

Living and Dying Well
Keeping the law safe for sick and disabled people

A Question of Public Safety

A fundamental reappraisal is needed of the concept of safeguards for 'assisted dying'

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Living and Dying Well is a public policy research organisation established in 2010 to promote reasoned and measured discussion and debate on the subject of 'assisted dying' – the current euphemism for physician-assisted suicide. Living and Dying Well takes the view that legalisation of 'assisted dying' would pose serious risks to public safety and that debate needs to focus on rigorous analysis of the evidence rather than on campaigning spin. Our website can be found at www.livinganddyingwell.org.uk

A QUESTION OF PUBLIC SAFETY

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Introduction

Campaigners for the legalisation of 'assisted dying'ⁱ tell us that any such law would contain safeguards. As a general statement that may sound reassuring. But drafting safeguards in the comfort of a campaigning office is one thing: making them work in the real world amid the stresses of serious illness and the pressures of clinical practice is another. In this paper we scrutinise the safeguards that have been proposed to date and then examine some of the problems underlying them.

How safe is safe?

No law can be made completely safe. Humanity being what it is, there will always be those who find loopholes in any legislation and, even with the best of intentions, there will always be oversights and errors in making laws or implementing them. This is not, of itself, an objection to legislating. However, Parliament has a duty to ensure that the degree of safety built into legislation matches the gravity of the risk and that safeguards are realistic, robust and practicable.

In the case of proposals to legislate for 'assisted dying', Parliament has to ask itself:

- Is the gravity of the risk in question – ie a risk to human life - reflected in the safeguards that are proposed?
- Are the proposed safeguards realistic and tough enough to work in the difficult circumstances in which they would have to be applied – ie are they real-world-proved?

The Safeguards Proposed

The safeguards that have been included in unsuccessful bids to change the lawⁱⁱ have varied in detail but have shared certain common features. They have generally envisaged that 'assisted dying' would:

- be available to terminally ill peopleⁱⁱⁱ but not to others;
- include measures designed to establish the mental capacity of those seeking it;
- require a declaration by witnesses to the effect that an applicant appears to be of sound mind and to be acting voluntarily;
- provide for all applicants to be briefed on alternative courses of action, including palliative care.

In addition, all these failed proposals have assumed that the tasks of assessing applicants for 'assisted dying' and prescribing or administering lethal drugs to those thought to meet the criteria would be carried out by doctors.

It is perhaps worth remarking at the outset that terminal illness, as a qualifying condition for 'assisted dying', is a rather permeable safeguard. If, as some argue, 'assisted dying' can be justified for the terminally ill on grounds of personal autonomy, incurable illness or physiological or existential suffering, why should it not be available also to other seriously-ill people who have a longer life expectancy? There are many people who have long-term disabling and progressing (but not terminal) clinical conditions, such as multiple sclerosis, heart and lung disease or Parkinson's, and whose suffering can be expected to be more long-lasting. It is arguable therefore that a criterion of terminal illness contains within itself the seeds of subsequent extension to encompass other clinical conditions and, as such, cannot of itself be regarded as a robust safeguard. Our analysis in this paper addresses terminal illness as a qualification for 'assisted dying' simply because this has been a feature of the safeguards that have been proposed. But the wider perspective needs to be borne in mind.

Just how Safe Are The Safeguards?

Six years ago we were members of a parliamentary select committee which examined Lord Joffe's 2004 Assisted Dying for the Terminally Ill Bill. This Bill contained safeguards almost identical to those that are now being proposed by 'assisted dying' campaigners. The committee's three-volume report^{iv}, however, revealed serious reservations on the part of many expert witnesses over just how effective such safeguards would be. Let us look at some of them.

Six Months to Live?

The committee was told by the Royal College of Physicians that prognosis of terminal illness was "a probabilistic art" and that "prognosticating may be better when somebody is within the last two or three weeks of their life" but that, "when they are six or eight months away from it, it is pretty desperately hopeless as an accurate factor"^v. The Royal College of General Practitioners stated that "it is possible to make reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months, then the scope for error can extend into years"^{vi}. These judgements would seem to be corroborated by data now emerging from the US State of Oregon, where physician-assisted suicide was legalised in 1997 and where some terminally ill people who are given lethal drugs by doctors on the basis of a prognosis of six months or less are living for much longer^{vii}. Nearer to home there is the case of the Libyan Abdelbaset al Megrahi.

Released from prison in 2009 on the basis of a prognosis of three months, he is still alive at the time of writing. Such cases are by no means exceptional in clinical practice.

Why does the fallibility of prognosis matter? It matters because, for anyone who might consider 'assisted dying', an important factor in their decision could be the length of time left remaining to them. Statements such as 'six months to live' may sound authoritative to the layman, but doctors themselves know that prognosis is an inexact science. As one physician put it to the select committee, "the reality in clinical practice is that we can be wrong"^{viii}.

In its report, therefore, the select committee recommended that, "*if a future bill should include terminal illness as a qualifying condition, this should be defined in such a way as to reflect the realities of clinical practice as regards accurate prognosis*"^{ix}. This important recommendation has been ignored. The campaigners have persisted with their definition of terminal illness as involving a prognosis of six months or less. The evidence is clear, however, that terminal illness, if it is to be a qualifying condition for 'assisted dying', needs to be defined in a much more restrictive way - in terms of a few weeks at most, not several months.

Of Sound Mind?

The Mental Capacity Act 2005 sets out a two-stage process for establishing whether a person has or lacks the mental capacity needed to make a specific decision. In the first stage it is necessary to ascertain whether the person concerned is suffering from a disorder of the mind. Such disorder may stem from conditions such as depression or may result from or be exacerbated by the side-effects of the illness or of the medication being taken to relieve it. It is then necessary to establish whether a disorder is such as to deprive the person of the capacity required to make the decision in question. The judgement of mental capacity must be decision-specific: a person may be judged to have sufficient capacity to make some decisions but not others - for example, those with serious risks or consequences. A decision to seek 'assisted dying', if the practice were ever to be made lawful, would be at the high end of the spectrum of risk. This is not to say it would be impossible to be sure that one person seeking 'assisted dying' had and another had not the required mental capacity for such a life-or-death decision but rather that there is a large grey area covering persons who lie between these extremes and that, given the nature of the decision, a very high level of assurance of mental capacity would be required.

The safeguards that have been proposed in this area have been modelled on Oregon's physician-assisted suicide law. They suggest that the assessment of mental capacity in an

applicant for ‘assisted dying’ should be left to the assessing physician or physicians, with referral for psychiatric examination limited to cases where doubts as to mental capacity exist. The select committee expressed the view in 2005 that every applicant for ‘assisted dying’ should be referred for psychiatric assessment. Experience of Oregon’s physician-assisted suicide law appears to corroborate this view. In Oregon referrals of applicants for physician-assisted suicide for psychiatric examination are in practice rare, and independent analysis in 2008 of a sample of patients who had been prescribed lethal drugs with which to end their lives revealed that one in six of them had been suffering from undiagnosed clinical depression^x. A suicide wish is normally regarded as grounds for psychiatric referral. In the interests of protecting the individual, a request for legalised assistance with suicide should be treated in the same way. To say this is not to suggest that all such requests necessarily derive from mental disorder or incapacity but simply to recognise the gravity of the decision in question and the need to have a high level of assurance as regards mental capacity and freedom from mental disorder.

Informed Consent?

Another safeguard proposed in Lord Joffe’s 2004 ‘assisted dying’ bill was the requirement that an applicant must be informed of “the alternatives, including, but not limited to, palliative care, care in a hospice and the control of pain”^{xi}. In its report the select committee drew attention to evidence from Help the Hospices that “experience of pain control is radically different from the promise of pain control, and cessation is almost unimaginable if symptom control has been poor. On this view patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed”^{xii}. The select committee recommended therefore that, “***if a future bill is to claim with credibility that it is offering assistance with suicide or voluntary euthanasia as complementary rather than alternative to palliative care, it should consider how patients seeking to end their lives might experience such care before taking a final decision***”^{xiii}. This recommendation too has been ignored.

It is sometimes suggested that a ‘palliative care filter’ – ie a requirement that an applicant for ‘assisted dying’ should receive specialist palliative care input before being allowed to proceed – would infringe the right of patients to refuse treatment. This is not so. There could be no question of forcing specialist palliative care onto an applicant for ‘assisted dying’. A palliative care filter is simply a requirement that, to ensure the patient’s request reflects informed consent, he or she should experience care overseen by a specialist palliative care team before confirming a wish to receive ‘assisted dying’.

Patient choice does not mean that patients can have whatever clinical procedures they wish on their own terms. A doctor has to be sure that any treatment is likely to be of

therapeutic benefit rather than simply what the patient asks for. A requirement to experience good palliative care is unlikely to deflect the determined applicant from ‘assisted dying’ but can cause others to reappraise their situations. It is an important safety requirement in any ‘assisted dying’ law.

Free and Wholehearted?

Two other safeguards need to be mentioned. One is the need to ensure that an applicant for ‘assisted dying’ is acting voluntarily. The bills we have seen to date do no more than require a witness, who must not be a relative or partner, to state that “it appears to him that the patient is of sound mind and has made the declaration voluntarily”^{xiv}. Such statements are of little value. They represent no more than a superficial appraisal by someone who is not close to the person concerned. Most of the people whom we meet every day appear to be of sound mind and acting voluntarily, but it would be naïve to suppose that such surface impressions tell us what is really going on in someone’s mind. It would require an investigative process, with careful interviewing of the applicant and others known to him or her, to establish whether or not someone seeking ‘assisted dying’ was wholehearted in the request or acting either under external influence or as a result of internalised pressure, such as concern about being a burden to others, or because of unrelieved fear of the dying process. A statement by someone acting as a witness of what “appears” to be the situation is just not enough.

What Happens Afterwards?

The other safeguard has been conspicuous by its absence from the ‘assisted dying’ bills we have seen. Following the model of Oregon’s physician-assisted suicide law, it has been proposed that a qualifying applicant for ‘assisted dying’ should be given lethal drugs by a doctor, either directly or via a pharmacist, and that these should be kept at home to be ingested, or not ingested, at the discretion of the recipient. There have been no arrangements put in place, however, for ensuring that, if and when the lethal drugs are ingested, they are swallowed knowingly, voluntarily and without assistance.

The problem here is that there is no way of knowing whether the conditions that appeared to exist at the time when the drugs were supplied – a willing and mentally capable patient fully resolved on ending his or her life – continue to obtain when those drugs come to be taken. Were they, for example, ingested during a bout of transient depression? or following a family dispute? or with assistance, solicited or otherwise, from others? or without knowledge – for example, after being mixed surreptitiously with food by another person with malice aforethought? The assistance that the campaigners have in mind when they talk of ‘assisted dying’ is the provision by doctors of lethal drugs to

patients *for self-administration*. But the systems they have proposed would be unable to prevent further (illegal) ‘assistance’ with the act, whether requested or unrequested. Any such illegal action would be unlikely to come to light as there would be no police investigation after the event, since the death would have been officially sanctioned in advance.

Lethal Drugs in the Community?

There is another problem with supplying lethal drugs to be retained in the community – that a person for whom they have not been prescribed, such as a child or a mentally disturbed adult bent on self-destruction, might ingest them. The rules envisaged here are far too lax. For the safety of all concerned lethal drugs need to be kept in safe official custody. If Parliament were ever to license their use for assisted suicide, it should be on the basis that the drugs would be taken to the qualifying applicant only if and when requested and that their willing self-administration would be witnessed by a representative of the appropriate authority.

Improving the Safeguards

A Fundamental Re-Think

It is a frequent refrain of ‘assisted dying’ campaigners that those who disagree with them will never be content with any safeguards. The reality is that the campaigners have not made a serious effort to address the deficiencies in the safeguards they have proposed. They have been content to fall back on those that exist in the few jurisdictions where ‘assisted dying’ has been legalised and to argue that, if these are good enough for the US State of Oregon (for example), they will do for Britain. Moreover, as we have seen, they have ignored the recommendations of a comprehensive parliamentary review of ‘assisted dying’. The result has been a set of safeguards that may look reassuring on paper but, on closer inspection, can be seen to be seriously lacking in realism and strength.

It is not our intention to design safeguards to try and mitigate the dangers of an ‘assisted dying’ law. Any such law inevitably involves risk. Tougher safeguards can make the practice safer, but they cannot make it safe. The campaigners sometimes suggest that illegal action by doctors is taking place already and that legalising ‘assisted dying’ will regulate the practice and thereby make it safer. The evidence, however, is against them. Independent research^{xv} into end-of-life decision-making by doctors in Britain and certain other countries has concluded that the incidence of covert ‘assisted dying’ by UK doctors is “extremely low” and that in Holland and Belgium, where voluntary euthanasia has been legalised, the incidence of involuntary – and therefore illegal – euthanasia is significantly higher than in Britain. Follow-up research^{xvi} published in 2009 concluded

that in the UK “euthanasia, physician-assisted suicide and the ending of life without an explicit patient’s request are rare or non-existent”. The argument therefore that legalisation brings regulation and thereby increases patient safety does not stand up. The safest course is not to license ‘assisted dying’ in the first place.

Nonetheless it is possible to show where the safeguards so far proposed are seriously deficient. We have drawn attention already to a number of specific areas, many of them cited as defective six years ago by the select committee. However, something more than fine-tuning is required. What is needed is a fundamental reappraisal of the assumptions underlying the campaigners’ proposals for ‘assisted dying’.

The essential requirement of any set of safeguards must be to separate out the very small number of strong-minded and highly determined individuals who might not be harmed by a change in the law from the much larger population of seriously ill people who are less than wholehearted about ‘assisted dying’ but who could be drawn into the practice, whether by feelings of obligation to their families, or through fear of the dying process or ignorance of modern medical science, or as a result of depression, or because of pressures applied, however subtly and even unconsciously, by others.

There is also a need to move away from the presumption underlying much of the campaigning that an ‘assisted dying’ law is inherently desirable and that, while safeguards to protect the majority are obviously needed, they are of secondary importance to giving choice to a minority. The question needs to be approached the other way round – namely, that the first requirement in considering the legalisation of ‘assisted dying’ is to establish whether robust and workable safeguards can be devised to protect the vulnerable. It should be remembered that a major reason for abandoning capital punishment in the 1960s was that the wrong people were occasionally deprived of their lives. If Parliament is now to be asked to consider legislating to allow the deliberate bringing about of the death of seriously-ill people, public safety rather than personal choice must be the paramount consideration.

In addition, therefore, to tightening up specific safeguards, there is a need to consider what might be called structural changes – ie changes to the underlying ‘assisted dying’ machinery that is envisaged. In our view the most important of these concerns the role of the medical profession.

‘Assisted Dying’ and Clinical Practice

The proposals we have seen to date in Britain all assume that ‘assisted dying’ must be *physician*-assisted dying. There are, however, real problems with this concept. To invite seriously ill people to approach individual physicians for ‘assisted dying’ is to invite a

postcode lottery in the practice and the growth of the ‘doctor shopping’ that has been seen in Oregon. There are also variations among doctors in their knowledge and experience of end-of-life care and in their communication skills with patients. Under the sort of ‘assisted dying’ proposals we have seen to date, therefore, we could expect to see considerable variation around the country in the way any such law was implemented.

However, the main difficulties with physician involvement in ‘assisted dying’ come at the strategic level, where they have a direct bearing on the issue of safeguards. The role of doctors is to treat illness or, where that is not possible, to relieve its symptoms and thereby improve quality of life. The only connection between ‘assisted dying’ and a profession dedicated to supporting rather than ending life is that doctors treat seriously ill people and they have access to lethal drugs. The underlying ethics of medicine, however, are at variance with ‘assisted dying’, as was underlined by the General Medical Council in its evidence to the select committee six years ago. The GMC stated unambiguously that:

“A change in the law to allow physician-assisted dying would have profound implications for the role and responsibilities of doctors and their relationships with patients. Acting with the primary intention to hasten a patient’s death would be difficult to reconcile with the medical ethical principles of beneficence and non-maleficence”^{xvii}

The campaigners, however, want medical involvement in the practices they are seeking to legalise. They tell us that, in those places where ‘assisted dying’ has been legalised, patients continue to trust their doctors, from which they argue that doctor-patient trust will not be harmed. This argument, however, misses the point. Of course patients trust their doctors. They have little alternative, whatever the legal regime in force, simply because few patients have the knowledge and experience to challenge the medical advice they are given.

In reality, it is the trust which is such an essential ingredient of the doctor-patient relationship that makes ‘*physician-assisted dying*’ so dangerous. It is not uncommon for seriously ill patients to ask their doctors to help them to ‘end it all’, but very few of these requests are serious and determined. Almost invariably they are cries for help from patients who have come to the end of their tether and are wanting better symptom control and support or who want their fears of the dying process to be addressed. A good doctor will respond by seeking to establish what lies at the root of the request and what needs to be done to help the patient. However, the agreement of a trusted professional to consider ‘assisted dying’ as a therapeutic option could all too easily signal to the patient, however unwittingly, that a hastened death was the appropriate course of action to contemplate in that patient’s clinical condition. Such signalling might not matter in the case of a very small number of highly resolute and strong-minded individuals. But we

have to think of the majority of seriously ill people, who can be very sensitive to nuances and subliminal messages in what they are told by their doctors. This potential conflict between doctor-patient trust and 'assisted dying' was underlined in 2010 by the Director of Public Prosecutions, whose guidelines for the handling of cases of assisted suicide stated that any such offence would be regarded as aggravated if perpetrated by "a medical doctor, nurse or other healthcare professional" and if the deceased had been "in his or her care"^{xviii}

Another argument sometimes advanced in favour of physician involvement in 'assisted dying' is what might be called the 'comfort' argument - that terminally ill patients should not be abandoned by their doctors on their final journey and that it would be unfeeling to expect them to seek 'assisted dying' outside the health care system. The problem here, as in so much else in this debate, is that the campaigners are focusing their attention on a small number of people who are fully resolved on 'assisted dying' and they are failing to see the many others who are not so determined but are vulnerable to seeking it.

No one wants to add to the suffering of terminally ill people. However, it is hard to believe that the serious and resolute applicant for 'assisted dying' would be discouraged from proceeding simply by having to seek it outside the health care system. There is an inherent contradiction in expecting doctors to work to improve patient treatment and care and simultaneously to abandon such efforts in order to pursue active steps to end a patient's life. Embedding 'assisted dying' in health care could easily encourage patients who are less than wholehearted about the project to suppose that it is like any other medical treatment, that it is being offered for their good and that, notwithstanding any reservations they may feel about it, it is probably for the best – otherwise why would any doctor agree to proceed with it? If 'assisted dying' is to be a highly exceptional event, resorted to only by the most resolute and strong-minded, the bar must be set high in the interests of protecting the rest of us. It should not be part of clinical practice.

Yet a third argument advanced in favour of physician participation in 'assisted dying' is that doctors have access to the poisons needed for accomplishing it. There is, however, a difference between a doctor writing a prescription for lethal drugs and a doctor doing that as part of his or her clinical care within the health service. There is no reason why, if 'assisted dying' were ever to be legalised, lethal drugs could not be prescribed by a physician, nurse or pharmacist (for these latter, as well as doctors, can legally prescribe) acting outside the parameters of health care – for example, under contract to an official assessment agency. It is not necessary to embed 'assisted dying' in health care simply in order to obtain the lethal overdoses required to enable seriously ill people to kill themselves.

Conclusions

Safeguards have not been taken seriously enough by the campaigners. There has been a tendency to focus on the desirability of 'assisted dying' as a choice for some and to regard safeguards for the many as a necessary but secondary concern. The specific safeguards proposed to date have not been modified or strengthened despite clear recommendations for change and evidence from overseas jurisdictions that more rigorous safety standards are needed.

The starting point in devising safeguards should be an acceptance that, if 'assisted dying' were ever to be legalised, it should be as a highly exceptional event resorted to only by persons whose circumstances are themselves highly exceptional. It is in our view doubtful whether safeguards could be devised that would meet this requirement. No legislation can be risk-free, but where what is at stake is the deliberate and premature ending of human life there is a need for a very high level of safety assurance – much higher than would be derived from the safeguards so far proposed.

There is a need, however, not only for stronger specific safeguards relating to such issues as prognosis, mental capacity or the experience of palliative care but also for a change in the mindset of those designing them. This requires a clear recognition that the purpose of the law is to protect society as a whole rather than to give choices to individuals.

There is a need also for a fundamental reappraisal of the machinery of 'assisted dying' envisaged by the campaigners, with particular attention given to the dangers of incorporating the practice within the provision of health care. Physician involvement in either the assessment or the implementation of 'assisted dying' is as unnecessary as it is dangerous, and it raises, for the majority of doctors, serious ethical conflicts as well posing the risks of postcode lotteries and 'doctor shopping'. We would do well to remember the maxim *salus populi suprema lex* – the most important law is public safety.

ⁱ 'Assisted dying' is a term coined by the campaigners. It has no meaning in law but is intended to cover physician-assisted suicide and/or physician-administered euthanasia for people who are terminally ill. We use the term throughout this paper as a form of shorthand.

ⁱⁱ For example, in Lord Joffe's Patient (Assisted Dying) Bill (2003) and Assisted Dying for the Terminally Ill Bills (2004 and 2005), Lord Falconer's proposed amendment to the Coroners and Justice Bill (2009) and MSP Margo MacDonald's End of Life Assistance Bill (2010)

ⁱⁱⁱ Defined as those suffering from a life-threatening illness with a prognosis of life of six months or less

^{iv} House of Lords report 86-I (Session 2004-05)

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- v House of Lords Report 86-I (Session 2004-05), Paragraph 118
- vi House of Lords Report 86-I (Session 2004-05), Paragraph 118
- vii See Report of the Oregon Public Health Division 2010 on the operation of that State's "Death with Dignity Act".
- viii House of Lords Report 86-I (Session 2004-05), Paragraph 119
- ix House of Lords Report 86-I (Session 2004-05), Paragraph 269(c)(iii)
- x "The prevalence of depression and anxiety in terminally ill patients pursuing aid in dying from physicians", *British Medical Journal* 2008; 337:a1682
- xi Section 2(3)(e)
- xii House of Lords Report 86-I (Session 2004-05), Paragraph 258
- xiii House of Lords Report 86-I (Session 2004-05), Paragraph 269(c)(vi)
- xiv See, for example, Lord Joffe's 2004 bill, Section 4(4)(b) and 2005 bill, Section 4(3)(b)
- xv "National Survey of End-of-Life Decisions made by UK Medical Practitioners", Seale C, *Palliative Medicine* 2006:3-10
- xvi End-of-Life Decisions in the UK involving Medical Practitioners, Seale C, *Palliative Medicine* 2009;00: 1-7
- xvii House of Lords Report 86-II (Session 2004-05), Page 11
- xviii Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, Crown Prosecution Service, 25 February 2010