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## CHAPTER NINE

# DYING TO GO TO COURT: DEMANDING A LEGAL REMEDY TO END-OF-LIFE UNCERTAINTY

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Voluntary euthanasia, or the ‘right-to-die’, as it is currently termed, is one of the most visible and divisive bioethical issues to be routinely debated in medically advanced countries. Central to the issue is the conflict between the rights of individuals to determine their own lives and, by extension, the ending of that life, and the duty of the state to protect the lives of its most vulnerable citizens. For some, the medical hastening of death by way of a deliberate intervention is the next step in a trend which has seen technological advances in medicine turn death into something which can now be orchestrated, negotiated and timed (turning off a ventilator, deciding not to treat, etc.). For others, this is a step too far and must be resisted at all costs. As attempts to legalise and institutionalise the practice of euthanasia have increased over the last century, it is no longer considered a private matter between doctor and patient but rather has become a matter of public concern where the language of rights now dominates. In the UK, the primary focus for this dramatic conflict of rights is the courtroom. Legal redress is sought, as individuals living with serious progressive illness lose confidence in the medical profession to sufficiently ease their suffering as their body deteriorates and their capacities lessen. Not only is the law valued for the potential remedy it provides, but a favourable judgement also offers some formal validation of a particular ethical position. In recent years, the courts have become the most productive (and provocative) forum for shifting the terms of the debate and applying pressure on British lawmakers.

This chapter focuses on a high-profile legal challenge which was mounted in the UK in 2008 and was finally determined by judges in the country’s supreme court in 2010. The case involved a woman named Debbie Purdy and her husband Omar Puente. Debbie had been living

with multiple sclerosis, an incurable and degenerative disease, since 1995. The couple wanted to challenge the possible application of the criminal law in cases where individuals have asked their relatives to aid them in travelling abroad to a jurisdiction where they may lawfully be helped to die. Since 2002, a number of Britons have travelled to Switzerland, where right-to-die organisations can legally assist in their suicide in accordance with a unique provision in its 1942 law allowing anyone to assist in a suicide for altruistic reasons. In the UK, the Suicide Act 1961,<sup>1</sup> explicitly states that it is illegal to encourage or assist the suicide or attempted suicide of another person and that the offence is punishable by up to 14 years in prison. Debbie's was an appeal to the judicial process to help her clarify the risks to her husband of a future decision to end her life abroad. In lieu of a medical remedy for her disease, Debbie sought out a legal remedy in terms of knowledge about the likelihood of her husband being prosecuted, should she ask him to accompany her to Switzerland at some unspecified future time.

The principal outcome of the case has been the publication, in 2010, of a policy statement which, for the first time, puts into written and public form reasons why the decision might be taken not to prosecute a person for helping another to die. This chapter discusses the development of this new policy document, and the moral reckoning which determined its final form. Although the chapter focuses on the specifics of Debbie's case and its outcome, it also extrapolates from those specifics to comment on the broader cultural context in which assisted suicide is undoubtedly gaining social acceptance. The central focus of the chapter is the way in which the law was used instrumentally by campaigners to bring about a policy which has changed the way assisting someone to die is regulated. As other chapters in this volume relate, the technicalities of the law might on the face of it appear quite alienating for ordinary citizens who are seeking redress for a perceived injustice. However, in the case put forward here, it was the technicalities of the law which were debated and wrangled over in lieu of any political or medical consensus about the moral or ethical rightness of assisting people to die. It was these technicalities which were used as an instrument to extract a significant concession from the Director of Public Prosecutions (DPP), forcing him to devise a new policy document. Some may view this as an example of the law overstepping its boundaries, changing policy where it should rightly be left up to those democratically elected to do so. Others argue that the

law is simply too blunt an instrument to tackle the delicate ethical dilemmas which arise around end-of-life decisions. However, in this case, the law was *productive*. It produced an outcome which, on the face of it, may appear only as yet another regulatory instrument, but concealed within that is what is perceived as a validation of the demands of right-to-die campaigners, and the opening up of further opportunities for applying legal as well as political pressure on politicians to change the law in a more definitive way.

This chapter is based on data gained from anthropological research conducted from 2007 to 2009, as Debbie Purdy's case journeyed through the British courts. The overall aim of the research was to trace and contextualise the values, beliefs and convictions of both sides in the right-to-die debate. The research conducted was multisited and involved following the 'chains, paths, threads, conjunctions, locations' (Marcus, 1998: 90) where the terms of the debate were decided. I interviewed Debbie Purdy at length early in 2008 before her application for Judicial Review was heard and before media attention turned her into a recognisable public figure. I was present at her Court of Appeal hearing in February 2009 and interviewed her again over the phone afterwards. I also spent a week working for her lawyer collating information collected through questionnaires sent to the relatives of people who had died at Dignitas. I formally interviewed the Human Rights Officer of the campaigning organisation Dignity in Dying which supported her case and had other informal contact with the Chief Executive, the Head of Legal Strategy and Policy and the Director of Campaigns and Communications at two AGMs and various public events and conferences. In addition, the larger research project led me to interview a wide array of campaigners lobbying both for and against legalised assistance to die, along with other people who were planning to travel to Switzerland for help to die. This knowledge informs my approach and helps me to ground the outcome of the case in the wider political context.

## DEBBIE PURDY'S PREDICAMENT

If I could write the future, we would clarify the law as it stands, change the law in the next couple of years, and in the meantime someone would find a cure for primary-progressive MS.

(Debbie Purdy writing in her 2010 autobiography: 280).

Debbie Purdy was diagnosed with primary progressive multiple sclerosis (MS) in 1995, when she was just 32, although it is likely that she was experiencing the symptoms of the disease for years before that. MS is the most common disabling neurological disease affecting young adults. It affects about 100 000 people in the UK.<sup>2</sup> Symptoms include, among others: loss of sensitivity and muscle weakness/spasms leading to mobility difficulties; problems with coordination and balance; fatigue and acute and chronic pain; and difficulties with speech and swallowing. Debbie has a progressive form of the disease and there is no known cure or remedy. Shortly after diagnosis she asked her doctor what she could expect and he replied: ‘the only thing I can tell you is that it’s not going to get any better. And that’s pretty much it’ (Purdy 2010: 36). However, Debbie is not ‘dying’. She has lived with her disease for a long time now, and although her symptoms steadily increase, she may live with it for many years to come. In fact, people with MS have a life expectancy which is only five to ten years lower than that of the unaffected population (Compston and Coles 2008). Even if her life were to be considerably foreshortened, it is not this which she fears so much as the prospect of future ‘unbearable’<sup>3</sup> suffering which may cause her to feel that her life is no longer worth living. It is at this point that Debbie would like the option of hastening her own death. Ideally, she would like to be assisted to die in the UK with the help of a doctor. However, in lieu of a change in the law which would allow this to happen, the most likely place for her to want to hasten her own death would be Zurich, Switzerland, with the help of the organisation, Dignitas.

Dignitas, founded in 1998, is one of three Swiss organisations which help foreign nationals to die. However, Dignitas is the only one to have repeatedly made tabloid headlines in the UK, the majority of which have portrayed its activities in a very negative light (cf. Hall 2009; Weathers 2011). The organisation operates strictly within Swiss law, which states that people who assist in a suicide can only be prosecuted if they are motivated by self-interest. As such, the fees which Dignitas charge people only cover its operating costs and no profit is made. A retired doctor initially meets and assesses the individual wishing to die and, if they are satisfied that the various conditions are met, they then write the lethal prescription. The

prescription is then collected by a Dignitas volunteer who prepares the drug and gives it to the individual to self-administer. The death ‘event’ itself is therefore de-medicalised, and I will return to this concept later in the chapter. When cases of Britons being assisted to die at Dignitas have been reported in the British press, it is often referred to as a ‘clinic’. However, the setting is intentionally non-clinical and there is no medical professional present when the lethal liquid is taken. On the day of Debbie Purdy’s appeal hearing in February 2009, Dignitas released the information that 100 Britons had died there since 2002. In January 2012, this figure had increased to 182 Britons (Beckford 2012).

The context in which Debbie’s case arose is one where notions of the ‘good death’ are slowly changing. Cross-culturally, the ‘good death’ has been identified as one where there is some degree of control over the arbitrariness of physiological deterioration (Bloch and Parry 1999: 12) and where death comes at the end of a long and successful life, at home and without violence or pain (Seale and van der Geest 2004: 885). While these attributes continue to hold in the UK, the point of cleavage has become whether the good death must be a natural death or whether it can be artificially procured. Palliative care philosophy, which occupies the mainstream in terms of an ideal-type model of end of life care, has much in common with right-to-die philosophy in that both seek to personalise and individualise dying and both emphasise that choice and control should reside with the dying person herself (Walter 1994). However, where the two movements differ is that palliative care philosophy takes the position that it seeks neither to hasten nor to postpone death (Maddocks 1996). Right-to-die philosophy, on the other hand, takes the view that for some, natural death can cause such a profound loss of control over the physical boundaries of the body, as Lawton (2000: 7) documents in her ethnography ‘The Dying Process’, that they can experience a diminishment of self. It is in such situations, advocates argue, that only by artificially hastening a person’s death can social and biological death be realigned, and a person’s suffering be brought to an end. It is an uncontrolled natural death which Debbie Purdy fears awaits her, and it is this which inspired her to take up her legal challenge to make viable her option of an artificial death abroad.

When I interviewed Debbie, she told me that she characterises herself as a ‘loud-mouthed, obnoxious’ pro-choice activist: ‘I’m not the type of person to just drift into the background’. She sat on the board of Dignity in Dying, the UK’s main organisation campaigning for the

legalisation of assisted dying,<sup>4</sup> for a number of years before stepping down in 2007 to begin her legal challenge. For some time she has worked as a ‘simulated patient’ for a medical school, a project that aims to educate doctors about how to engage appropriately with disabled patients. She thinks that disabled people should have the same access to services as everyone else, but she also thinks that disabled people should be allowed to decide what they want for themselves, even if that deviates from what is expected of them. She doesn’t support the paternalism she encounters in the disability rights movement and resents being called ‘vulnerable’. As she told me: ‘If you are going to argue for disabled rights, then you have to argue for their right to decide what they want. It’s easy to say you support free speech with someone who is agreeing with you.’

By this rationale, Debbie Purdy feels strongly that disabled people should be able to choose an assisted death, without needing to be ‘protected from ourselves’. This is why she launched her case in 2007 with the help of Dignity in Dying which arranged her legal representation and her media appearances.

Assisted suicide first entered Debbie’s consciousness through the media coverage of Dianne Pretty’s legal case six years earlier. In 2001, Dianne petitioned the courts to allow her husband to help her commit suicide with legal immunity (meaning he would not be charged for committing a crime after her death). It was never specified how or where her suicide would take place. Dianne was living with motor neurone disease and was paralysed from the neck down, making it very difficult for her to take her own life. Dianne took her case to the House of Lords and then to the European Court of Human Rights, where it was finally dismissed. When Dianne heard that she had lost her case, she declared that ‘the law has taken away my human rights’. This comment highlights the way in which the language of human rights is often used rhetorically to register disapproval of state law. Its appeal rests in maintaining a critical distance from the law, and its ability therefore to stretch the boundaries and limits of the law (Douzinas 2000: 344). Dianne’s case was the first to frame requests for help to die as a ‘human right’ in an attempt to do just that: stretch the limit of the law and give a desire for a certain type of death transcendent value (Douzinas 2000: 367).

Dianne’s case, like Debbie’s, was supported by Dignity in Dying (at that time called the Voluntary Euthanasia Society) and marked a new

phase in the campaigning strategy of the organisation. The impetus now appears to be to highlight the suffering of specific individuals with whom the public can identify, in order to promote its cause. These individuals become ‘spectacles of suffering’ so that ‘whether or not anyone speaks to his or her suffering, an observer is likely to understand and acknowledge that suffering is taking place’ (Williams 2007: 137). At the same time, the courts have been viewed instrumentally as a potentially more expedient route to success when compared to the more cumbersome parliamentary process. It was Dianne Pretty’s high profile appeal that raised public awareness of assisted dying in Britain and paved the way for Debbie Purdy subsequently to bring her own legal challenge.

Debbie’s case was this. If, at an unspecified future date, she feels compelled to travel to Switzerland for help to die because her MS has advanced to a stage where she no longer feels her life is worth living and she determines of her own accord that she is suffering ‘unbearably’, she may need to ask her husband, Omar Puente, to accompany her and assist her with the journey. If he were to agree, there is a possibility that he would be prosecuted under Section 2(1) of the 1961 Suicide Act which makes it illegal to encourage or assist in the suicide or attempted suicide of another person.<sup>5</sup> Debbie was not seeking immunity for Omar, as in the Pretty case where Dianne sought immunity for her husband. Rather, Debbie was asking for the DPP, at whose discretion a criminal case against Omar would be brought, to clarify exactly what counts as ‘assistance’ and what factors he would be likely to take into account when deciding whether or not to prosecute him. Her lawyers claimed that Article 8<sup>6</sup> – the right to respect for private and family life – of the European Convention on Human Rights was engaged in Debbie’s decision to want to take her own life, and that the state was only entitled to interfere with this right ‘such as in accordance with the law’ (ECHR, Article 8(2)). In order that individuals like Debbie and Omar know in advance what is ‘in accordance with the law’, it was argued by her team that there needed to be a clear statement of policy outlining the factors tending for and against a prosecution. Debbie said that if she was not 100% certain that Omar would not be prosecuted after her death, then she would not allow him to accompany her. As she told me: ‘I’ve got to be certain that my decision will not hurt him.’ Her argument was that in lieu of a clear prosecutorial policy she would be forced to travel to Switzerland and die earlier than she wanted to while she still had the



physical capacity to travel alone. For this reason, Debbie always framed her claim not as a ‘right-to-die’ but as a ‘right-to-live longer’. This sentiment is similarly reflected in the title of her autobiography: *‘It’s not because I want to die’*.

What was intriguing about Debbie’s case was that although it was *her* campaigning efforts that brought the legal challenge in the first instance and it was *her* future death decision which was the focus, it was her husband’s potential actions that were the subject of the legal dispute. This actually mirrors Dianne Pretty’s case in which it was Dianne’s husband, Brian, whose potential actions were being judged. Debbie’s husband Omar is the one who risks prosecution for helping her to make the journey to Switzerland. However, he has said in many interviews with the press that he will go with her regardless of the risks. It is Debbie who refuses this offer out of a desire to protect him. They are trying to determine the freedom of their future selves. Yet the criminal law operates retrospectively and is not anticipatory. It responds to what has already happened and the discretion to prosecute cannot be exercised in advance. It is not designed to offer certainty in the face of future events which have yet to take place. This is the limit to the remedy the law can provide.

Debbie and Omar are mutually implicated in her death decision. Right-to-die rhetoric would have us believe that demands for help to die are purely a matter of individual choice and a desire for individual control. Advocates argue that such demands are made by individuals who want to determine the end to their own lives through their own subjective assessment of whether they are suffering ‘unbearably’. As Debbie told me: ‘I don’t want to be in other people’s control. I don’t want to be at their whim. I want to have complete control and autonomy about what I do and how I do it.’

This focus on the individual as the locus of decision-making is indicative of a more general reliance on individual autonomy as the cornerstone of medical law and ethics (Mason and Laurie 2006: 6). At its most pared down, autonomy relies on ‘negative liberty’ or freedom from interference, as famously described by Isaiah Berlin (2006 [1958]). O’Neill (2002: 29) describes autonomy as a ‘capacity’ or ‘trait’ which individuals have and which they manifest by acting independently. John Stewart Mill (2006[1859]) influentially extended the idea beyond independent action to include the enabling of self-expression or the flourishing of individuality. For some philosophers,

this extension too closely aligns the concept with liberal individualism which champions the fulfilment of the unimpeded individual, while ignoring the impact of that fulfilment on the broader community. After all, the social dimension of life requires that individual autonomy be qualified by the legitimate interests and expectations of others (Mason and Laurie 2006: 5–7). This is what is known as the communitarian approach to ethics.

In the UK, it was the case of *Re C (adult: refusal of medical treatment)*[1994] that established the legal precedent granting patients the right to refuse treatment, including life-sustaining treatment,<sup>7</sup> on the grounds of self-determination with regard to a person's own body. The legal consequences of unauthorised invasion of that bodily integrity include civil actions for damages and criminal liability for assault (Mason and Laurie 2006: 349). The right was made unequivocally enforceable with the case of *Ms B (adult: refusal of medical treatment)*[2002].<sup>8</sup> However, where the law is seen to value individual autonomy over and above the obligations we owe to those around us, there are concerns that an exaggerated absoluteness and hyper-individualism can take hold (Glendon 1991: x–xi) which neglects people's unavoidable dependency on others and the fact that an individual's decision has consequences for other people. As Butler writes: 'Although we struggle for rights over our own bodies, the very bodies over which we struggle are not quite ever our own' (Butler 2004: 26).

In demanding a human right to have her private life respected, Debbie's decision depends on her husband and his support. She cannot act alone. Despite the fact that it is Debbie who has pursued the case, in reality it is he who will feel the effects of the law should he be prosecuted for helping her. What becomes clear from reading Debbie's autobiography (2010) is that Omar was always a reluctant passenger in her campaign. She writes of his 'hurt look' when she talked to journalists about the prospect of taking her own life and recalls his response when she first asked him if he would come with her to Dignitas: 'Of course I would come, Debbie. I don't even have to think about it. But for now can we not talk about it? Can we just get on with enjoying our lives together?' (Purdy 2010: 232). Omar is intimately involved in Debbie's decisions. He must anticipate her death, not because he chooses to, but because Debbie is a determined campaigner who has decided to prepare for her death in a very public way. When

she says ‘I’ve got to be certain that my decision will not hurt him’, it is clear that she conceives of her death decision as hers alone to make, and yet she refuses to criminally implicate Omar, indicating the limits to her autonomy. As Strathern highlights, ‘To an age that thinks of itself as individualistic, the revelation of relationship can come as something of a surprise. The person as an individual turns out to be the person as a relative’ (Strathern 2005: 10).

In the public spectacle which surrounded Debbie’s case in its passage through the courts, Omar featured heavily in the extensive press coverage. Her autobiography is presented as something of a love story, and pictures of the two of them together grace both the front and back covers. The strength of their relationship was a fact which implicitly strengthened their case in the court as well as in the eyes of the public, a point I will expand on later.

Another crucial factor in Debbie and Omar’s case, which was often overlooked in its reporting, was the many hypothetical circumstances at stake. *If* she finds herself ‘suffering unbearably’ at some point in the future, she *might* want to have an assisted death at Dignitas. Perhaps she is anticipating the worst, but she wants to be prepared anyway. As she told me:

I don’t want to make the decision now. Until you are in an unbearable situation you don’t *really* know what is unbearable. When I was twenty-one, I thought being in a wheelchair would be the most terrible thing that could happen – that I’d kill myself if that ever happened. It’s not that bad. You learn to cope in a different way, you learn to see yourself in a different way. You are not prevented from being you.

Debbie does not yet know what degree of bodily deterioration and loss of function she can tolerate while still finding life worthwhile. She does not know which capacities and activities will, in her eyes, represent the essential components of an acceptable life and indeed there is no certainty that she will ever have to confront these questions. As Lawton’s (2000: 7) ethnographic work shows, in a British cultural context, in order for selfhood to be realised and maintained, certain specific bodily capacities and attributes *must* be possessed, namely the bodily ability to act as the agent of one’s embodied actions and intentions. People who lack this ability can fall out of the category of personhood and experience a ‘diminishment of self’. In some respects, Debbie’s appeal to the law to provide a remedy for her uncertainty stems from her lack of trust in her doctor’s ability to prevent or

ameliorate just such a diminishment of self. As philosopher Onora O'Neill (2002: 17) emphasises, while an increase in patient autonomy (often consumer choice by another name) has challenged the asymmetrical relations of knowledge and power which historically defined the doctor–patient relationship, transforming the patient from a grateful supplicant into a wary consumer, it has also resulted in a loss of trust. This has been exacerbated, O'Neill argues, by a culture of blame and accusation which is widespread both in the media and in the literature of campaigning organisations. A loss of trust in professionals, when combined with a pervasive rights rhetoric, results in a culture in which, according to O'Neill (2002: 10), 'incoherent demands' like a 'right to health' can gain political traction. Given that no human action can secure health for all, she argues that there can be no obligation to meet that demand. Many who oppose a 'right to die' might similarly argue that it is an 'incoherent demand' because there can be no obligation for doctors to bring about the kind of death the individual chooses. As Mason and Laurie (2006: 7) stress, the doctor, as the administrator of the lethal drugs, is also himself a moral agent and might be affected by the task. As already established, Debbie's rights claims stem not only from a loss of trust in her doctors, but also from a sense in which she may suffer in a way which is beyond the scope of medicine to remedy. Because there is no cure for her bodily deterioration, doctors cannot give her confidence in her future. By seeking a 'right' to die, she is appealing to the law to provide that certainty and to offer the implicit recognition that there are certain types of illnesses that can result in certain types of suffering and diminishment of self, which medicine cannot ameliorate.

The unpredictability of the progressive symptoms of her disease was causing Debbie ontological insecurity (Giddens 1990; Richards and Rotter 2013). As Toombs (1995: 20) points out, for people with progressive disability, time may be disturbed in that the future, rather than the present, assumes overriding significance. Yet the future also becomes inherently problematic because of its unknown aspect. There is a lot of uncertainty in Debbie's approach to her future, but she wants the law to help her keep her options open. One gets a sense of her uneasy relationship with her future when she writes in her autobiography: 'I want to know where I stand, so I don't have to decide now about what may happen in the future' (2010: 280).

The desire for ontological security is also evident in Debbie's recounting of her life story for the media and the subsequent publication of her autobiography. These can be theorised as a way of trying to establish narrative control over the events of her life. The construction of such narratives creates the 'necessary illusions' by which people imagine that their actions and words make a difference in determining the shape of their lives (Jackson 2002: 14). In Debbie's own words, her legal battle has given, and continues to give, her life purpose, now that she has become a recognisable public figure who is called upon to comment on other right-to-die cases that make the headlines. The 'clarity' she wanted to bring to the law has actually brought clarity to her own biographical narrative, particularly her biography-in-illness, at a time when the progression of her MS was depriving her of bodily and ontological security. Her high-profile litigation and the media spectacle which surrounded it has also given her dying (when it eventually happens) an extraordinary aesthetic. It could be argued that it is in the media that Debbie's protracted dying has been recognised in its specificity, not in the court with its focus on the 'technocratic rationalities of law' (Riles 2006: 59) and where the specificities of each case must be downplayed in order to give precedence to general principles of law (Good 2008: S50–51). It is the media which challenges the so-called public absence of death (Walter et al. 1995) by granting extensive coverage to extraordinary deaths such as Debbie's.

## THE JUDGEMENT

Debbie Purdy and Omar Puente's request for clarification from the DPP was refused at the Judicial Review in June 2008 and at the Appeal hearing (which I observed) in February 2009. However, in July 2009, five Law Lords in the House of Lords, the highest court in the UK,<sup>9</sup> ruled unanimously in the couple's favour and ordered the DPP to produce a crime-specific policy identifying the factors he was likely to take into account in deciding whether or not to consent to prosecuting a suicide assistor. Debbie and Omar appeared jubilant outside the House of Lords on the day of the verdict. Standing alongside their lawyers and the Chief Executive of Dignity in Dying, Debbie and Omar smiled and kissed each other affectionately for the assembled press photographers. The legal ruling was the leading story on every TV news channel, and the couple appeared on the front cover of every newspaper in the

country. Headlines focused on Debbie's point, which I cited earlier, that she was not demanding a 'right-to-die' so much as a 'right-to-live-longer': 'This has given me my life back';<sup>10</sup> 'I feel like I have my life back' – Right-to-die victory for Purdy;<sup>11</sup> and 'We've got our lives back' – Debbie Purdy Triumphant'.<sup>12</sup> The five Law Lords determined, in the end, that the law needed to give citizens clarity, and that, in this instance, clarity was unjustifiably lacking. Their sympathies clearly rested with Debbie and Omar: 'It cannot be doubted that a sensible and clear policy document would be of great legal and practical value, as well as being ... of some moral and emotional comfort to Ms Purdy and others in a similar tragic situation' (Lord Neuberger para 101).

The recognition shown here for the law's role in giving 'moral and emotional comfort' seems to contradict the usual association of the law with dispassionate, objective rationality. Nussbaum (2004: 5, 54) argues that while some would like to regard the law as entirely separate from emotions, in reality it ubiquitously takes account of people's emotional states, and the judge's (or jury's) compassion is constantly solicited. In statements such as this, the judges formally acknowledged Debbie's suffering and recognised the law's role in offering her some certainty over the legality or otherwise of possible future actions.

Following the Law Lords' final decision, in September 2009, the DPP produced his 'interim guidance',<sup>13</sup> accompanied by a call for public participation in a 12-week consultation exercise. In the interim guidance, the DPP stated that factors against a prosecution included: the 'victim had a clear, settled, and informed wish to commit suicide'; the 'victim had: a terminal illness; a severe and incurable physical disability; or a severe degenerative physical condition'; and the person suspected of assisting in the suicide was a 'spouse, partner, or a close personal friend' who was 'wholly motivated by compassion'. He made no reference to assistance being received from a medical professional.

Nearly 5000 responses were received from the public and the DPP's final 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide' was published in February 2010. Issues raised by respondents in the public consultation resulted in a fundamental shift of emphasis from the interim policy. Most significantly, all mention of the physical condition of the person being assisted to die was removed. The relationship between the assistor and the person being assisted was also removed. An important added factor which tended in favour of prosecution was whether the assistor was a medical doctor, nurse or

other healthcare provider. These changes are all significant in terms of how they relate more broadly to some of the central conflicts within the assisted suicide debate. Before I move to discuss these conflicts, it should be noted that the existence of a policy of this nature is seen as moving the UK a step closer to effectively decriminalising a non-medicalised form of assisted suicide. It removes the risk of prosecution, albeit within carefully defined parameters, for those assisting loved ones to die both at Dignitas *and* in the UK. Figures released 18 months after the publication of the policy showed that 30 suspected assistors had not been prosecuted (O’Dowd 2011). However, the policy has not quelled the concerns or intense lobbying efforts of either proponents or opponents of assisted suicide. While proponents continue to fight for a formal legal right to a medically hastened death, the most recent manifestation of which is Lord Faulkner’s *Assisted Dying Bill* 2014-2015, opponents continue to demand that the lives of those with a terminal illness or a severe, degenerative or, incurable physical disability are protected.

#### THE POLICY – ASSISTED SUICIDE DE-MEDICALISED AND DECRIMINALISED?

The removal from the policy document of any mention of the physical condition of the person who had taken or attempted to take their own life was a significant victory for those who oppose a change in the law on assisted dying. Their concern centred on the idea that positing a physical condition as a ‘reasonable’ motive for a person wanting to take their own life effectively sent a powerful symbolic statement that life with such a physical disability, whether terminal or severe and incurable, is of a lower quality. By identifying a certain category of person in this way, it is argued that an implicit judgement is made about whole groups of people who are living with severe and incurable illness and disability. As Asch (2001: 302) writes, the cultural emphasis on self-sufficiency leads people to doubt that anyone who cannot execute ‘normal’ life tasks like eating, walking or managing personal hygiene could enjoy life as much as someone who performs these tasks without assistance.

This is what the Italian philosopher Agamben (1998) called ‘bare life’: a human life that is left exposed to death when it becomes separated from its normal political status and the protection of the law.

Lock's (2002) analysis of organ transplantation in Japan and the USA drew attention to the way in which the law creates certain categories of persons in order to facilitate certain outcomes; in her example, the category of the 'brain dead' in order to facilitate the harvesting of organs. To stipulate in a policy document certain categories of ill or disabled persons who would 1) be more likely to want to commit suicide and 2) whose assistors would be less likely to be held criminally accountable, would not just facilitate an outcome of leniency to people in Omar's situation but would also, according to opponents' arguments, send a strong message that certain categories of persons were less worthy of protection by the state. This would likely exacerbate the fears of those currently living with severe illness and disability who had no desire whatsoever to hasten their own death.

An alternative view is that certain physical conditions, specifically terminal or degenerative diseases, can result in bodily and existential suffering, the experience and continuation of which some people can feel is 'unbearable' to them. To be officially diagnosed with a known illness which has severe symptoms is recognised by the majority of people (if social attitudes polling is accurate) as being a reason someone might want to hasten their death. Hausmann's (2004) discourse analysis of press coverage of assisted dying found that illness was nearly always seen as a decisive factor in justifying a sympathetic response to assisting someone's suicide: 'Whereas this sympathy cannot be openly expressed by stating categorically that "serious illness is enough to justify the killing of people", it can be argued that this same sentiment is expressed more subtly by making extensive reference to the poor health of the patient' (Hausmann 2004: 215).

Indeed, a medical diagnosis is a fundamental requirement made of those wishing to die at Dignitas. This is because it is seen to legitimise someone's request to die. However, there is an important qualifier which those advocating for a right-to-die say undermines opponents' arguments that whole categories of persons are assumed to be living 'potentially worthless lives' (Greasley 2010: 324). This qualifier is that the medical diagnosis and the statement that a person is 'suffering unbearably' are necessary but not sufficient conditions for warranting help to die. What is of overriding concern is that a 'considered and persistent request'<sup>14</sup> is made by individuals themselves. To those who support a change of the law, the need for a voluntary request demonstrates that to legalise hastened death would not result in whole



categories of persons being implicitly judged, but would instead show respect for the autonomy of someone who, by their own subjective determination, had judged their own suffering to be ‘unbearable’.

Here we return to the thorny issue of autonomy. As already described in this chapter, the inter-subjective aspect of people’s end-of-life decisions is often obscured by right-to-die rhetoric and its focus on individual autonomy. Debbie may see her death decision as hers alone to make, but how she experiences her suffering on a daily basis is dependent on the care and support she receives from Omar. Biggs (1998) has interrogated this inter-subjective/inter-corporeal aspect from a feminist perspective. She argues that it is no surprise that the loudest voices demanding legal reform belong to women like Dianne and Debbie. She relates this to the gendered nature of care in society as a whole (Young and Cullen 1996), and the fact that women’s perceptions and tolerances of their own illnesses and infirmities are inescapably coloured by their role as carer. Many women feel concerned at the prospect of becoming the cared-for rather than the carer, and this makes them feel particularly vulnerable (Biggs 1998: 294). Similarly, Arber et al. (2008) found that older women were twice as likely as older men to refuse life-prolonging medical technologies, which they attributed to women’s greater life course involvement in caring and empathising with the wishes and concerns of others.

It is such inter-subjective evaluative judgements which made the DPP’s job of producing a codified response very difficult. In trying to write a policy document which was not encumbered by the rhetoric of either ‘side’ in the debate, the DPP decided, on balance, to omit all reference to the physical condition of the person taking their own life. He tried to depoliticise the policy-making process while the campaigners tried to use it as a forum for political action. As a result of his attempts to defuse tensions and limit the scope of his policy, the DPP now has a document that emphasises the compassionate motivation of the assistor, but makes no mention of the motivation of the person who wants to take their own life. Some have argued that ‘this makes the basis upon which the assistor is expected to feel compassion rather unfathomable’ (Biggs 2011: 86).

The second ‘factor’ which appeared in the DPP’s interim guidance and disappeared in the final policy was that of the relationship between the person taking their own life and the person helping them. Being a spouse, partner or a close friend of the person requesting help was not

included as a mitigating factor in the final version of the policy, due to the fact that some relatives might be manipulative. However, while the DPP may have been persuaded that this was not a relevant factor, the media coverage of Debbie and Omar's case suggests that it was deemed to be relevant by journalists and by the wider public. Their relationship also seemed to be of significance to the judges in the Court of Appeal who described Omar's potential assistance with her suicide as a 'final act of devotion' and 'the culmination of a lifelong loving relationship' motivated by 'raw compassion and devoted love' (Para 7,10). In the final House of Lords ruling, their relationship continued to be viewed as significant: 'the difficult and tragic cases where a loving relative assists a person' (Lord Neuberger, para 97). And later: 'the offender will often be a relatively reluctant participator, and will often be motivated solely by love and/or sympathy' (Lord Neuberger, para 102).

The involvement of relatives or 'compassionate friends' in techniques of hastening death is a form of de-medicalised assisted suicide. For many commentators, modern death became over-medicalised in the twentieth century. Illich (1977) was possibly the most scathing critic, declaring the medical profession to be a 'disabling profession' destroying our will to self-care. Howarth and Leaman (2001: 411) refer to de-medicalisation as 'the point at which the medicalisation of social life is turned back, or reversed.' For Ost (2010), the involvement of relatives in assisted suicides might result in a better death than were it to be a wholly medicalised procedure. Ost gives the following reasons for this: that a less medicalised and less clinical procedure would produce 'a less tense affair'; that it might reassure the person concerned that their relatives approve of their decision; and that they will benefit from the emotional support that their relatives provide (2010: 507). It is clear from her reasoning that Ost, like Lord Neuberger, assumes the involvement of a beneficent spouse or relative, which the DPP decided was not an assumption which was likely to reassure the public or properly safeguard 'vulnerable' individuals. As one lawyer I interviewed said, 'There is often a misconception that families actually like each other.'

The third factor which was not part of the DPP's interim guidance but featured in the final policy and which tended in favour of prosecution was if the assistor was 'acting in his or her capacity as a medical doctor, nurse, or other healthcare professional'. Again, this points to the 'de-medicalised' notion of assistance to which the policy

relates. Medicalised forms of assisted dying inspire three predominant fears among those who oppose any change in the law. The first of these fears relates to what is generally known as the ‘slippery slope’ (or what philosophers term ‘consequentialist’ arguments), which is the idea that once the *principle of intentional killing* has been revoked, there can be no future principled opposition to an extension of the law to incorporate other categories of persons who may reasonably be entitled to enlist help to die. The second fear is that hidden pressures will come to be applied to elderly, frail or otherwise ‘vulnerable’ people who may be made to feel a ‘burden’ by others, particularly their relatives, and so avail themselves of the law to satisfy others. Thirdly, there is a fear that legalising medical assistance to die would result in an irreversible change in the medical profession’s ethics and code of practice. For all of these reasons, there continues to be vociferous opposition from a number of parties (not all religious) to a medicalised form of assisted death. The majority of British doctors, for example, do not support assisted suicide, opposition being particularly strong among palliative medicine specialists (Seale 2009). The DPP’s inclusion of a list of healthcare professionals in his ‘reasons in favour of prosecution’ showed his desire to differentiate a version of non-medicalised assisted death, which encompasses those travelling to Dignitas, now effectively decriminalised, from medically assisted death which remains illegal. In 2014, the new DPP amended the policy yet again. This time it was to clarify that healthcare professionals would only face a greater chance than others of being prosecuted if it was shown they had a duty of professional care to the ‘victim’, rather than the fact of their professional identity per se. For example, family carers who happen to be healthcare professionals but who want to assist a loved one to die are not exposed to greater risk of prosecution, neither are retired British doctors who write medical reports for people applying to die with Swiss right-to-die organisations.

The central paradox of the assisted suicide debate is that while on the one hand advocates reject the professionalisation and over-medicalisation of dying and advocate giving ‘choice’ to patients about how and when they want to die, on the other hand they are demanding a medicalised form of assisted suicide whereby it is doctors who would decide who qualifies under any act of parliament and doctors who would supervise the process. A palliative care physician told me that campaigners’ insistence on an entitlement or ‘right’ to a hastened death

assumes that this ‘translates into some kind of obligation for other people to do it ... which is bizarre!’ Certainly there are some pro-campaigners who would like to follow the Swiss model and take the procedure out of the hands of doctors entirely. However, the more mainstream pro-lobbyists would prefer to retain the involvement of the medical profession. One of the most obvious reasons for this is that they are the main gatekeepers of the medications which are required (Lewis 2007: 130). Another reason, I would argue, is that doctors’ involvement imbues that decision or that act with greater legitimacy than receiving help from a relative, friend or Dignitas volunteer. Assisted dying campaigners like Debbie Purdy seem caught up in both rejecting professional determination over their lives and wanting the legitimacy that an official medical diagnosis or legal judgement brings. Professionals have a special position in the political economy and however society may try to rationalise their services, professional ideology is suffused with a ‘transcendent value’ (Friedson 2001: 122) that people want conferred upon their decisions. The question is whether giving doctors the power to decide on someone’s ‘bare life’ (Agamben 1998) is actually in the interests of society as a whole, or whether it dangerously concentrates power in the hands of one profession.

## CONCLUSION

The ultimate conclusion to the case study I have presented here will be Debbie’s death. Whether she dies an ‘artificial’ death with the help of Dignitas, or a ‘natural’ death with or without the help of the pain-easing medications offered by palliative care professionals, her death undoubtedly will gain international media coverage and will be scrutinised by all of those who are invested in the debate for evidence of its ‘goodness’ or ‘badness’. The more immediate outcome of her case which has significance beyond the life of one individual has been the publication of a policy document which for the first time gives the reasons why a person might not be prosecuted for assisting someone to die. The existence of this policy marks a controversial shift in the social sanction of deliberate death in the UK. While it seems fair to assume that most people, regardless of whether they support assisted dying or not, would not want to see Debbie’s husband Omar prosecuted for helping her to travel to Dignitas, there is still a concern, particularly

among those who resist a change in the law, that the policy goes some way towards creating exceptions to the prohibition on killing. Those who, like Dianne Pretty and (possibly, at some future time) Debbie Purdy, might want to be classified as ‘exceptions’ to that prohibition, argue that the law is not protecting them but rather abandoning them to the vagaries of their diseases and to the suffering those diseases cause. For Dianne, it was as if she was being ‘made to live’ (Foucault 2003: 241) by a state which had taken away her human rights. The law had failed to provide a remedy for her suffering. Defenders of the status quo, however, argue that if the state were to enable these women and other people with similarly incurable illnesses to die with the help of a doctor it would create a dangerous exception to the prohibition on killing and thereby expose people to being designated what Agamben terms ‘bare life’ or ‘life which ceases to have any juridical value and can, therefore, be killed without the commission of homicide’ (Agamben 1998: 139). While the DPP’s policy does not apply to so-called ‘mercy killings’, where the would-be helper actually takes the person’s life, this provision is barely enough to stem the rising fears of an opposition concerned about the unintended or unforeseen effects of creating such a legal exception.

In the common law system, once an exception is made, that exception establishes a precedent, which can then ground the logic to establish further exceptions: ‘the ends of one analytical practice become the means of the next’ (Riles 2004: 783). This can be considered the legal ‘slippery slope’ which so concerns those campaigning against a change in the law. Two successive legal challenges have since been brought in order to apply further pressure on the law and exploit the exceptions exposed by Debbie Purdy’s successful appeal: that of Tony Nicklinson<sup>15</sup> and a subsequent appeal brought by his widow, Jane Nicklinson, and two others, Paul Lamb and a man named only as ‘Martin’ (Richards 2014).<sup>16</sup> Effectively, Debbie’s lawyers and the campaigners who instructed them used the law instrumentally to force the development of a key policy document which the British parliamentary system had not seen fit to create. The charge laid against this type of activism is that assisted dying is in danger of being legalised ‘by the back door’,<sup>17</sup> and that the judiciary is overstepping its role.

The ruling in Debbie Purdy’s case provided some remedy for the uncertainty about Omar’s possible treatment by the state following his journey to Switzerland and, according to Debbie, has extended her life

in that she no longer feels the need to travel to Switzerland before she is ready or before her suffering has become ‘unbearable’. However, the existence of the policy has not totally removed uncertainty about Omar’s possible prosecution or provided a remedy for the uncertainty about how Debbie’s disease will progress. Neither the court nor medical science can cure her disease, predict her future suffering or determine how long she will live. While the lawyers in the courtroom spent only a short amount of time outlining the bare facts of Debbie and Omar’s dilemma before moving to debate the general points of law arising from the case, the media obliged the couple with air time and column inches in order to tell the specifics of their story. Debbie’s autobiography, published presumably on the strength of her legal victory, gives her further opportunity to provide a detailed account of her life, including her life-in-illness and her fears about the future. Debbie is now a public figure, an ordinary person whose death planning or death-in-waiting has made for an extraordinary spectacle. Disputing Aries’s view that modern death ‘no longer makes a sign’ (Aries 1985: 266), Walter et al. (1995: 593) have argued that the mass media is where death makes its sign, and does so in a more public and accessible way than the medical discourses of death. The instrumental use of both the law and the media in Debbie’s case gave a platform to those trying to apply pressure on the government to change the law on assisted dying. Her legal victory and the opinions of the judges validated her account of her suffering, while the official written policy made public an ‘implicit legitimisation’ of her option to go to Dignitas (Greasley 2010: 325). Debbie’s successful legal case has provided further impetus to the pro-campaigners to bring more test cases to the courts and has helped them to apply political pressure on the lawmakers in London. As long as people continue to opt for the services of Dignitas, and these journeys are reported in the media, the public will be reminded that there are certain types of suffering which lie beyond the scope of the medical profession to ameliorate.

## POSTSCRIPT

In December 2014, it was widely reported in the British media that Debbie Purdy had died as a result of refusing food and fluid at a hospice in the north of England. In a ‘final article’ published in *The Independent on Sunday* in January 2015, reportedly penned by Debbie herself before

her death, she describes how life since 2012 had become ‘unbearable’ to her, following a worsening in her MS. She wrote that both she and Omar were concerned, despite the CPS policy, that Omar might still be prosecuted if he helped her to travel to Switzerland, due to the fact that ‘Omar is black’. She therefore determined to end her own life without assistance, by refusing food and fluid.

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## NOTES

- 1 Amended in 2009 by the Coroners and Justice Act
- 2 Simon Gillespie, Chief Executive of the Multiple Sclerosis Society, in evidence to the Commission on Assisted Dying 23 March 2011, available online at [www.commissiononassisteddying.co.uk/wp-content/uploads/2011/04/Simon-Gillespie-Transcript.pdf](http://www.commissiononassisteddying.co.uk/wp-content/uploads/2011/04/Simon-Gillespie-Transcript.pdf)
- 3 This term is from the Dutch *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002* and was also used in the UK's *Assisted Dying for the Terminally Ill Bill*.
- 4 It is useful to mention terminological distinctions here. Dignity in Dying draws a distinction between 'assisted dying', defined as assisting a terminally ill, mentally competent adult to shorten the dying process at their request, and 'assisted suicide', where the person asking for help is chronically, but not terminally ill (Wootton 2010). While this terminological distinction is not widely adhered to by those in the right-to-die movement, I regard it as a useful distinction to make and so have conformed to this terminology throughout the chapter.
- 5 Section 2(1) of the Suicide Act was amended by the Coroners and Justice Act 2009. The language was updated from 'aid, abet, counsel or procure the suicide of another' to 'encourage or assist', but the criminal offence remains the same.
- 6 Article 8: 1) Everyone has the right to respect for his private and family life, his home and his correspondence. 2) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.
- 7 The case involved a 68 year old man with paranoid schizophrenia who had developed gangrene in a foot while serving a prison term. Despite being told he had only a 15% chance of survival if his lower leg was not amputated, the man refused the operation saying he preferred to die with two feet than to live with one. The

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- hospital questioned his capacity to exercise his autonomy in this matter, but the court held that although his general capacity to make decisions was impaired by his schizophrenia, he understood the ‘nature, purpose and effects’ of the treatment being refused and so was within his rights ([Mason and Laurie 2006](#): 375).
- 8 Ms B was paralysed from the neck down and her life was sustained only by a ventilator. She requested that the ventilator keeping her alive be switched off. The dilemma for the doctors was whether she had legal capacity to make such a decision. After conflicting psychiatric reports about her mental capacity, her case went to court and the judge presiding attended Ms B’s bedside to hear her story and assess her mental capacity in person. Ms B was found competent to make the decision and the ventilator was switched off. As a symbolic gesture, notional damages of £100 were awarded in recognition of the technical assault that the health carers had committed by continuing to treat Ms B against her wishes ([Mason and Laurie 2006](#):377).
  - 9 It has now been superseded by the Supreme Court.
  - 10 *The Daily Mail*, 31 July 2009.
  - 11 *The Guardian*, 31 July 2009.
  - 12 *The Independent*, 31 July 2009.
  - 13 [www.cps.gov.uk/consultations/as\\_policy.html](http://www.cps.gov.uk/consultations/as_policy.html)
  - 14 This was the phrase used in the House of Lords *Assisted Dying for the Terminally Ill Bill*.
  - 15 In 2012, Tony Nicklinson, who was paralysed from the neck down and unable to speak following a stroke, sought a declaration from the courts that it would not be unlawful, on the grounds of necessity, for a doctor to assist in the termination of his life. Mr Nicklinson was represented by the same lawyers as Debbie Purdy, and, as in her case, they also appealed to Article 8 of the ECHR (respect for private life). Mr Nicklinson lost his case and died of pneumonia six days later after refusing food and fluids.
  - 16 In 2013, Jane Nicklinson (Tony Nicklinson’s widow); Paul Lamb, who is paralysed from the neck down following a car accident; and a man named only as ‘Martin’, who has locked-in syndrome, appealed the decision of the High Court in *Re Nicklinson (on the application of) v Ministry Of Justice [2012]*.
  - 17 Richard Hawkes, Chief Executive of Scope, in ‘People who assist suicide will face test of motives, says DPP’, *The Guardian*, 25 February 2010.