

Assisted death: a basic right or a threat to the principal purpose of medicine?

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ABSTRACT There is much debate in the UK and abroad around whether the law should be changed to license doctors to prescribe lethal drugs to assist terminally ill patients to commit suicide. Here, Sir Graeme Catto argues that terminally ill mentally competent adults should be able to choose the time and place of their death. Opposing him, Baroness Ilora Finlay argues that both the Assisted Suicide (Scotland) Bill and Lord Falconer's private member's bill in the House of Lords endanger patients' safety and require doctors to assess patients against criteria that cannot be verified.

KEYWORDS assisted dying, euthanasia, legislation, physician-assisted suicide

DECLARATIONS OF INTERESTS Baroness Finlay is Co-Chair of Living and Dying Well, an independent thinktank.

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Terminally ill, mentally competent adults should be able to choose the time and place of their death

G Catto

In me thou see'st the glowing of such fire
That on the ashes of his youth doth lie,
As the death-bed whereon it must expire
Consum'd with that which it was nourish'd by.
This thou perceivest, which makes thy love more
strong,
To love that well which thou must leave ere long.
– Shakespeare, Sonnet LXXIII

Terminally ill, mentally competent adults should, I believe, be able to choose the time and place of their death if that is their settled wish; 82% of the UK population support this view.¹ As a compassionate society we should be ashamed and angry that we still deny the dying the dignified death so many seek. For too many grieving relatives and friends the lasting legacy is not of a life well lived but of a grim institutionalised death in uncaring surroundings.² We can no longer ignore the many moving (if anecdotal) reports of these types of death appearing regularly in the media. Although we wish to die peacefully at home, most of us will die in hospital. Why not ask patients for their views and provide real choice at the end of life? Would that be a threat to the principal purpose of medicine?

My father was a GP who visited terminally ill patients at home. I have no doubt that as part of the care he provided he helped ensure a peaceful and dignified death as doctors had always done. Teamwork and problems in providing continuity of care have, however, changed that doctor–patient relationship irrevocably. My own clinical practice caused me to consider end-of-life issues. As a nephrologist I encountered a small number of dialysis patients who decided that they could no longer cope with their illness and stopped treatment. Although not terminally ill in the conventional sense, they exercised their right to refuse life-sustaining therapy and died as they chose. I also cared for terminally ill patients admitted to hospital because they could no longer be cared for at home. These individuals did not want to be in hospital, did not want further treatment but were not able to die with dignity at the time and place, and in the manner of their choosing. Why not?

OPPOSITION TO A CHANGE IN EXISTING LAWS

Three principal reasons are generally given by the small but vociferous minority opposed to a change in the law. The first is that 'vulnerable' individuals may be coerced against their will into seeking an assisted death. The

TABLE 1 Numbers of assisted deaths in Oregon, USA, since the change in law

Year	Reported prescriptions written for medication for assisted death	Reported deaths by ingestion of the prescribed medication
1998	24	16
1999	33	27
2000	39	27
2001	44	21
2002	58	38
2003	68	42
2004	60	37
2005	65	38
2006	65	46
2007	85	49
2008	88	60
2009	95	59
2010	97	65
2011	114	71
2012	116	85
2013	122	71

Source: Oregon Government Annual Report³

second is the 'slippery slope' argument: once the law is amended to allow the choice of an assisted death for the terminally ill, it will soon to be further changed to allow other groups to choose when they die. The third maintains that improved palliative care would make assisted dying unnecessary. All three propositions have been disproved by what has happened in Oregon, USA.³

Assisted death in Oregon

In Oregon the law was changed 16 years ago to allow terminally ill, mentally competent adults the choice of an assisted death. There has been no evidence of coercion; those who opted for an assisted death, while often physically frail, were feisty, articulate individuals who had made their views well known, often against the wishes of their family. There has been no attempt to widen the scope of the law beyond the terminally ill. Palliative care is excellent in Oregon, widely available and has continued to develop since assisted dying legislation was introduced.⁴ Over the years, the proportion of terminally ill patients opting for an assisted death has remained relatively constant at around 0.25%, although the absolute numbers have increased slightly from 16 to up to 85 annually (Table 1). Of course, many more patients express an initial interest in assisted dying but find that their needs are met by conventional palliative care. Knowing the choice is available, should their suffering become unbearable, is also reassuring. The population of Oregon remains supportive of the assisted dying legislation, reassured that an assisted death is available if needed.

ASSISTED DEATH IN THE UK

While the UK population overwhelmingly supports a change in the law,¹ three powerful institutions have expressed concern. The churches are opposed, although 78% of people of faith are in favour.⁶ Those with disabilities are in favour (75%), while their representative organisations are against.⁷ The medical bodies are mostly opposed, although more than two-thirds of GPs believe that the Royal College of General Practitioners should change its stance on the issue, subject to a number of safeguards.⁸ It is not clear how these institutions have determined their position on assisted dying, given the difference between their official view and the opinions of their members.

LORD FALCONER'S COMMISSION

What can we learn from other countries and states? Different approaches were assessed by Lord Falconer's Commission on Assisted Dying which reported in 2012. The Commission concluded that 'the current legal status of assisted dying is inadequate and incoherent' and recommended that legislation be introduced to allow terminally ill, mentally competent adults the right to an assisted death if that is their settled wish, subject to a number of safeguards.⁹

Terminology is important in these recommendations. 'Assisted dying' is defined as the right to a prescription which the terminally ill, competent person can take to end his or her life, and this is the specific change in the law that I advocate. 'Assisted suicide' is a wider term which encompasses the non-dying such as those with life-limiting conditions having the option to self-administer a life-ending prescription (this is the model proposed in Margo MacDonald MSP's Assisted Suicide [Scotland] Bill which is being considered in the Scottish Parliament at the time of writing). With voluntary euthanasia, the system adopted in the Netherlands and Belgium, both terminally ill and non-terminal but incurably ill patients' lives can be directly ended by doctors, usually on the subjective basis of unbearable suffering. I believe, as the Commission recommended, that the patient, not the doctor, should take the final action. Usually that will be to drink lethal medication, although for some it will be to operate an intravenous injection pump. Few patients, able to demonstrate both their mental capacity and settled wish to end their life, are unable to operate an intravenous injection pump, connected if necessary to a computer.

LEGALISING ASSISTED DYING IN THE UK

In spring 2014 Lord Falconer will introduce a bill in the House of Lords to legalise assisted dying. Two doctors, acting independently, will be asked to confirm the diagnosis, indicate that the prognosis is likely to be six months or less and confirm that the patient has been informed of all the available palliative care options, is

mentally competent and has formed a settled wish without coercion for an assisted death. When the legislation has been passed, appropriate training courses will be provided and the National Institute for Health and Care Excellence has offered to provide guidance on the lethal medication. Doctors with a conscientious objection to assisted dying will be able to opt out.

Because prognosis is an inexact science, concerns have been expressed that some patients will survive longer than the estimate of six months. Evidence from Oregon shows that when told that they are terminally ill, patients do not immediately take lethal medication but wait until their symptoms become unbearable, shortening their lives by only a few days or weeks. They are able to take responsibility for the time that is left and, if they wish, die with dignity at the time and place of their choice.

Increased longevity inevitably results in more of us dying from chronic conditions. The recent inquiry into the Liverpool Care Pathway showed that decisions to treat or withdraw treatment, including food and fluids, were made without patient involvement; indeed, some patients sucked mouth sponges to slake their thirst.¹⁰ Continuous terminal sedation is now given to around 16% of dying patients, almost always in hospital or hospice care, although it is not clear how many gave their informed consent.¹¹ The outcome is inevitable, but the patient may take some days or even weeks to die, a process that

many find distressing. The current law not only fails to protect those opposed to an assisted death but prevents the rest of us, the majority, from dying with dignity at a time and place of our choosing.

The guidelines issued by the Director of Public Prosecutions in England and Wales indicate that relatives are unlikely to be prosecuted if, for compassionate reasons, they assist a competent individual to die at their informed request, but they will be subjected to a police investigation.¹² As that relatively tolerant approach does not apply to healthcare professionals, lethal medication is difficult to obtain. For that reason almost 250 seriously ill patients have travelled from the UK to Switzerland for an assisted death.¹³ Only those who can afford the significant costs and are sufficiently fit for the journey are able to consider this option, causing many to end their lives earlier than necessary.

Death comes to us all. When facing death, we should be able to choose how we wish to end our days. Enabling terminally ill, mentally competent adults to have an assisted death if that is their settled view is part of that choice. Few will ultimately take that option, but many will be reassured to know that it exists if their views change. Far from being a threat to the principal purpose of medicine, choice at the end of life is an essential component of a compassionate profession and a caring society.

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Assisted dying laws do not take into account the reality of clinical practice and patients' lives

IG Finlay

Should doctors be licensed by law to supply lethal drugs to some of their patients to help them commit suicide? That question has been put to both the Scottish and the Westminster Parliaments in recent years and received a firm 'no' in reply. It is a question likely to be put again – there is an Assisted Suicide Bill¹ before Holyrood and a similar Private Member's Bill in the name of Lord Falconer² before the House of Lords in London.

These proposals, like those before them, place decisions on who should and should not be assisted with suicide on the shoulders of doctors. Yet they reveal a remarkable naivety about the pressures of today's clinical practice and the vulnerability of patients. And both these Bills are silent as the grave as to how the doctors concerned are expected to make these life-or-death judgements.

The late Margo MacDonald's Bill requires a doctor who is faced with a request for assisted suicide simply to state that 'to the best of my knowledge' the request is being made voluntarily and is not being influenced by others, that the doctor is 'of the opinion' that the patient has the capacity to make the request and that the patient's view that his or her quality of life is unacceptable 'is not inconsistent with the facts currently known to me'.³

Lord Falconer's Bill south of the border follows a similar pattern. It requires an assessing doctor to confirm that a patient seeking assisted suicide 'has the capacity to make the decision to end their own life' and 'has a clear and settled intention' which has been reached 'voluntarily, on an informed basis and without coercion or duress'.⁴ Lord Falconer seems to sense that there is something missing and his Bill allows the relevant Minister to draw up codes of practice to guide these decisions. But these codes would only appear after Parliament had agreed to license physician-assisted suicide (PAS), so the decision to legalise would have to be taken in complete ignorance of what the safeguarding regime is. In other words, the Bill is asking Parliament to sign a blank cheque.

The real world of clinical practice is very different from the idealised world that these bills envisage. They depict a doctor who has no strongly held views on PAS and who will examine any request dispassionately, without prejudice and without time pressures of other workload; a doctor who can confidently and accurately predict the course of a progressive illness; a doctor who knows the patient concerned, and his or her personal and family circumstances, well enough to be able to say with assurance that there is no pressure, subtle or otherwise, at work in the background; and a doctor who knows what level of capacity is required for a decision to

commit suicide and who is able to confirm that it is present in the patient concerned.

Now look at the realities. Physician-assisted suicide is a divisive issue in the medical profession on both sides of the border. The great majority of doctors do not support it and would be unlikely to have anything to do with it if it were to be legalised. With 77% of general practitioners opposed to such a change in the law,⁵ the net result would be to place the assessment of requests in the hands of a minority of willing practitioners who might well see suicide as a reasonable response to serious illness and might not bring to the task the level of challenge it deserves. Even patients' regular doctors often know little of them beyond the consulting room – how prone they are to depression or despair, what unresolved fears they have, what family dynamics are operating in the background. A doctor selected specifically and solely to consider a request for assisted suicide would know almost nothing beyond the case notes.

Prognosis of progressive and incurable illness is notoriously unreliable, particularly where non-malignant life-limiting illnesses are concerned.⁶⁻⁸ Some patients even improve from a seemingly hopeless situation to resume an active and fulfilling existence. Oregon's own data since 1997 show a mean of 47 days from request to death by legalised PAS, with a range of 15 to 1,009 days,⁹ despite the requirement of a prognosis of six months or less.¹⁰

Although assessing patients' capacity is a normal part of a doctor's role, its purpose is to protect the patient from harm. Let us not forget that doctors have an important role in suicide prevention strategies. To ask them to assess capacity with a view to clearing the way for assisted suicide is to turn the process on its head. Moreover, capacity is decision-specific: some decisions require a higher level of capacity than others. A decision to end your life has to be at the top end of any such spectrum of risk and calls for a very high level of assurance.

The evidence is that assessing capacity for PAS is difficult.¹¹ Only 6% of Oregon psychiatrists report confidence in assessing such capacity at a single consultation,¹² and another Oregon study found one in six of those legally supplied with lethal drugs had undiagnosed clinical depression.¹³ UK psychiatric experience suggests that cognitive impairment occurs in 30% of patients with motor neurone disease, but may not be apparent.¹⁴ In a terminally ill Canadian cohort, those with a significant desire for death had a higher prevalence of mental illness.¹⁵

But it is not only the world of the doctor that these bills have failed to grasp. There is also the world of the patient to be considered. The bills are transparently written with the strong-minded and no-nonsense patient in mind, who has thought long and hard about suicide rather than ill health, who is in a completely loving and settled family situation and who is clear beyond doubt about wanting to end it all. Such patients exist, but they are the rare exception rather than the rule. In more than 40 years of clinical practice, including a quarter of a century of treating terminally ill patients, I can count them on the fingers of one hand. Most patients are knocked sideways by a terminal diagnosis.^{16,17} Many of them veer from hope to despair and back again, with depression and fear alternating with acceptance.¹⁸ Many visibly struggle to come to terms with their mortality; feeling a burden to others fuels suicidal thoughts.¹⁹ In a word, they are vulnerable.

The doctor–patient relationship is not just another commercial customer–supplier relationship. In most cases, the doctor has a near monopoly of expertise and experience and patients, of necessity, look to us, not just for diagnosis and treatment, but for counselling and reassurance. In this highly asymmetric relationship doctors have a special duty of care for patients, which includes recognising vulnerability. Patients not infrequently say to their doctors that they would like ‘something to end it all’, but a good doctor will explore more deeply to find out

what lies behind the request. Seriously ill patients can be highly sensitive to real or imagined nuances in a doctor’s behaviour. To take a request for PAS at face value can all too easily be misread as agreement that the condition is every bit as bad as the patient fears and that suicide is in the patient’s best interests.

Poor care,^{20,21} inadequate support for patients and families and dismissive attitudes that do not value individuals certainly inflict terrible suffering, but the answer to that is to improve care, not to license PAS. Legalisation of PAS and/or euthanasia is no mere adjustment of the law: it changes the dynamic. Oregon’s numbers of PAS deaths are four and half times what they were 16 years ago;²² by 2012 one in 34 of all deaths in the Netherlands were by PAS/euthanasia.²³

The criminal law is there to protect us, all of us, from harm. The law as it stands, in conjunction with the ‘do no harm’ principle that lies at the heart of clinical ethics, meets that requirement. It rests on a clear and rational principle – that we do not involve ourselves in deliberately bringing about the deaths of other people. Once we starting redrawing that boundary of the law around this or that group of people, it becomes no more than a line in the sand, easily crossed and hard to defend against encroachment. The elasticity with which ‘assisted dying’ laws have been applied in jurisdictions which have licensed these practices should serve as a warning that such legislation is inherently unstable.

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