

Assisted dying: a palliative care physician's view

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ABSTRACT – Lord Joffe's revised Assisted Dying for the Terminally Ill Bill was defeated in the House of Lords in May 2006, but it may return to Parliament in Autumn 2006. Assisted dying is being promoted as a logical extension to patient autonomy for those who are terminally ill and suffering intolerably, and proponents claim to have overwhelming public support. Those who have most experience of caring for the terminally ill, however, come out most strongly against any change in the current law. This paper suggests that estimates of public opinion are unreliable; that assisted dying is unnecessary if we are prepared to prioritise good end-of-life care; and that a change in the law would do little to protect patients but would put other vulnerable members of society at risk.

KEY WORDS: assisted dying, euthanasia, palliative care, physician-assisted suicide, terminal illness

The term 'assisted dying' is often used to cover both euthanasia (voluntary or otherwise) and physician-assisted suicide (PAS), and indeed this is the term used in the title of Lord Joffe's Bill that was reported on by a House of Lords Select Committee in November 2005.¹ As a great part of my work as a palliative care physician is to assist people to die, namely to ensure that they die peacefully and comfortably, it is with some reluctance that I use this term here.

What better way to summarise the philosophy underlying palliative care than with the words of the late Dame Cicely Saunders:

*You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.*²

Palliative care recognises that each person has unique physical, emotional and spiritual needs, all of which need to be addressed. It aims neither to hasten death nor prolong life at all costs, but accepts that when a patient is dying the relief of suffering, be it physical, emotional or spiritual, takes precedence over both of these concerns. The overwhelming majority of those who work in palliative care, however, believe that this relief of suffering should never extend to the intentional hastening of a patient's death by means of

euthanasia or PAS, and would consider such means as a complete abrogation of the duty to care. It would appear that in other specialties too, those who have most experience of caring for the terminally ill come out most strongly against any change in the current law.

Public opinion

Campaigners for assisted dying usually confidently declare that over 80% of the general public are in favour of a change in the law. The Select Committee concluded, however, that results from opinion polls determining public attitudes to euthanasia could not be accepted at face value as an authentic account of opinion within the UK, being largely knee-jerk responses to emotive questions with little understanding of the complexities involved. Part of the problem is that the results of good end-of-life care do not make good headlines: 'Cancer patient dies without pain' will hardly pull in the readership! The pro-assisted dying campaign is fuelled by a handful of well publicised cases that create confusion and fear about the accepted ethics of end-of-life decisions, about the safety of morphine and related drugs, and about the seemingly inevitable prospect of a horrible death for certain patient groups. The public is therefore led to believe that many doctors are already killing patients and so it might as well be legalised, that the appropriate withdrawal of burdensome life-prolonging treatments is in essence euthanasia, that giving morphine to people hastens their death, and that patients with neuro-degenerative diseases usually choke to death. Having followed this debate in the media over the last two years the extent of misinformation is disturbing.

Physician-assisted suicide

Whereas Lord Joffe's 2004 Assisted Dying for the Terminally Ill Bill sought to legalise both voluntary euthanasia and PAS, his revised Bill restricts any legislation to the latter. This was probably a pragmatic response to the findings of the Select Committee, in that a Bill that is restricted to PAS is far more likely to be successful. The received wisdom is that PAS would be more acceptable, and somehow more ethically justifiable than euthanasia, as the patient has the final decision as to whether to take the lethal cocktail or

not. The fact is that PAS is euthanasia one step removed, and its legalisation will inevitably lead to acts of euthanasia. What happens to those who fail, or experience complications? Or those who cannot swallow? Furthermore, is this 'right' to be restricted to those who can physically self-administer the drugs? In terms of a participating physician's moral responsibility, I believe there is no difference: the physician is still the moral agent, without whom the act would not take place. One may disagree with the Dutch in pursuing this route, but one has at least to acknowledge their honesty: the medical profession in Holland makes no moral or ethical distinction between euthanasia and PAS as the intention in both is to end the patient's life. In fact, evidence to the Select Committee suggested that doctors involved prefer euthanasia, as problems and complications arising from PAS may force them to intervene and administer a lethal injection.

The heart of the matter

I think it is important that we recognise what is at stake. Assisted dying is being promoted as a logical extension of patient choice and autonomy. For the sake of a small proportion of patients (and the pro-assisted dying activists stress that it is an extremely small proportion):

- We are to violate long-accepted codes of medical ethics. The principles of the Hippocratic Oath have underpinned medicine for over two thousand years: 'I will give no deadly medicine to anyone if asked, nor suggest such counsel'.
- We are to create a division in the medical profession – those who kill or facilitate the killing of their patients, and those who do not.
- We are to put Britain, the country that pioneered and is the benchmark for excellence in the care of the dying, at odds with the international medical community.
- We are to abandon the prohibition on killing which has underpinned our legal and moral framework for centuries.
- We are to risk harming the relationship of trust between doctors and their patients, turning healers into potential killers – an irony given that the public has been so traumatised by the Harold Shipman affair.
- We are to put at risk other vulnerable people in our society – the elderly, mentally ill, disabled, terminally ill – who may find themselves going down the route of assisted dying when they otherwise would not have done so.

I do not wish to dismiss the legitimate desire to place patient autonomy at the centre of our decision-making processes, because we should all aspire to patient-centred care. We do, however, need to weigh the consequences of such a radical step, and consider the available alternatives. I believe that a change in the law to allow assisted dying is unnecessary and poses dangers to other vulnerable members of society.

Assisted dying is unnecessary

With access to adequate palliative care, in most cases, the physical symptoms of terminal illness can be relieved. Some patients

Key Points

Proponents of assisted dying claim overwhelming public support, but public opinion is shaped by misinformation and a lack of understanding

Those who have most experience of caring for the terminally ill come out strongly against any change in the current law

Effective provision of palliative care would make assisted dying unnecessary for all but a very small minority of patients who wish to exercise absolute autonomy

To allow assisted dying would have far reaching consequences for society and would pose risks to the vulnerable

have complex symptoms and it may not be possible to eliminate them, but they can usually be alleviated. With a multidisciplinary and holistic approach palliative care can also address emotional, psychological, spiritual, and existential distress. In the last days of life, with the *appropriate* use of sedatives and strong painkillers, there is no reason why anyone should experience uncontrolled physical symptoms. This does not deny the fact that many people in the UK are still dying badly with uncontrolled symptoms and that is a tragedy because it need not happen. In such circumstances it is really not surprising that loved ones or carers might believe that ending someone's life can be the most compassionate response to their suffering. Many of those whom I have heard argue most passionately have had first hand experience of watching someone they love die in pain or struggling with other symptoms. Why is this still happening? Although specialist palliative care in the UK is of high quality, it is inadequately resourced and unevenly spread. Furthermore, many health professionals are still struggling with inadequate training in how to meet the needs of the dying. This is a political issue and a matter of priorities – are we prepared to care properly for the most vulnerable in our society or shall we opt for the quicker and cheaper alternative of assisted dying?

Some are concerned that assisted dying is happening already and we need to regulate it in order to protect patients. Given the fact that the majority of patients still die in hospital it seems unlikely that this is a significant problem. Indeed the Select Committee concluded that it was unlikely that covert euthanasia was being practised on anything like the scale which some surveys suggest, a conclusion supported by recently published evidence.³ If some doctors are committing euthanasia, then they should be investigated. If something is deemed to be unacceptable you do not legalise it simply because some people are engaging in it anyway. Would legislation to regulate the practice better protect patients? Probably not. Doctors who are prepared to ignore the law will be just as willing to do so with regard to the safeguards incorporated into any new legislation. The experience in Holland bears this out. Prior to codification of the law in 2002 in order to regulate practice, about a thousand patients a year were dying without their consent. Unfortunately this has not changed since 2002, and evidence to the Select Committee

noted that there did not appear to be any association between the development in jurisprudence and law and cases of lives ended without request. In Holland there is systematic under-reporting of cases, and doctors still complete misleading death certificates.

Legislation poses risks

My view is that legislation to allow assisted dying would pose a danger to many other vulnerable people in our society, and that if we open the door to assisted dying for a select few this will inevitably lead to others pursuing the same route. The very ill, the severely disabled and the elderly already often feel themselves to be a burden. How many of these would feel pressure, whether real or imagined, to request an early death? How easy might it be to create a sense of duty to die? That sense of duty would be difficult to detect, no matter how exhaustive the safeguards. I have dealt with countless terminally ill patients and their families. I know the pressures that are faced – emotional, financial, practical. The dismay for instance when told that a patient is not dying quickly enough to be able to stay in the hospice, but can no longer manage at home and therefore needs to go to a nursing home against the patients wishes. The strain on relationships and working life, and lives put on hold when a loved one is deteriorating slowly but inevitably. Would it not be more convenient to hurry things along - for everyone's sake?

One can also see how in time this 'right' should be extended to those who are not terminally ill but want to die, and to those who are unable to ask for it, or do not want it, but are deemed to be suffering unbearably or have a poor quality of life. And once we accept the principle that there is such a thing as a life that is not worth living, it then simply becomes a matter of opinion as to which lives are not worth living. Fears about a 'slippery slope' are all too real. Whether by incremental extensions of the law, elastic interpretation of the criteria, or even perhaps downright abuse, more patients than initially envisaged will go down this route. Lord Joffe himself admitted to the Select Committee that, although the Bill should initially be limited, he would prefer it to be of much wider application.

In Holland, which has a similar healthcare system to our own, there is clear evidence that some patients have been killed without consent or against their wishes, and legislation has not protected everyone. What is chilling is that once you begin to allow assisted dying it may with time become easier to justify and carry out. Evidence to the Select Committee indicated that for Dutch society as a whole there has been an increasing acceptance of euthanasia, reflecting a gradual change in opinion about the moral aspects involved.

Proponents point with admiration to Oregon, and how well assisted suicide is working. The truth is, we do not really know what is happening since there is no obligation to report. The Oregon Health Division relies on self-reporting by the very doctors who have practised assisted suicide. These reports are filed, but not investigated by the authorities and there are no penalties for not reporting. In those that are filed it seems certain that complications with PAS are under-reported, and the few cases

that have been made public have often raised concerns, such as whether the patient was competent or acting under duress. Psychiatric evaluations are rarely carried out, and patients often have to consult widely in order to find a doctor who is prepared to declare that they fit the criteria.

Autonomy

Few patients in my experience want to exercise the option of assisted dying. I frequently come across patients who feel that they no longer wish to go on living, but this desire fluctuates from day to day. Most patients who raise questions are really using it as a vehicle to discuss other issues, such as intolerable pain, but with appropriate care almost all stop asking about assisted dying. It is apparent, however, that for some people good palliative care is not enough. Their suffering derives more from simply having the illness, with fears about the consequent loss of control, increasing dependency, and perceived loss of dignity. Others may have symptoms that are particularly difficult to control, and it is not the dying phase that is the issue, but life in the weeks or months before that. These are the individuals that are the index cases for extending the assisted dying option. This is one observation, however, and this is offered with some trepidation, but also with the humility of one who has witnessed amazing courage and dignity in the face of dreadful situations. These existential issues, our inter-relationships and inter-dependence with those around us are what make us human, they are part of our living and our dying, and much of our growth and development as people comes through confronting and overcoming in such arenas. I have seen amazing transformations. Dignity, in dying as in living, has little to do with retaining control, and nothing to do with dependence or disability. Those who maintain that it has are promulgating a falsehood, and in many ways contributing to the distress of those who are struggling with loss of control and loss of dependence. We must question what is suffering, and such questions are pertinent because any legislation would have to define 'unbearable' or 'intolerable' suffering. We can never be anaesthetised to all life's unpleasant experiences. I would suggest that death is not a dignified process, and it can never be without suffering – it is a question of degree.

Society has to wrestle with whether or not to satisfy the autonomy of those who, regardless of the alternatives available, want to be able to dictate the manner and timing of their dying. There are many examples in our society of where individual autonomy has to be limited because of the risks posed to others and the ramifications for society as a whole. I believe that this is such a case. One can not help but be moved by their distress, and sympathise with them in their predicament. And it is their prerogative to take their own lives, if they so wish, whether one agrees or not with their decision. However, when they seek to involve others, and obtain the legal and moral sanction of society for that, then I believe passionately that we need to say no. In fulfilling their autonomy, we will be undermining the autonomy of other patients. My own response in such circumstances would be:

I will come alongside you, support you through this, do all I can to help you to live until you die, and ensure that you die peacefully and without pain when the time comes, but I will not help you end your life or end it for you.

Conclusion

Legislation to allow assisted dying is unnecessary, it is dangerous and, I believe, morally wrong. Many still argue that assisted dying is a compassionate response to unbearable suffering. I would assert that this is far from the truth. The compassionate response is to engage with that suffering and come alongside those who suffer, relieving where we can and sharing it, in our common humanity, when we cannot. If a society sanctions the killing of its most vulnerable, I believe it embarks on a path that might lead to the dissolution of its conscience and the killing of compassion.

Conflict of interest

Dr Stephenson is a member of the Care Not Killing alliance.

References

- 1 House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill. Assisted Dying for the Terminally Ill Bill. Volume 1: Report. London: The Stationary Office, 2005.
- 2 Saunders C. Care of the dying – 1: The problem of euthanasia. *Nursing Times* 1 July 1976, 1003–5.
- 3 Seale C. National survey of end-of-life decisions made by UK medical practitioners. *Palliat Med* 2006;20:3–10.