niekamp (2003) have questioned whether, in the Netherlands, requests for voluntary euthanasia or assisted suicide by older people are taken less seriously because of raised suspicions in this population group and fears of being accused of ageism.

The second question of equality is whether or not older people who are in need of services, care and support to ensure a reasonable quality of life in the face of great impairment can actually access that care and support. If older people fear exclusion from good care, whether resulting from a lack of availability or quality or from negative attitudes towards older people (Care Quality Commission, 2011; Francis, 2013), then this may create an environment conducive to opting for an assisted suicide. In the next section, I examine Debbie Purdy's successful right-to-die legal challenge and the CPS policy which was developed as a result. However, I begin the examination of her case with the circumstances of her death, five years later, in which it is possible to see evidence of both of the inequalities identified above.

Assisted suicide policy in the UK: the case of Debbie Purdy⁹

In December 2014, it was reported in the national media that Debbie Purdy, a well-known face in the UK's right-to-die movement, had died as a result of voluntary refusal of food and fluid in a hospice in Bradford (see Allen, 2014; Tran, 2014). The *Independent on Sunday* newspaper reported her death on its front page, offering an exclusive on her 'last article' and 'final testament', reportedly penned by Purdy herself shortly before her death, although most likely ghost-written given her poor state of health. In the article she described how, in the years immediately following the House of Lords ruling in her favour, she felt she had been given 'permission to live, to enjoy life' and that she was able to spend quality time with loved ones. However, by 2012 her multiple sclerosis (MS), diagnosed in 1995, had worsened to the extent that she could no longer move in or out of her wheelchair without assistance, was losing movement in her hands, had difficulties sleeping without developing bedsores, and her life, in her eyes, had 'become virtually impossible' and 'unbearable' to her. Purdy felt that the social care system had let her down, arguing that she had been unable to access the physiotherapy which she needed

in order to remain mobile and that as a consequence she struggled to maintain her independence. Here is an example of a perceived failure of the publicly funded social-care system to adequately support someone to live well with a debilitating condition. This is a reason which is often cited by opponents for not legalising assisted suicide/voluntary euthanasia (see arguments put forward by the campaign group Care Not Killing¹⁰). Purdy herself wrote that the experience: ‘rein- forced my conviction that [. . .] we really need to explore all possibilities to see if we can make life more acceptable’ before allowing someone the choice of an assisted suicide.

In choosing to voluntarily refuse food and fluid, Debbie Purdy made a deliberate choice to hasten her own death and bring her suffering to an end. However, the process of ending her life in this way she also found to be ‘unbearable’ and ‘undignified’ (Purdy, 2015). The article described that whilst she supported the proposed Assisted Dying Bill [2014] she would not have been able to make use of it because she did not have a prognosis of less than six months. For this reason she also supported assisted suicide for people who, like herself, were incurably but not yet terminally ill.

The publication of Purdy’s reflections on events during the six years since winning her legal case offer an illuminating postscript to what was a significant legal judgment in the history of the right-to-die movement in the UK. By beginning a discussion of Debbie Purdy’s case with the story of her death, we can see that whilst her legal case may have been about her right to clarity regarding the assistance which her husband could lawfully give her when taking her own life, in the end, the mode of death she opted for did not require his assistance. She may have considered it ‘unbearable’ and ‘undignified’ but it was a mode of death that did not require third party assistance and avoided any legal repercussions for her husband.

In 2008, Purdy had brought a high-profile legal challenge to clarify the possible risk of a criminal prosecution in cases where individuals ask their relatives to aid them in travelling abroad to a jurisdiction where they may lawfully be helped to die, namely Switzerland. Right-to-die organisations in Switzerland can lawfully assist people in their suicide in accordance with a unique provision in Article 115 of the country’s criminal code, effective since 1942, which permits anyone to assist in a suicide for altruistic reasons. This rule also applies to assisting in the suicide of foreign nationals and has given rise to what is popularly known as ‘suicide tourism’. Between 2009 and 2012 126 Britons had died with the help of a Swiss right-to-die organisation (Gauthier et al., 2014). The premise of Purdy’s Judicial Review was the

hypothetical risk to her husband, if, at some future time, he were to assist her to travel to Switzerland for an assisted suicide. Purdy's argument was never that this was a course of action she was certain she wanted to take. It was the unpredictability of her progressive symptoms which was causing her to experience a heightened state of uncertainty and she was appealing to the law to remedy that uncertainty (Richards, 2015; Richards and Rotter, 2013).

In July 2009, the House of Lords, the highest court in the U.K.¹¹, ordered the Director of Public Prosecutions to produce a crime-specific policy identifying the factors which must be taken into account by the Crown Prosecution Service when making the decision whether or not to prosecute a person who assists another's suicide. In their decision, the five Law Lords expressed sympathy for Purdy and her husband:

It cannot be doubted that a sensible and clear policy document would be of great legal and practical value, as well as being [...] of some moral and emotional comfort to Ms Purdy and others in a similar tragic situation.

(Lord Neuberger, para.101)

Two months after the Law Lords delivered their judgment, the DPP produced some interim guidance (CPS, 2009) and invited the public to participate in a 12-week consultation exercise, during which 5,000 responses were received. The final 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide' was published in February 2010. The main factors tending against prosecution which were listed in the final version of the policy were: that the individual had reached a voluntary, clear, settled and informed decision; that the person assisting in the suicide was wholly motivated by compassion; and that the actions of the suspect were of 'only minor encouragement or assistance' or constituted 'reluctant encouragement or assistance' with evidence that they had attempted to dissuade the person from their course of action.

The new policy has produced some clarity for those contemplating assisting in a suicide as to what actions and intentions would be likely to expose them to a possible prosecution. Whilst the CPS has been adamant that the policy does not decriminalise assisted suicide and that no one is being offered immunity in advance, the high numbers of cases which have not been prosecuted since the publication of the policy has led to press speculation that assisted suicide has *de facto* been decriminalised 'by the back door' (Beckford,

2013; Beckford and Blake, 2010). Another significant aspect to the CPS's policy is that it does not solely apply to actions taken by a person when enabling someone to travel to Switzerland for help to die. It also applies to actions taken in the UK, for example, offering technical or practical assistance with the act itself. According to Lewis (2011), this has widened the scope of what was intended by the Law Lords when requiring the CPS to issue the policy, and has accelerated informal legal change on assisted suicide.

Since Debbie Purdy's successful legal challenge, another high-profile right-to-die legal case was launched (by the same legal team) on behalf of a man named Tony Nicklinson. Totally and permanently paralysed as a result of a stroke in 2005, Nicklinson was seeking a declaration that voluntary euthanasia by a doctor on the grounds of 'necessity' could be a defence to a prosecution for murder. His case reached the Supreme Court but was dismissed in 2014 on the grounds that, while there was potential incompatibility between the blanket ban on assisted suicide and Article 8 of the Human Rights Act [1998] – the right to respect for private life – parliament should be given more time to consider the issue. Nicklinson himself died of pneumonia after refusing food, fluid and medicines, before his case reached this stage. However, the lasting significance of his case was the volume of media attention it received, including the first successful use of social media as a means of mobilising public sympathies for the right-to-die cause.

After Nicklinson's death in 2012, Brittney Maynard, a 29 year old diagnosed with a terminal brain tumour, found internet fame when her campaign to have a physician-assisted suicide in California went viral.¹² The global interest in Maynard's story shows the international nature of this social movement and the way in which personal suffering becomes imbued, via the media, with political meaning (Richards, 2014). All forms of media, both old and new, now provide the main battleground for the right-to-die debate whose terms – assisted dying, suicide, euthanasia – and what they signify are being perpetually altered and contested.

Conclusion

Voluntary euthanasia and assisted suicide have been the subject of heated public controversy since the end of the nineteenth century when the development of analgesics first made the practice a realistic possibility. Since that time, what was an elite group of pro-euthanasia supporters has turned into

a large social movement which now commands significant mainstream support, and has arguably managed to (finally) shake off the association with the Nazi euthanasia programme and with the eugenics movement.

The cultural changes which have made the moral climate for legalising voluntary euthanasia and/or assisted suicide more propitious are multiple but stem broadly from the rise of individualism and consumerism evident in Euro-American societies. If, as the editors of this collection suggest, 'death shines a light on how we live our lives', then the increasingly vocal demands for the right to a medically assisted suicide could be perceived as an extension of the choice and control people now expect to have in all aspects of their life. One of the questions raised by this debate is whether there are people who are left out of a choice-driven model of healthcare. Some frail older people, for example, who perhaps do not fit the ideal-type of the autonomous, clear-thinking consumer, may be left vulnerable to a change in medical ethics which would allow doctors to intentionally end someone's life. Could the fact of having assisted suicide as a medical 'option' create conditions, for example, where dependency, high care needs and intensive resource use could become less tolerated in society? A clear tension between protectionism (some would read paternalism) and autonomy runs through this debate and the question for policymakers is whether it is possible to develop a policy or legislation which can deliver both.

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Notes

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- ¹ When debating Lord Faulkner's Assisted Dying Bill in the UK House of Lords in January 2015, an amendment was proposed to change the name of the bill to the Assisted Suicide Bill. This proposal was defeated by 179 votes to 106.
 - ² The Assisted Dying Bill was debated in the UK House of Lords in 2014 and voted through to committee stage before running out of time when Parliament was dissolved in 2015 for the general election. In September 2015, the bill was re-introduced into the House of Commons by Rob Marris MP as a Private Member's Bill, and members of parliament voted against the Bill, 330 to 118.
 - ³ The Assisted Suicide (Scotland) Bill was debated in the Scottish Parliament in May 2015 and rejected by 82 votes to 36.
 - ⁴ The list of organisations which responded to the public consultation on the Assisted Suicide (Scotland) Bill 2014, included faith-based groups, campaign groups for specific diseases, carers' associations and legal groups. The list of consultation respondees is available at: <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/79563.aspx>.
 - ⁵ The term 'eugenics' was coined in 1883 by Darwin's cousin, Francis Galton, from the Greek meaning 'wellborn'. He defined it as the 'science of improving stock', and 'using agencies of social control' to improve 'the racial qualities of future generations' (Dowbiggin, 2003, p. 15).
 - ⁶ See for example an article published in the *Catholic Times* in April 2006, published at the time Lord Joffe's Assisted Dying for the Terminally Ill Bill was being debated in the UK House of Lords. The article, entitled 'Legalising euthanasia turns carers into killers', was accompanied by a photograph showing pictures of children murdered by the Nazi T4 euthanasia programme, with the tagline 'warning from the past'.
 - ⁷ It is interesting to note that in the 1930s there was an estimated 12 per cent overlap in membership between The Voluntary Euthanasia (Legalisation) Society (VES), and The Eugenics Society, founded in 1907 (an estimate which Kemp (2002, p. 88) views as conservative).
 - ⁸ Resuscitation techniques were improving with the use of cardiac massage and re-starting the heart during cardiac surgery. The artificial respirator was also developed in the 1950s and antibiotics and surgery techniques were generally continually improving and diversifying.
 - ⁹ Although this section does not include empirical data, it should be noted that I interviewed Debbie Purdy twice in the lead up to the House of Lords ruling.
 - ¹⁰ <http://www.carenotkilling.org.uk/about/>.
 - ¹¹ It has now been superseded by the Supreme Court.
 - ¹² Assisted suicide legislation won the support of the Californian State Legislature in September 2015 in no small part due to intense lobbying by supporters of Britney Maynard. If passed, California, America's most populous state, will become the fourth US state to allow physician-assisted suicide.