

4 It's my life – it's my decision?

Assisted dying versus assisted living

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I do not hold a moral, religious or ethical position on the right to live or die. Like many other disabled people who live close to death, my perspective is purely practical. In this chapter, I look at two sets of circumstances, one in which disabled people have sought to change the law and one in which we are fighting to maintain the status quo. The first concerns the existing right of doctors to cease to treat a patient if, in their clinical judgement, it has no benefit and would prolong intolerable suffering. The second involves the on-going campaign for the legalization of assisted dying and voluntary euthanasia.

Society today still discriminates against people with severe disabilities and illnesses. Our lives are seen by many as inferior to those of non-disabled people. Against this background, there is the inherent danger that actions to withdraw treatment and legalize assisted dying will place disabled people at greater risk. These issues were well explored in two recent attempts to change current UK legislation, one heard in the High Courts of Justice and the other in the House of Lords.

Withdrawal of treatment

The issue of withdrawal of treatment was central to the case of *R (Burke) v. The General Medical Council (GMC)*¹ heard in the High Court in 2004 which concerned Mr Oliver Leslie Burke, a 43-year-old man with cerebella ataxia. The GMC is the body charged by the UK Government with regulating the medical profession. Mr Burke challenged guidelines issued by the GMC concerning the withdrawal of life-prolonging treatment on the grounds that it was unlawful and incompatible with Articles 2, 3 and 8 of the European Convention on Human Rights (Articles 6 and 14 were also invoked). Specifically Burke claimed that 'a patient is entitled to have the question of whether or not care in the form of artificial nutrition and hydration is withdrawn resolved by a court or tribunal in accordance with Article 6(1)'.

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And that

where death is not imminent, the withholding or withdrawal of artificial nutrition and hydration, leading to death by starvation or thirst, not through natural causes, would necessarily be a breach of the claimant's rights under Articles 2, 3 and 8 and would be unlawful under domestic law.

To familiarize the reader with Leslie Burke's precise concerns, it is worth quoting brief extracts from the relevant Articles of the European Convention on Human Rights (1950) cited in his claim.

- Article 2 states: 'Everyone's right to life shall be protected by law'.
- Article 3 states: 'No one shall be subjected to ... inhuman or degrading treatment ...'
- Article 6 states: 'In the determination of his civil rights ... everyone is entitled to a fair and public hearing ... by an independent and impartial tribunal established by law'.
- Article 8 states: 'Everyone has the right to respect for his private and family life ...'
- Article 14 states: 'The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination ...'²

These rights are recognized by UK law – in both our common law and the Human Rights Act 1998. In the main the court found for Mr Burke, although the GMC overturned much of the judgement on appeal. Nevertheless, this case was of great significance to disabled people who felt as Leslie Burke did, that the withdrawal of life-prolonging ANH (artificial nutrition and hydration) should not be at the sole discretion of the doctor.

Leslie Burke's case challenged the current power relationship between doctor and patient. Burke believed *each* party had a breadth of knowledge and experience not available to the other. In addition, he argued that it should be ultimately his decision to continue receiving food and water and to 'die naturally'.³ In the judgement, Mr Justice Munby considered the knowledge base of both patient and doctor to be of equal merit and determined that neither should take precedence over the other *as a matter of course*. He concluded that, if the patient so wishes, life-prolonging treatment should be provided unless, if by doing so, it prolonged a situation that 'from the patient's point of view [would] be intolerable'.⁴

Many of us saw the judgement as a significant achievement for disabled people's rights. First, for our future safety because many felt the quality of their lives would be questioned when they became highly incapacitated; and second, because the court understood, perhaps for the first time, that doctors should not be asked or expected to pass sole judgement on what is 'in the best interest' of the severely ill or disabled patient. Disabled people felt

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the judgement raised their status from passive recipient of care to 'expert patient'.⁵ In addition many physicians across the UK were equally relieved, many agreeing that the patient or their chosen, trusted close relatives, friends and advocates are in the best position to make such life and death decisions.

In my opinion Mr Justice Munby sought to strike a balance between the patient's wishes and the doctor's professional judgement. He highlighted parts of the GMC's guidance that failed to give equal weight to patients' expertise in their own situations and their right to make decisions about the withdrawal of their end-of-life treatments.

For example, the doctor's only obligation under part of the guidance is to 'take account of' what are referred to as the competent patient's 'wishes', 'preferences' and 'views'. Having done so, he is not required to take heed of the same. It rests with the doctor in charge of the patient's care to 'make the decision' regarding whether or not to withdraw treatment.

In addition, the guidance places too much reliance on the doctor's assessment of the patient's 'quality of life' in determining 'best interests'. Recognizing that doctors can and do share many of society's fears and prejudices about disability, the court decided that a higher test of 'intolerability' was needed.⁶

This judgement, although short-lived, in my view, went some way to redress the balance of power as to who decides, and on what grounds, life-prolonging treatment is to be withheld or withdrawn. It challenged the historical relationship between doctor and patient and decided that greater equality was needed. For severely disabled people it made us feel safer too. It would have resulted in an environment of knowledge about the life, or expected life, of the patient, beyond their diagnosis.

Subsequently the Court of Appeal overturned much of the judgement. In the opinion of the Appeal Bench, common law provides sufficient safeguards for the competent patient, i.e. a person who is able to communicate his or her wishes. In the case of incompetent patients, i.e. those no longer able to communicate their views, artificial nutrition and hydration should not be withdrawn until the doctor had considered the views of those caring for the patient and his or her relatives. In cases of doubt or conflict, the case must be referred to the courts to decide.

Mr Burke then appealed to the European Court of Human Rights (ECtHR). Regrettably, the Strasbourg Court approved the view of the Court of Appeal that it is not for the High Court to authorize medical actions but merely to declare whether a proposed action is lawful. Doctors are fully subject to the sanctions of the criminal and civil law and would only be recommended to obtain legal advice, in addition to proper supporting medical opinion, where a step is controversial in some way. Any more stringent legal duty would be 'prescriptively burdensome'.

In so far as having his views taken into account once he becomes incompetent the court considered that Mr Burke is able to make a living will or

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advance statement. Mr Burke's concern remains that once he loses competence to determine his own best interests, doctors may decide to withdraw ANH without being under an obligation to obtain the approval of the High Court first.

Mr Burke commented:

I am to say the least extremely disappointed with the ruling from the ECtHR, I only hope that if I am lucky enough to be in hospital, the doctors treating me will not believe at some stage that it will be in my best interests for ANH to be withdrawn even when death is not imminent, effectively letting me die of starvation and thirst when I am no longer able to communicate my wishes.

I will be making a living will, even though it will give me no comfort, for as it stands living wills are not legally binding and can be disregarded if the wishes contained conflict with the doctor's view.

Despite the reassertion that medical authority must prevail, Leslie Burke's case attracted significant media interest which sparked much debate both within groups of disabled people and wider society. Disabled people were shocked to realize that their lives could be ended prematurely against their wishes. In the mainstream media, the fact that a severely disabled person with a progressive condition did not crave death was seen as newsworthy, demonstrating yet again how disability is perceived as a fate worse than death. Mr Burke was well able to articulate his position and there was widespread sympathy for his desire for certainty that he would never experience the withdrawal of artificial nutrition and hydration, even when close to death. The Disability Rights Commission (DRC) intervened in his case and I was pleased to be one of those who gave expert witness testimony to the court in support of his application.

The Leslie Burke case sought equality in the relationship between patient and doctor. In essence his view (and mine) is that the doctor alone must not decide when to withdraw treatment. The intention of campaigners for the legalizing of assisted dying seeks to strengthen the patient's position further, so that he or she may request death. Would this step provide the ultimate choice and control over one's life that disabled people have fought for decades? In my opinion, such a move would not liberate us further, but would take us backwards, leading to less choice and control. It would be a 'negative right', endangering countless more disabled people than it seeks to help. In this next section I will set out my reasons for believing this to be the case.

Assisted dying

On 12 May 2006 the House of Lords debated Assisted Dying for the Terminally Ill, a Private Member's Bill presented by Lord Joffe. The Bill

had the backing of the Voluntary Euthanasia Society (recently renamed Dignity in Dying) and, according to their polls, the support of the British public. Yet the Bill failed to get the endorsement of a single organization of disabled people, and the Disability Rights Commission came down firmly against its passage. Three major national disability charities condemned it and a fast growing number of individual disabled people mobilized under the banner Not Dead Yet UK⁷ to make their concerns heard.

So why were so many people the Bill was intended to help, terminally ill and disabled people, so frightened by what it sought to achieve? The answer is that this is not a simple matter of increased choice for those disabled people who live their lives close to death. It raises deep concerns about how disabled people are viewed by society and by themselves. Many people who do not know anyone with motor neurone disease, multiple sclerosis or my own impairment, spinal muscular atrophy, believe we would be better off dead. Society's obsession with the body beautiful only reinforces the negative stereotype that disability is equal to a state worse than death. Even more assert, 'I couldn't live like that!'. Due to this predominant social negativity, life-and-death decisions about disabled people will always be influenced in a discriminatory way. Lord Joffe's Bill fed into this culture by endorsing these views and seeking to sanction the killing of terminally ill and severely disabled people (albeit at their request) as a solution to extreme situations of what they saw to be personal suffering.⁸

In order to understand the public's apparent call for voluntary euthanasia we need to explore further the social context underpinning this demand. Terms such as 'wheelchair bound' and 'handicapped' appear daily in the press without their pejorative meaning being questioned. Despite a growing international awareness of disability as a human rights issue, the notion of elimination of our specific diversity is supported.

In the words of Professor Mike Oliver:

We know the Nazis killed 200,000 disabled people in Germany but we still practise death making in the here and now and still hidden from view. We avert our eyes just like the Germans did all those years ago. There are no gas chambers but there are things going on that we talk about in hushed tones using terms like 'euthanasia', 'mercy killing' and 'termination'.⁹

It is a sad fact that a large part of the public thinks disabled lives are flawed or simply not worth living. In a recent UK newspaper poll 32 per cent said they would want to abort the pregnancy if they found they were carrying a disabled child.

This societal backdrop influences the medical profession as it does everyone else. Doctors are subject to the same cultural messages and negative stereotyping of disability as everyone else. For example, as pointed out by Dr Ian Basnett,

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research on the attitudes of accident and emergency doctors found that only a fifth imagined they would be glad to be alive if they were quadriplegic, whereas over 90 per cent of people with quadriplegia reported they were glad to be alive'.¹⁰

If therefore, assisted dying were to be made legal, we could not necessarily depend upon the medical profession to be the custodians of an assisted dying, 'second opinion' safeguard. Dr Ian Basnett illustrated this well in an article for the *Observer* newspaper,

I became quadriplegic following a sporting accident 17 years ago. I was ventilator dependent for a while and at times said to people, 'I wish I was dead!' I am now extraordinarily glad no one acted on that and assisted suicide was not legal. I think the first difficulty I faced was the fact that, like many people, I had a terribly negative image of disability. When you suddenly become severely disabled you still have that viewpoint. Before I was disabled, I was working as a junior doctor. That brought me into contact with disabled people and I remember clerking in a man with quadriplegia. My reaction was, how could anyone live like that? I said to my then girlfriend, 'I'd rather be dead, if I couldn't play sport'.¹¹

Proponents of the Bill claimed safety was not an issue, citing the 20-plus 'safeguards' contained in the Bill to 'ensure that only competent adults who have made a considered and persistent request would be entitled to use it'.¹² Supporters of the Bill claimed it was only intended to help that small minority who, in a similar situation to my own, do not think as I do but want to die. They say that the Bill was not about disabled people but those who are terminally ill, in the last few months of their lives. They cite people having conditions such as multiple sclerosis and motor neurone disease as the potential beneficiaries of this law. This angered the disabled people's movement in Britain, as people with these conditions *are* disabled people. The Dignity in Dying campaigners sought to separate out impairments like MS as 'terminal illnesses' and therefore feed into the medical model of disability.

One may feel it is a compassionate act to help someone end a life that is intolerable to them. The danger is the assumption that disability, in this case the physical conditions brought about by multiple sclerosis etc., is sufficient to explain the intolerable nature of a life.

The relentless dictate that certain medical conditions will affect our lives and those of the people around us is used unashamedly by Dignity in Dying and others who campaign for legalizing euthanasia. When the language used is of someone with MS being 'incurably ill', and descriptions of those who wish to assist them to die as performing 'supreme acts of compassion', we start to understand the strength of such a negative medical model.

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Every day disabled people are made fully aware of how their quality of life is contingent on the goodwill of others. There is no right to Independent Living Support or palliative care. As the Joffe Bill said – the patient should be ‘inform[ed] of the benefits of the various forms of palliative care’, but there is no guarantee in law that such care will be available.

As might be reasonably expected, the views of individual disabled people are sometimes at odds with the collective consensus. Diane Pretty was a British disabled person who went as far as the European Court of Human Rights to fight for her legal right to be assisted by her husband to die. What alarmed me and confirmed my fears about assisted suicide was the public and press response to her situation. Every newspaper supported the ‘mercy killing’ of those who suffer from terminal impairments.

Diane Pretty was presented to the press as a tragic and pathetic individual. She received maximum coverage, none of which ever questioned, even fleetingly, her suicidal tendencies. Indeed when she said on camera, ‘I’m already dead’, her misery was in no doubt, no one bothered to look further than the illness for additional causes of hopelessness. The collective view was that ending her life was the only way to put her out of that misery. Against this backdrop the general public could be forgiven for believing that anyone with a substantial level of disability will inevitably be deeply depressed and preoccupied with thoughts of dying. However, when disabled people like me contemplate this reasoning we shudder. I never met Diane but I wish we could have spent some time together. Her life was very different from mine and I would have liked to know the reasons for that. Did she choose to live confined in a downstairs room rather than have adaptations to her home or be rehoused? Did she want her husband to be her full-time carer rather than accept more support from social services? Why was she not fully confident of how her medical team would take care of her as her illness progressed?

Whilst despair is a common reason for contemplating suicide, research evidence from palliative care specialists shows that most people who seek assisted suicide give ‘not wanting to be a burden’ as the principal reason for seeking death.

Epithets such as ‘tragic’, ‘burdensome’ and even ‘desperate’ are frequently used to describe disabled people’s lives, and unless you are extraordinarily strong it’s all too easy for disabled people to succumb to this negativity and internalize this oppression which could end in their suicide.

There is thus concern from disabled people’s organizations about the language used to describe end-of-life situations for disabled and terminally ill people. Often words are used which convey the fears of the able-bodied rather than the realities of disabled people. That such conjecture might too easily be enshrined in law can be demonstrated by this extract taken from the report of the House of Lords Select Committee on the Assisted Dying Bill.

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The need for qualifying conditions for assisted suicide or voluntary euthanasia to be set which reflect the realities of clinical practice as regards the prognosis of terminal illness and which define a patient's suffering in as objective a manner as possible – e.g. 'unbelievable' rather than 'unbearable' suffering.¹³

Unbearable suffering is not just a matter of physical pain. For example, someone may find life 'unbearable' when they have become physically unable to communicate and cannot afford the equipment that would enable them to have a vital connection with their family and others around them. In one US case a man fought vigorously for the right to die via the courts and media coverage highlighted his communication impairment. A software company provided specialist equipment and others raised funds to provide him with home-based support. With this support and equipment he regained the dignity and independence he thought was lost forever and decided that he no longer wished to die. Life was 'bearable' again.¹⁴

Returning to the Leslie Burke case, Mr Justice Munby emphasized a patient's right to refuse treatment when, 'from the patient's point of view', their situation has become intolerable. For outsiders to assume that the condition itself is the locus of unbearable suffering is to ignore the social, economic and personal context of disability. Society was content to consign Mrs Pretty to the graveyard, yet no one has proposed a similar end for Professor Stephen Hawking. Surely, if the Mrs Prettys of the world are so different that they would be better off dead then the same should be said of Stephen Hawking? Or do we want Hawking to live because of his intelligence? To grade the disabled population in this way one must rely on prejudice since no logic or reason is found there.

I have been fortunate to benefit from excellent medical care. I live in an adapted bungalow, my local authority (government) provides proper care support in the form of a direct payment package that enables me to select and employ personal assistants. I have a powered wheelchair and other assistive technology, some of which I used to write this chapter. Without this social and health care support, I am quite sure I would feel suicidal. Lord Joffe and others who supported his Bill place too little value on the importance of public service support with personal well-being.

Services inevitably involve costs and although in Britain we have a National Health Service and public social care provision, choices offered to disabled people are resource-based. Assisted dying could become an insidiously 'attractive' and inexpensive option in comparison to funding the treatment and support disabled people need. This is of particular concern given that a survey by the Nuffield Trust and the *Nursing Times* found that the NHS is already failing to care adequately for hundreds of thousands of patients who die each year, many without proper pain relief.¹⁵ If assisted dying were to become law, the relationship between caregivers and receivers would be irrevocably damaged.

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Apart from fears of burdening loved ones or indeed society, people also cite pain as a reason for wanting the option to call upon others to assist them to die. If you are asked, 'Would you prefer to be assisted to die rather than be in "unbearable" pain?', the answer seems straightforward. But is it? Alison's story is a powerful example of why pain as eligibility criteria for assisted dying is too tenuous.

I am 47 and was born with severe spina bifida. I am completely dependent on my wheelchair for mobility. I am doubly incontinent and I have the lung condition emphysema which often makes breathing very difficult. I also have osteoporosis (brittle bones) which has caused my spine to collapse, trapping nerves. This causes extreme pain which is not always controlled, even with morphine. When the pain is at its worst I cannot move or speak. This can go on for hours, and there is no prospect of relief. Some years ago a combination of the above led me to feel that I couldn't go on living. For ten years I wanted to die and I made several serious attempts to kill myself. I hoarded painkillers and swallowed huge overdoses, washing them down with whatever alcohol I could lay my hands on. I wanted death, and I knew exactly what I was doing.

Fortunately for me, I have friends who were brave enough to intervene, who called 999 and had me rushed to hospital. I was treated against my will more than once.

If euthanasia had been legal, I would certainly have requested it and I wouldn't be here now. In fact, under the rules that now apply in Holland, I would have qualified for euthanasia. Two things helped me realize that, in spite of my many disabilities, life can be sweet.

The first was my friends who refused to accept my view that my life had no value. They helped me re-establish a sense of my own infinite human value, a value which isn't diminished by being severely disabled and having to depend on others.

The second was that I went to India to visit two children I had been sponsoring through a project to help those with disabilities. They called me mother and I became part of their lives – they were to change my life completely.

Alison went on to form a charity providing assistance to disabled children in India. Alison is not unique. The Royal Association for Disability and Rehabilitation (RADAR) has published a booklet, 'Assisted dying – the facts', which includes a collection of personal stories similar to Alison's.¹⁶

Having looked at the evidence from Holland and listening to the eminent physician, Professor Lord McColl in the House of Lords last spring, I am also persuaded of the so-called 'slippery slope' argument against legalizing assisted dying. He said,

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When a Dutch doctor was asked what his first case of euthanasia was like he said, it was dreadful. 'We agonised all day. But the second case was much easier and the third case was a piece of cake.' Many elderly people in Holland are so fearful of euthanasia that they carry cards around with them saying that they do not want it.¹⁷

Lord Joffe's attempts to draft and redraft the Assisted Dying Bill further illustrate the problem of the slippery slope. Following each previous rejection, he has returned to Parliament with a more restrictive Bill. His most recent version of the Bill contained two further safeguards. First assistance would be given only to the 'terminally ill' – the 'disabled' were to be excluded, so we supposedly had nothing to fear. Second, the doctor would be permitted only to prescribe the lethal dose, requiring the patient to self-administer and thus protecting anyone requesting assistance to die but then having a change of heart.¹⁸

A moment's thought will quickly show that these are not safeguards but mere devices to silence objectors. The more restrictive the Bill, the easier it is to argue for its scope to be expanded once it has passed into law. None of us will be safe. Consider two patients lying side by side in hospital. Both ask their doctors to prescribe lethal medication. Although their symptoms and prognosis are similar, one has a terminal illness whereas the other is classed as disabled. One gets the drugs, the other does not. Or will the second patient be reclassified? Then consider the patient with a progressive condition. Better to swallow the lethal dose this week, than risk being too ill to do so next week. Were assisted dying to be legalized, such inequalities would create pressure for the safeguards to be relaxed. When would that process stop? When assisted dying becomes just another treatment option available to all?

Lord Joffe has said on more than one occasion that he does not believe legislation should be as restrictive as his proposed Assisted Dying Bill. To have any chance of success, he knows that he must play the long game as part of his strategy of eventually achieving legalized assisted dying for all groups who say they are suffering unbearably.

I would argue that society has a duty to relieve such suffering, ~~however experienced,~~ rather than use death as a way of sweeping it away. Without good palliative care, someone near death may find life 'unbearable'. Someone who is disabled long-term may find life 'unbearable', if there is inadequate home-based support, e.g. if they have to live in an institution or in undignified circumstances at home.

There is now increasing pressure from the Independent Living Movement to stop disabled people being institutionalized against their will. This has been taken up by Lord Ashley in a Private Member's Bill.¹⁹ Some disabled people engaged in this campaign have spoken openly about how they would rather die than live in institutional care. Undoubtedly, this is campaign rhetoric; however there is more than elements of truth behind the fear.

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There needs to be policy imperative from the British Government to introduce an agreed entitlement to essential community living support services and palliative care so that people do not feel a burden – this needs to extend to cover support for family members and carers. That way ‘unbearable’ suffering could be turned into a bearable life – and in turn a more bearable death.

Those who argue that sufficient safeguards can be included in any proposed legislation to weed out those who could be helped with palliative care or social service support need to reconsider. The last Joffe Bill claimed to apply to people with just weeks or months to live. The reality is that there can be no watertight safeguards to determine whether a person is indeed terminally ill and in the last months of life, neither whether they are ‘suffering unbearably’ nor whether the cause of that suffering is the actual illness or unmet physical, mental or social needs.

Who ‘qualifies’ for the right to be assisted to die under proposed legislation is therefore highly contestable. Not only would this present doctors with impossible dilemmas about when to treat and when to assist to die but, if physician-assisted suicide were once to be legally sanctioned, then *limiting* access to such assistance to die could be said to be discriminatory.

For this reason there would inevitably be calls to extend the legislation over time to include more and more people in the name of equality and human rights (as has proved to be the case in Holland). The slippery slope that so many reject as anecdote will reassert itself.

Legalizing premature death as a treatment option will place the seed of doubt about one’s right to demand help – not to die – but to live with dignity. I believe it may place pressures on people who think they are close to the end of their lives to consider death as preferable to fighting for support to live with dignity.²⁰ It will be the cheapest, quickest and simplest option. In addition, consider older people who are anxious not to cause their families any distress.

Fear of dependency and being cared for is not without good grounds. A local newspaper reported in 2005 that an elderly mother was compelled to wash her disabled adult daughter with a bucket and flannel because support services were unable to fund the level-floor shower they had been assessed as needing.²¹ This could be deemed ‘unbearable suffering’. It may also be ‘unbearable’ to witness your partner become exhausted and to feel you are now nothing but a ‘burden’. Studies in Oregon and Holland find that a substantial proportion of people seeking assisted deaths again give ‘not wanting to be a burden’ as their reason. Believing oneself to be a burden strikes at the heart of our feelings of self-worth.

Rachel Hurst, in her plea to the bioethics community at their fifth world congress said,

It takes a particular sort of courage to rise above these negative impacts and have a faith in your own worth, or the worth of your disabled family

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member. It takes courage and a clear understanding that disability arises from the social barriers of attitude and environment to your impairment, not the impairment itself. A similar sort of courage and understanding has been needed by women as they overcame the discriminatory images of subservience and earth mother or the courage and understanding that have been needed for black people to overcome slavery and apartheid. Just as we all recognise that society needs the difference of women and people of different races and backgrounds, so society needs people with impairments.²²

I believe the background noise to this debate is reinforcing negative perceptions of disability. It feeds into desires for a body beautiful and a perfect life untroubled by illness. It promotes premature death as a choice option, especially for people with severe disability or terminal conditions. This choice agenda is false because it will insidiously lead to less choice. To make a real choice we need to live in a society that values us equally, where we can live with dignity and have access to proper pain relief. In the safety of that environment, perhaps then we can turn our attention to assisted dying. Disabled people who currently live under a cloud of uncertainty as to whether their lives are worth living will then be in a better position to debate about a real choice, to end their lives. Personally, when and if that time comes, I do not think people will want a right to assisted dying in such a supportive climate.

Thankfully, there is an antidote to Lord Joffe and his solution to personal distress. As mentioned earlier in this chapter, Lord Ashley's Right to Independent Living Bill seeks to guarantee the services that terminally ill and disabled people need to live with dignity. It is a Bill of hope whereas Lord Joffe's was the Bill of fear.

Sometimes academic debate does not get to the heart of the matter, so I will end this chapter with a poem. This poem was written by Micheline Mason, a disabled writer and poet whose leadership of the inclusion movement is known throughout the world.

Not Dead Yet

I have lived to see another spring
To breathe in the blossom's perfumed air
To feel again the sun warming my skin
To wonder at the life we share

I have another chance to notice
Shining eyes meeting my own
Some with love, some with questions
The hope, fear, pain we have all shown

I can touch again those I care for
With my hands, my mind, my heart

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They touch me as if for the first time
New thoughts, our dreams just start

Physical pain I have known plenty
Impairment holds little fear for me
But to feel unwanted, a burden, a weight
Is the intolerable pain I flee

The answer cannot lie in murder made easy
In fuelling guilt, complicity and dread
It lies in the courage to create a kinder world
In which no one would choose to be dead

Happily, I am not dead yet
I have lived to see another spring
I will use every precious moment I have left
This welcome change to bring²³

Notes

- 1 [2004] EWHC 1879 (Admin); [2005] 2 WLR 431.
- 2 Council of Europe, The European Convention on Human Rights (Rome, 4 November 1950) and its Five Protocols (Paris, 20 March 1952, Strasbourg, 1963–1966), considering the Universal Declaration of Human Rights proclaimed by the General Assembly of the United Nations on 10 December 1948.
- 3 Radio 4 news broadcast, 29 July 2005.
- 4 Judgement at para. 213(o).
- 5 The Expert Patients Programme (EPP) was instituted in April 2002 by the Department of Health, as a National Health Service programme that recognizes and supports patients' rights to take charge of their own conditions and treatment.
- 6 Judgement at para. 211.
- 7 Not Dead Yet UK, founded in 2006, is a network of over 100 UK-based disabled people opposed to assisted suicide and euthanasia. Their activities are organized through the website www.livingwithdignity.info. Not Dead Yet UK shares many of the principles and views with its US-based cousin, Not Dead Yet, founded in 1983: www.notdeadyet.org.
- 8 I refer the reader to my earlier point that the Disability Rights Commission has withheld its support of Lord Joffe's Bill, in part because people with terminal illnesses are likely to be classified as disabled people under the Disability Discrimination Act.
- 9 Oliver, M. (1999) 'Disabled people and the inclusive society', public lecture, Strathclyde Centre for Disability Research.
- 10 Paper presented by Dr Ian Basnett, Labour Party fringe 2004.
- 11 *Observer*, Sunday 31 March 2002.
- 12 Taken from 'Questions and answers on the Assisted Dying for the Terminally Ill Bill 2005–6', on the website: <http://www.dignityindying.org.uk>
- 13 Select Committee on the Assisted Dying for the Terminally Ill Bill Evidence 2004–05 [HL].
- 14 DRC Assisted Dying Policy Statement, October 2005.
- 15 'How do you deal with death?', *Nursing Times*, 1 February 2001.

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- 16 Royal Association for Disability and Rehabilitation (RADAR) 'Assisted dying – The facts', 2006.
- 17 House of Lords Official Report (Hansard), 12 May 2006, column 1285.
- 18 The Assisted Dying for the Terminally Ill Bill [HL] states:

'terminally ill' means an illness which in the opinion of both the attending and consulting physician (a) is inevitably progressive, (b) cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily), and (c) will be likely to result in the patient's death within six months'.

Clause 1 of the Bill states:

Subject to the provisions of this Act, it shall be lawful for (a) a physician to assist a patient who is a qualifying patient to die (i) by prescribing such medication, and (ii) in the case of a patient for whom it is impossible or inappropriate orally to ingest that medication, by prescribing and providing such means of self-administration of that medication.

- 19 Disabled Persons (Independent Living) Bill [HL], second reading in the House of Lords on 8 June 2006.
- 20 Among those denied euthanasia or PAS by the GPs, 'not wanting to be a burden', 'tired of living,' and 'depression' were reasons most often given by patients to justify their death requests (p.1699). Jansen van der Weide, *et al* 'Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide', *Arch Intern Med*, 165, 8/22 2005.
- 21 *East Anglian Daily Times*, 16 July 2005.
- 22 Hurst, R. 'Ethics and disability, celebrating diversity', paper given to 5th World Congress on Bioethics, 2000, Sydney, Australia.
- 23 Micheline Mason, 2006.