



living and dying well

Clear thinking on the end-of-life debate

**LEGALISING ASSISTANCE TO END LIFE
Memorandum of Evidence to the
Health Committee of the New Zealand Parliament**

About Living and Dying Well

1. Living and Dying Well (LDW) is a public policy research body established in the United Kingdom in 2010 to examine the evidence surrounding the end-of-life debate, with a particular focus on whether what is sometimes called 'assisted dying' should be legalised. LDW's role is to promote understanding of this complex and controversial subject through careful and rational analysis of the evidence. Its Patrons and Members include experts in the law, medicine, mental health, ethics and other disciplines relevant to the end-of-life debate who share a concern that public safety must be of paramount importance in this area.

2. LDW's view of this issue is that, before a change in the law can responsibly be authorised, serious evidence is required that the existing law is dysfunctional or oppressive; and, if (and only if) that is the case, that what would be put in its place would be better. In our judgement these two tests have not been met.

Definitions

3. It is important to clarify terminology. What is sometimes called 'assisted dying' or 'end of life choice' comprises physician-assisted suicide (PAS) and/or physician-assisted euthanasia (PAE). PAS denotes the supply of lethal drugs by a doctor to a patient to enable that patient to end his or her own life. PAE denotes the administration of lethal drugs by a doctor to a patient in order to end that patient's life.

The Social Dimension

4. Much of the pressure for legalisation has its roots in social changes over the last few decades. Three such changes in particular need to be recognised. As medical science has advanced, it has become possible to extend lifespans and postpone natural death. However, extended life is not always accompanied by extended good health and we are becoming vulnerable as we age to long-lasting and sometimes distressing degenerative illnesses, such as multiple sclerosis, Parkinsons, heart disease or dementia. It is interesting to note that, while official campaigning for legal change is often narrowly focused on terminal illness, grass-roots pressures frequently centre on chronic rather than end-stage conditions. In the UK the legal challenges to existing law which have been brought before the courts in recent years have usually related to individuals who would not be eligible for 'assisted dying' under the terms of the campaigning that is taking place.

The same advances in medical science have fostered a growing unfamiliarity among the public with the process of dying. As new treatments have offered the potential for saving and extending life, clinical intervention and hospitalisation have become the norm. Whereas once most people died at home cared for by their local GPs, district nurses and families, today they often die on hospital wards receiving life-prolonging interventions. As a result three generations have lost first-hand experience of being with and caring for someone who is dying and of coming to see death as a natural conclusion to life. As death has progressively become detached from life, dying has become for many a subject of dread.

The last quarter century has been characterised by the growth of a choice agenda. What was developed originally as an economic concept has migrated into the social and ethical field and has, in its turn, encouraged the emergence of a culture that places increasing emphasis on individual rights as distinct from social responsibilities.

The Law

It is our understanding that New Zealand law in this area is similar to the law in the UK. In brief, there is no law against declining interventions that may prolong our lives or even, if we feel it is appropriate, against ending our own lives. There already exists, therefore, a 'right to die'. What does not exist is a right to involve others in bringing about our deaths whether indirectly by assisting our suicide or directly by administering euthanasia.

The incidence of these offences in Britain is very small. Where they occur, decisions have to be taken as to legal action. In England and Wales, as in New Zealand, a decision to prosecute must satisfy two tests - the evidential test, meaning that there must be sufficient evidence to satisfy a court beyond reasonable doubt; and the public interest test, which requires that the circumstances surrounding the offence are such as to justify a prosecution to protect the public. Such prosecutorial discretion applies to the criminal law generally and in both jurisdictions there are published policies setting out how such decisions are reached. In England and Wales there is, in addition, a published policy¹ relating specifically to assisted suicide and listing various aggravating or mitigating factors which might be taken into account in reaching prosecution decisions.

Criminal laws are, however, more than just regulatory instruments. They also signal those actions of which societies disapprove. Most societies today take the view that, while we should not be judgemental about individual acts of suicide or attempted suicide, suicide itself is not something to be encouraged or assisted; and that, while it is possible to empathise with the giving of such assistance in highly exceptional situations, licensing such acts in advance and in prescribed circumstances is a different matter. Laws send social messages. An 'assisted dying' law risks sending the message, however unintended, that, if we are terminally or otherwise seriously ill, taking our own lives is something that it is appropriate to consider.

¹ 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide', Crown Prosecution Service, 25 February 2010

These issues of principle apart, there is the important question of whether a law which might meet the wishes of some people to have assistance to end their lives could be drafted and administered in such a way as to avoid exposing other, more vulnerable people to harm. Legislative proposals for 'assisted dying' are often framed around the needs of strong-willed and no-nonsense individuals who are clear about what they want, are fully in control of their lives and are not subject to hidden pressures. However, many people's experience of living is less about asserting their will and making autonomous decisions and more about coping with life as they find it. Looked at from this perspective, an 'assisted dying' law risks becoming a law to oblige the strong rather than to protect the weak. Advocates of legalisation argue that vulnerable people can be protected by the incorporation of safeguards into any legislation. This raises the question of what safeguards would exist and how effective they would be.

Safeguards

The degree of safety built into any law must be commensurate with the risks and consequences of failure. There can be little doubt that licensing doctors to hasten the deaths of patients lies at the high end of any risk register and, therefore, that the safeguards accompanying any such legislation need to be seriously robust. It is also important to recognise that simply stating in legislation that this or that must happen will not ensure that it does happen. Legislation must include practical measures to ensure that the intentions of the legislators are met.

The laws in operation in the handful of jurisdictions where PAS or PAE has been legalised prescribe conditions to be met and, to some extent, procedures to be followed. But they do not address the fundamental problem of how those called upon to make these difficult judgements are to make them. For example, it is easy enough to state that an applicant for 'assisted dying' must be terminally ill with less than six months to live and must not be acting under pressure of any kind. Such conditions may sound reasonable enough in principle but the difficulty arises in putting them into practice.

Prognosis of terminal illness at such ranges is fraught with error. According to the UK Royal College of General Practitioners, "*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*"². Establishing whether a patient requesting 'assisted dying' is under pressure is even more difficult. The traditional 'family doctor' who knows his or her patients and their families well and is a regular visitor to their homes is in many places a thing of the past. Doctors often know little of their patients' lives beyond the consulting room - whether they are liable to depression or mood swings or what family dynamics might be at work behind the scenes. And, as we observe below, in many, if not most, cases a request for 'assisted dying' would fall to be considered by a doctor who had never met the patient before.

² Evidence to House of Lords Select Committee of Assisted Dying for the Terminally Ill Bill, House of Lords Report 86-I (Session 2004-05), Paragraph 118.

The fundamental problem with the safeguards that usually accompany 'assisted dying' laws (or proposals) is that they assume the existence of a perfect world - a world in which seriously-ill people are clear that they do or do not want to end their lives; a world in which doctors know their patients well and are willing and have limitless time and expertise to assess them for the purpose; and a world in which families are loving and caring. The real world is rather different. For most people a terminal prognosis is a shattering experience that brings them face to face with their mortality. Some can deal with it in a matter-of-fact manner, but many veer between hope and despair. Most families are loving and caring - but some are not. And, even when they are, seriously ill people can feel pressures from within themselves to 'do the decent thing' and remove themselves as a care or a financial burden. In Washington State 59 per cent of those who took their own lives via legalised PAS in 2014 gave, as one of their reasons, that they did not wish to be a burden³.

This is not to say that adequate safeguards could not be devised. But, given the risks and irrevocability of what is being proposed, safeguards are needed that are more than just procedural. They need to be real-world-proofed. That has not been done.

Doctors

With the exception of Switzerland, whose law permitting assistance with suicide in certain circumstances dates from 1942 and was not enacted in the context of serious illness, those jurisdictions which have legalised 'assisted dying' in one form or another have placed responsibility for deciding who should and should not qualify for such assistance on the shoulders of doctors. This raises serious difficulties as the majority of doctors in most countries do not support such practices and are unwilling to participate in them.

The British Medical Association and the Royal Colleges of Physicians, General Practitioners and Surgeons are opposed to legalisation of 'assisted dying'. In 2009 the Royal College of Physicians stated, in a letter to the then Director of Public Prosecutions (DPP), that "*we believe that our duty of care is to work with patients to mitigate and overcome their clinical difficulties and suffering*" and that "*it is clear to us that this does not include being in any way part of their suicide*". The College went on to say that "*the trust afforded doctors and nurses gives their views considerable weight with their patients and the public*" and that involvement of doctors in assisting suicide was "*open to misinterpretation or cynical manipulation*"⁴. Reflecting this view, the DPP's policy for prosecutors lists, as one of sixteen aggravating factors that might incline towards a decision to prosecute, the circumstance where an assister with suicide "*was acting in his or her capacity as a medical doctor, nurse, other healthcare professional or as a person in authority, such as a prison officer, and the victim was in his or her care*"⁵. In other words, the

³ Washington State Department of Health, 2014 Death with Dignity Act Report, Page 7

⁴ Letter from Royal College of Physicians to Director of Public Prosecutions dated 14 December 2009

⁵ Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, Crown Prosecution Service, February 2009, Paragraph 43

involvement of doctors in assisting patients to end their lives is seen as a breach of doctor-patient trust.

The majority of doctors share this view. A 2015 poll of 1,000 GPs in Britain revealed that only 14 per cent (1 in 7) would be willing to conduct an assessment of a request for PAS if it were to be made legal⁶. Opposition is particularly strong among doctors who specialise in care of the dying. A survey of its members in 2015 by the Association for Palliative Medicine of Great Britain and Ireland found that 82 per cent opposed a change in the law and that 96 per cent would be unwilling to participate in legalised 'assisted dying'.

The result of such medical opposition is that many people seeking legalised assistance to terminate their lives would find themselves obliged to seek out a minority of willing doctors. These would have no prior knowledge of them as patients and would be ill-placed as a result to conduct knowledge-based assessments of the requests. They would also, by reason of their self-selection for the task, be doctors who might see assisted suicide or administered euthanasia as a reasonable response to serious illness and who might not as a result bring the same level of rigour to the assessment of requests that others might apply. To say this is not to question their integrity as individuals but to emphasise that, where life-or-death decisions are being taken, a serious level of challenge is needed.

Public Opinion

Public opinion polls suggest that a majority of people favour a change in the law. This is undoubtedly so in terms of what people tell the pollsters, but the polls cannot be taken at their face value. They are often sponsored by groups campaigning for a change in the law and couched in euphemistic and sometimes misleading terms.

It is necessary also to ask on what knowledge base the responses to such polls are given. Most people lead busy lives and can hope to have serious knowledge about only a handful of subjects of immediate concern to them. Whether we care to admit it or not, our knowledge of a wide range of issues is derived from what we have picked up in the press or the electronic media. The media's handling of the 'assisted dying' question is, however, distinctly one-sided. As an example, one out of every 25,000 deaths of Britons in the last ten years has taken place at the Dignitas assisted suicide facility in Switzerland. Yet each one makes the headlines and it is easy for the public to get the issue out of proportion. This not because of any wish to mislead on the part of the media but simply a consequence of the fact that news consists of the exceptional. In the same way, if we had no first-hand experience of air travel and our knowledge of it was derived entirely from what we read or heard in the news, we would probably tell pollsters that flying was dangerous.

Opinion polls in Britain supported going to war in 1914 and appeasement of the dictators in the 1930s. Today they show public support for such measures as

⁶ Survey by MedeConnect, May 2015

banning immigration and restoring capital punishment. Such polling is not without value but it is a dubious guide to serious policy-making.

The Overseas Dimension

Four out of fifty US States (Oregon, Washington, Vermont and California) have legalised PAS. In Europe, Belgium and Luxembourg have legalised PAE. The Netherlands has legalised both PAS and PAE.

Two things stand out particularly from the experience of these laws - that the incidence of legalised 'assisted dying' increases as the years pass; and that the take-up of PAE is significantly higher than of PAS. For example, in The Netherlands, where both PAS and PAE have been legal since 2001, the overall numbers have risen, and are continuing to rise, steeply - from 1,882 deaths in 2002 to 5,306 in 2014. In 2014 1 out of every 26 deaths in Holland was the result of PAE or PAS. Over 90 per cent of them were via PAE. Neighbouring Belgium, which legalised PAE alone in 2002, is showing a similar trend. On the basis of the latest Dutch data, a PAS-plus-PAE law such as is proposed in the draft End of Life Choice bill in the name of David Seymour could be expected to result in some 1,200 deaths per annum in New Zealand.

Oregon's 1997 PAS-only law is also showing a steadily rising rate of mortality. The number of deaths from PAS in 2014 was nearly seven times the number in the first year of the law's operation, and in one year alone (2014) there was an increase of 43 per cent. On the other hand, the numbers themselves were not huge - they rose from 16 in 1997 to 105 in 2014. Based on the 2014 data, a PAS-only law in New Zealand along the lines of Oregon's might be expected to result in approximately 120 deaths annually from this source. It should be noted, however, that the numbers, in both Oregon and The Netherlands, are rising year by year.

Campaigners for legalised PAS often claim that Oregon's PAS law is working without problems. It is impossible to corroborate this claim as there is no post-event scrutiny system in place to shine a light on how requests for PAS are being handled in practice - for example, whether they are being examined searchingly or dealt with on a tick-in-the-box basis. The official annual reports are little more than statistical analyses of deaths.

Independent research does, however, suggest that all may not be as well as claimed. For example, a report published in the British Medical Journal⁷ found that some of those who had ended their lives by PAS had been suffering from clinical depression which had not been diagnosed by the doctors assessing them. The official reports also indicate that for many of those who received PAS the length of time they had known the prescribing doctors was very short. Currently only one in three doctors in Oregon is prepared to participate in PAS⁸. The official reports also suggest that a number of those supplied with lethal drugs on the basis of a six-months-or-less

⁷ 'Prevalence of depression and anxiety in patients requesting physicians's aid in dying: a cross sectional survey', Ganzini L, Goy ER, Dobscha SK, British Medical Journal 2008;337:a1682

⁸ 'Lessons from Legalized Physician-Assisted Death in Oregon and Washington', Professor Linda Ganzini, from 'Palliative Care and Ethics' (Ed. Quill, TE and Miller FG, OUP 2014, Page 270

prognosis have lived for longer, in some cases much longer, before either ending their lives with those drugs or dying of natural causes. The reports are unspecific as to how many such cases are involved but the situation underlines the difficulty of predicting life expectancy at a range of several months.

If Oregon's experience of PAS is not without problems, the concerns raised by PAE in Holland and Belgium are more substantial. Apart from the large and growing numbers of such deaths, the last ten years have seen an increasingly elastic interpretation of the groups of people who might qualify for PAE. This is now being offered to growing numbers of people with mental as well as physical health conditions. In Holland such extension may fall technically within the terms of the 2001 law, which was not specific to terminal or physiological illness, but it is questionable whether what is happening now is what Dutch legislators intended 15 years ago.

Meanwhile, in Belgium euthanasia has been administered to persons whose situations would seem to fall well outside the terms of the 2002 law. For example, in 2013 twin brothers who had been born deaf, had spent their lives together and had discovered they would soon go blind applied for and were given PAE on the basis that they could not bear the thought of not seeing each other again. Moreover, Belgium's PAE law has recently been formally amended to make euthanasia available to children. Claims that similar drift is not occurring in Oregon and other PAS-only States in America cannot be substantiated in the absence of any post-event audit machinery. But it is worth recording that in 2015 the first formal attempt was made to extend the scope of Oregon's PAS law.

Such legislative drift points to a fundamental problem at the heart of these laws and draft laws. The problem is illustrated in the explanatory note to Mr Seymour's draft bill, which states that "*the motivation for this bill is compassion*". That is undoubtedly so and it is a laudable motivation. But it begs the question: if relief of suffering is the aim, why should 'assisted dying' be restricted to people who are expected to die of natural causes in the near future and withheld from others with longer-lasting chronic illnesses with which they may have to live for many years? Mental suffering may also be every bit as bad as, in some cases worse than, physical distress. Looked at from this standpoint, the 'assisted dying' laws that have been enacted or proposed can be seen to contain within themselves the seeds of their own expansion. While compassion may be the driving force behind campaigning, it cannot be the touchstone against which sound legislation is judged.

The Situation in Britain

The 'assisted dying' lobby in Britain has now dissociated itself from the PAE which has been legalised in Holland and neighbouring Belgium and has limited its ambitions to campaigning for PAS only. A number of Private Member bills to this effect have been proposed in the House of Lords during the last 10-15 years, none of which has made progress. This year, for the first time in 20 years, a Private Member's bill similar to Oregon's law was debated in the House of Commons. It was rejected by 330 votes to 118. Earlier in 2015 the Scottish Parliament considered a similar Private

Member's bill following careful scrutiny by its Health and Sport Committee. The bill was rejected by 70 per cent of MSPs.

Conclusion

This is a complex and multi-faceted subject transcending many fields of expertise and experience including the law, clinical practice, mental health, ethics, society and the experience of those jurisdictions that have chosen to go down the 'assisted dying' road. There are respectable arguments on both sides of the 'assisted dying' divide. What is needed, but is often in short supply in public debate, is serious evidence and rational analysis. In our view the evidence available does not support the view that the laws in this area are dysfunctional or oppressive. Nor are we persuaded that the legislation which has been enacted to date in some jurisdictions or proposed in others is sufficiently robust to protect vulnerable people from harm. This is not to say that, if a convincing case for changing the law were to be made, adequate safeguards could not be devised. It is that a much more rigorous approach is needed than what has been seen so far, with safeguards which reflect an understanding of the difficulties of making such life-or-death judgements and which are capable of standing up to the pressures of the real world.

It is also necessary to recognise how and why current campaigning for legalisation has arisen. The roots lie in social changes over the last few decades, in particular the move from dying at home to dying in hospital, often during heroic attempts to stave off inevitable death; and to a growing unfamiliarity with seeing loved ones die and caring for them as they do so. Unfamiliarity can breed fear, which can only be dispelled by public education about the facts of dying and about the choices, including the choice to die, which already exist at the end of life.

Actual and proposed 'assisted dying' legislation places responsibility for deciding who should receive assisted suicide or euthanasia on the shoulders of doctors. This raises serious difficulties. The opposition of most doctors to such practices means that persons seeking assistance to end their lives must often be assessed by minorities of referral doctors who have no prior knowledge of them as patients and are therefore ill-placed to judge whether many of the safeguards have been met. Moreover, incorporating 'assisted dying' within clinical care embeds it within a comfort zone and risks sending the message that it is, like other medical acts, a 'best interests' procedure.

This memorandum does no more than provide a birds-eye view of some of the principal features of the 'assisted dying' landscape. We stand ready to provide oral evidence if that would be helpful to the committee.

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December 2015