

Qualifying for the Right to Die -A Dubious Privilege: Assisted Dying for the Terminally Ill

Michele Wates

Draft of a conference paper presented at *Making Sense of Health, Illness and Disease* Mansfield College, Oxford July 2005, Inter-disciplinary.net: developing the future of learning, 4th global conference

As other papers presented at this conference have reminded us, illness is a socially defined phenomenon as much as it is a physical reality.

Over the course of the 20 years that I have lived with a progressive illness I have come to realise that society's view of the value and acceptability of my experience as a disabled person is often at odds with my own perspective as someone who lives with that reality from day-to-day. A woman I hardly knew once said to me, with disarming honesty, albeit with an awesome lack of tact, "If I was suffering from an illness like yours, I would probably kill myself ". I was aware that she was voicing a view that may be widely shared, though seldom expressed.

It is not only that some people believe that it would be better to die than to become disabled themselves, but also their belief that many disabled people (including those still very young or unborn and those who are for one reason or another not physically in a position to express a view on the matter) would be better off dead.

In the United Kingdom a Private Member's Bill on Assisted Dying for the Terminally Ill written by lawyer Lord Joffe and supported by the Voluntary Euthenasia Society (VES) has this year cleared the hurdle of consideration by a select committee at the House of Lords, passed its formal second reading and is now ready, as and when the government of the day decides that the time is right, to go to the House of Commons. If it is passed, this Bill will establish the legal right of

terminally ill people to physician assisted suicide. Throughout this paper where I refer to legislation, unless otherwise stated, I am referring to the Assisted Dying for the Terminally Ill Bill here in the UK.¹

The tone and thrust of public debate, reflected in a number of articles, radio and television programmes, films and plays suggest that society is in favour of such a change in the law and that it may only be a matter of time before it happens.

I believe that it is both timely and necessary at this point to question the wider implications of such a far reaching change to legislation. As someone with a long-term progressive illness and as a campaigner for the rights of disabled people I argue that we should regard with extreme caution the language of anti-discrimination, choice and human rights frequently used by those who promote the notion of legalising assisted killing.

It is necessary to question whose right to life might be undermined by establishing the right to die.

I should like at this point to summarise my arguments. Firstly, if physician assisted suicide was once to be legally sanctioned then *limiting* access to such assistance to die could be said to be discriminatory. For this reason the right would be extended over time to more and more people in the name of equality and human rights.

Secondly, moves to legalise assisted killing for the terminally ill have to be seen within the context of society's prevailing assumptions about disability and long-term illness.

Thirdly, the existence of assisted dying as a legal and relatively easily accessible option will have the undesired effect of undermining the provision of palliative care, treatment for depression and society's commitment to support independent living.

Fourthly, the availability of assisted dying as a legal and relatively easily accessible option has the potential to place mentally vulnerable,

seriously ill and growing numbers of elderly people under intolerable pressures.

I start with the point that limited access to assistance to die to those who might be described as "terminally ill" is inherently problematical.

At this point, late in the afternoon on the third day of a four-day conference, it would be understandable if delegates found their attention beginning to flag. On this particular occasion there may be a certain aptness in my presentation being assigned the so-called "graveyard slot" given the subject matter. Allow me to put to you a hypothetical scenario that hopefully will help us all to focus.

If a non disabled friend, who does not, as far as they are aware, have a serious illness, were at some point in the future to become depressed and suicidal, doctors would seek to treat them for depression. If I, as a person with a serious, progressive illness, were to become suicidal it would be a matter for debate, were the Assisted Dying for the Terminally Ill Bill currently under discussion in the UK to have become law at that point, as to whether I should be treated for depression or assisted to die at my own request. The difference is that I, unlike my friend, could argue that I was suffering unbearably as a result of my illness and that my illness is terminal. The argument would then come down to whether the professionals concerned agree with me at that point that my illness is "terminal", that my "suffering" is caused by my illness and that my suffering is indeed "unbearable". In my friend's case there would be no such discussions to be had. And so in opposing the proposed legislation I am, amongst other things, seeking to ensure that in the future I will have the same assurance as my friend that were I to become suicidally depressed, doctors would see it as their task to treat me for that depression and that if I was suffering they would see it as their task to relieve me of that suffering rather than seeing it as their

task, or even their legal obligation, to assist me in carrying out my wish to die.

Incidentally, under the proposed UK legislation, if I were to ask that my partner, relatives and friends should not be informed of my desire to kill myself either at this point or during the “waiting period” of at least 14 days after I had signed the declaration of my intent, they would presumably know nothing of my suicidal intentions until after my death when they would be informed that doctors had assisted me to die. If you do not find that prospect an alarming one, allow me to assure you that I do.

The proposed legislation implicitly draws a line between those who "qualify" to be assisted in committing suicide and those whom society would seek to prevent from committing suicide (even to the point of physically restraining or detaining someone who appears to be intent upon harming themselves). Some people would be seen as clearly qualifying within the terms of the legislation as framed whilst in other cases it would be arguable as to whether people qualified or not. Others would definitely not be covered by the legislation. And, as I suggest in my hypothetical example, whether or not a person is seen to qualify determines how the medical profession is required to respond to their needs.

There is an inbuilt problem with attempts to limit legislation on assisted dying to the terminally ill. The more the checks and balances around who "qualifies", the greater the chances that the legislation is construed as excluding certain categories and therefore discriminating against people who do not qualify. Ironically, in the very name of human rights it becomes necessary to include more and more people in the right to die. Herbert Hendin, medical director of the American Foundation for Suicide Prevention, and an opponent of physician assisted suicide, argues that this has already happened in Holland:

According to the Royal Dutch Medical Association, it did not seem reasonable medically, legally, or morally to sanction only assisted suicide, thereby denying more active medical help in the form of euthanasia to those who could not effect their own deaths. Nor could the Dutch deny assisted suicide or euthanasia to the chronically ill who have longer to suffer than the terminally ill, or to those who have psychological pain not associated with physical disease. To do so would be a form of discrimination.²

A further problem with interpreting the legislation has been expressed by the number of physicians who have expressed serious concerns that although the bill purports to be concerned only with individuals at the "end of life", predictions about the nearness or otherwise of death are notoriously uncertain. Human beings do not come stamped with expiration dates. In saying that the person who wishes to die must be, "in a terminal phase of life", Lord Joffe's Assisted Dying for the Terminally Ill Bill glosses over these complexities in a way that many doctors find deeply worrying.

I find it almost inconceivable that the pro-euthanasia lobby would be unaware of the potential for a series of challenges in relation to the terms used in the bill and the likelihood that this would lead to the extension of the dubious privilege of the right to die once the initial principle has been established. I sincerely believe that the rest of us need to become more savvy and not jump without question onto the "human rights" bandwagon in relation to assisted killing.

Incidentally, as a further aside on the changing use of language, I have lived with multiple sclerosis for over 20 years without ever hearing it described as a terminal illness, until now, in an article on the Internet by an American

writer promoting physician assisted suicide and euthanasia. An illness such as progressive multiple sclerosis, which many individuals live with for half a lifetime and more, may in this way come to be regarded as "terminal" in popular imagination, in the media, in ethical debate and ultimately in the context of legislation.

My second point is concerned with the role played in "end of life" decisions and discussions by prevailing assumptions about the reduced value of the life of a person who has a long-term illness or a life-threatening condition.

The point of view held by the doctor advising a patient with a serious, life threatening illness would inevitably have a bearing upon the information that they give to the patient and the extent to which they would be inclined to argue the case for palliative care measures, for example, or link the person up with appropriate care assistance or counselling for depression. The doctors advising the person who wishes to die, the solicitor required by the legislation to verify that they are of sound mind to make the decision and the courts who might retrospectively be called upon to comment upon what had happened would all be operating from within the context of pathological societal assumptions and attitudes towards illness and disability.

A person who articulates a wish to die; perceiving that their life lacks dignity and value as a result of either a newly acquired or a longstanding illness or impairment may find that they have either the open or the quiescent agreement of those around them. It is widely assumed that it is impairment and illness in and of themselves, rather than the social and physical environments in which impairment and illness are experienced, that lead to suffering and loss of human dignity. As a wheelchair user of many years standing, or rather sitting, I know from personal experience that a good wheelchair is a liberating piece of equipment and not a fate to be avoided at all costs. It has been my experience

that the quality of my life as a disabled person has not been determined by the progress of my illness and the extent of my impairments so much as by the access that I have had at any particular time to sufficient money, appropriate assistance, equipment, accessible buildings, transport and so on.³

This is what one might call a social model of disability rather than the pervasive medical model which sees disability and illness as something that can be described in terms of physical characteristics and psycho-social responses more or less separable from social and economic contexts.

My third point has been emphasised repeatedly by the disability rights movement around the world expressing concern that the existence of physician assisted suicide as a legal and relatively easily accessible option undermines treatment for depression, the development of palliative care and ongoing commitment to supported independent living.

Herbert Hendin makes the point says that whilst the argument is frequently made by proponents that legislation sanctioning assisted suicide upholds personal choice, it has been shown in the Netherlands that, "palliative care is one of the casualties and that hospice care lags behind that of other countries."⁴ Many disabled individuals argue that resources to support disabled individuals' living choices are put at risk in the climate established by moves to promote assisted dying.

Marilyn Golden, a policy analyst writing for the Disability Rights Education and Defense Fund (DREDF) in the USA summarises the case against the legalisation of assisted suicide as follows:

While an extremely small number of people may benefit... large numbers of people, particularly among those less privileged in society, would be at

significant risk of substantial harm. We must separate our private wishes for what we each may hope to have available for ourselves some day and, rather, focus on the significant dangers of legalizing assisted suicide as public policy in this society as it is today. Assisted suicide would have many unintended consequences.⁵

My final point, relating to potential pressures upon vulnerable, elderly and ill people to end their lives in the interests of their caregivers, is heightened by the fact that my talk is between two others concerned with the relationship between ethics and the funding of health services.

With an ageing population, we have to face the fact that society can be said to have a vested interest in not having to pay to support increasing numbers of people who are disabled and/or sick. It is insufficiently acknowledged that those who are terminally ill and those who look after them (both individually and at the broader societal level of state services, health care related businesses, voters and tax payers) may be perceived as having competing and conflicting interests. Whether this is indeed the case is a matter for debate; however it is essential to recognise the social and economic context within which the debate about physician assisted suicide is taking place.

It is possible to imagine a range of scenarios in residential care settings and even in nominally supportive families where there might be different views not only of what constitutes suffering but how that suffering might be brought to an end. Those who are receiving care and assistance may have different perspectives and, on occasion, conflicting interests from those who look after them. The Assisted Dying for the Terminally Ill Bill in effect wishes these complexities away, saying merely that "the physician should have satisfied himself that the request is made

voluntarily". I believe that the pressure upon those who find themselves "qualifying" in the terms of the Bill for the right to be assisted in killing themselves, whether this pressure came from outside or had been internalised, would in some cases be intolerable and that people who did not want to die might nonetheless feel that they should seek death. It is not enough that the legislation says that the physicians concerned should have satisfied themselves the request is made voluntarily. The pressures that people are under may in some cases have become internalised to the extent that they no longer open to the necessary scrutiny.

Media attention has been overwhelmingly focused on a small number of exceptional cases of people (often highly educated and relatively well-off) who object that they are no longer in a position physically to control their own destiny and that they should have the legal right to be assisted in committing suicide. In focusing on real life cases and fictional stories highlighted such as, *Whose Life Is It Anyway?*, *Million Dollar Babe* and *The Sea Within* we are in danger of straining at a gnat of human rights and swallowing a camel.

To summarize; As long as societies have had laws, a central tenet has been to protect people, especially those who may be physically and/or mentally vulnerable, from being intentionally, or for that matter unintentionally, killed. Legislation has now been passed in some countries and is under consideration here in the UK that represents a far reaching and fundamental shift in the moral basis of the law in relation to the taking of human life; establishing the principle that a person may invite others to lawfully kill them. This may be all the more dangerous a development given societal attitudes (including of course the attitudes of doctors and solicitors who respond to people's requests to die) regarding the quality of life, or rather the supposed lack of quality of life of people who have physical and/or mental illnesses.

Who “qualifies” within the terms of such legislation for the right to die is frequently disputable. Not only does this present doctors with impossible dilemmas in practise, but that "right", once established, is liable to be extended over time to include more and more people, in the name of equal rights and nondiscrimination; as has already proved to be the case in Holland.

There is a real danger that focusing upon the option of assisting sick and elderly people to die will supplant the focus of independent living aimed at ensuring that people who need assistance to live, whether rich or poor, have genuine living choices and control over their own lives.

Those who seek to legalise the right to “medical assistance to die” frequently use the language of human rights, access to choice, and anti-discrimination. Whilst views on this matter differ among disabled people, as in the general population, it is argued by many that legislation upholding "the right" of a small number of individuals resolved to die potentially jeopardises the human rights, access to choice and freedom from discrimination of many more people who are ambivalent about ending their lives or who have no wish to die.

Notes:

1. Joffe, 2004
2. Hendin, 1997
3. Wates, 2004
4. Hendin, 1997
5. Golden, undated

Bibliography:

Golden, Marilyn. *Why Assisted Suicide Must Not Be Legalized*. [Article online] (Undated paper accessed November 2004); available from

Disability Rights Education and Defense Fund
(DREDF)

<http://disweb.org/cda/issues/pas/golden1.html>

Hendin, Herbert et al., "Physician-assisted suicide and euthanasia in the Netherlands: lessons from the Dutch." *JAMA (Journal of the American Medical Association)* 277(1997): 1720-1722.

Lord Joffe. *Assisted Dying for the Terminally Ill Bill* [House of Lords] (draft Bill accessed November 2004); available from

<http://www.parliament.the-stationery-office.co.uk/pa/ld200304/ldbills/017/2004017.pdf>

Wates, Michele, "Righting the picture: disability and family life," in *Disabling Barriers, Enabling Environments* 2nd edn, eds John Swain, Sally French, Colin Barnes and Carol Thomas (London: Sage Publications, 2004), 135-141.