

DYING WITH DIGNITY BILL 2020
Submission by Living and Dying Well

Executive Summary

The Bill's title does not make clear what it is seeking to make lawful. The Bill proposes to legalise the supply – and in some cases the administration - of lethal drugs by doctors to terminally ill patients who appear to meet certain conditions. This would represent a major change to the criminal law. It is necessary to ask therefore whether the existing laws in this area are in need of change and, if so, whether the Bill's proposals are an appropriate way of making such a change. On both counts the evidence does not support the Bill.

The purpose of the criminal law is to protect society, and especially its most vulnerable members, from harm - including self-harm. The existing law accurately reflects both social attitudes to suicide and the ethics that underpin clinical practice. It combines deterrence of malicious acts with discretion not to prosecute in cases of genuine compassion. That is fundamentally different from creating a licensing system for providing lethal drugs to designated categories of people.

Even if a robust case could be made for changing the law, the provisions of the Bill would offer no serious protection to vulnerable people. Its broadly-worded eligibility criteria for receiving lethal drugs are no more than that – eligibility criteria. They mandate no minimum actions which a doctor considering such a request must take in order to ensure that the conditions prescribed actually exist. What the bill presents as safeguards are in reality nothing more than statements of what should happen in a perfect world.

The Bill proposes to place on the shoulders of doctors responsibility for assessing and deciding on requests for lethal drugs. While doctors are qualified to diagnose terminal illness, they are not qualified to assess other important aspects of such a request, including whether a request for lethal drugs reflects a settled wish to die or whether there are any internal or external pressures underlying a request. Moreover, as the experience of Oregon has shown, with most doctors unwilling to engage in such practices, those seeking lethal drugs would often have to be assessed by referral doctors who have no prior experience of them as patients and are ill-placed to make knowledge-based assessments.

Definitions

The bill's title does not accurately describe what it is seeking to make lawful. It is important therefore to clarify terminology. The bill is proposing that it should be permissible in law for doctors to prescribe lethal drugs in certain circumstances to terminally ill patients in order that those drugs might be used to bring about the patients' deaths through self-administration. The bill also proposes that in some circumstances a doctor might lawfully inject lethal drugs directly into a terminally ill patient. These two acts are commonly termed Physician-Assisted Suicide (PAS) and Physician-Administered Euthanasia (PAE) respectively. These terms are used in the paragraphs which follow.

The Questions

There are two questions to be addressed in respect of the bill.

- Is the existing law in need of change?
- If so, do the provisions of the bill represent an appropriate way of changing it?

The Law¹

PAS

Under the Criminal Law (Suicide) Act 1993 suicide ceased to be unlawful in Ireland. However, it remains unlawful to aid, abet, counsel or procure the suicide of another person. A person convicted of such an offence is liable to a sentence of imprisonment of up to fourteen years. The Act states, however, that "*no proceedings shall be instituted for an offence under this section except by or with the consent of the Director of Public Prosecutions*"².

PAE

As we understand, there is no law specifically relating to PAE in Ireland. Deliberately ending the life of another person, with or without the victim's consent, constitutes murder and is contrary to the Criminal Justice Act 1964 and to common law.

Thus, a doctor who under existing law in Ireland engaged in PAS or PAE would be committing a criminal offence. The bill is suggesting that such

¹ Oireachtas Framework for Committee Scrutiny of PMBs, Questions 1, 2, 15, 19

² Criminal Law (Suicide) Act 1993, Section (4)

acts should not be criminal in certain circumstances – specifically, where a patient is terminally ill, has a settled wish to die, has decision-making capacity and is not under coercion or duress.

In deciding whether the existing laws are in need of change the committee will doubtless wish to assess whether they reflect social values, deter unacceptable behaviour and deal with any breaches of the law in an appropriate manner.

Most societies rightly regard with compassion people who take or attempt to take their own lives. They do not, however, regard suicide as something to be assisted, aided or abetted. The existing law in Ireland reflects these social values. It forbids assistance with suicide while its requirement that no proceedings may be undertaken without the consent of the Director of Public Prosecutions recognises that such offences are fact-sensitive and that there could be exceptional circumstances in which a breach of the law does not call for prosecution in the public interest. This combination of deterrence with discretion ensures that the offence of assisting suicide is rare, while the serious penalties that the law holds in reserve to deal with malicious or manipulative assistance ensure that the small number of cases that do occur tend to be those where there has been much soul-searching, reluctance and genuine compassion on the part of the assister.

What the bill is proposing – the creation of an advance licensing system for assisting the suicides of specified groups of people – changes the dynamic completely. It sends the social message to persons who are seriously ill that taking their own lives is seen as an appropriate course of action and it removes the deterrent against malicious assistance – as a person with malicious or manipulative intent would have nothing to fear from pressuring another to seek legalised assistance other than that the request might be refused.

It is unsurprising therefore that, where assistance with suicide has been legalised, the death rate from this source has been seen to rise steadily. In the US State of Oregon, for example, the number of legally assisted suicides has risen twelvefold since the law was changed. Oregon's 2019 official death rate from this source is the equivalent of 161 cases of assisted suicide annually in the Republic of Ireland if the law were to be changed in line with Oregon's law. It should be noted, however, that the

provisions of Oregon’s law are more restrictive than those contained in the bill and the figure of 161 is therefore likely to be an under-estimate.

The same arguments apply to physician-administered euthanasia. It is also noteworthy that, where PAE has been legalised, the resulting death rate is even higher than the death rate for PAS. In The Netherlands in 2019 one in twenty-five of all deaths throughout the country was the result of legalised PAE.

We submit therefore that the existing laws in this area in Ireland are not in need of change. They combine deterrence of malicious or manipulative acts with discretion to deal appropriately with genuinely compassionate acts. The experience of the minority of jurisdictions which have gone down the road which the bill proposes is far from reassuring.

The Law and Clinical Practice

The existing law applies equally to doctors as to other members of the community. PAS and PAE are unlawful acts by whomever they are committed. The existing law, however, reflects the ethical rules that govern the conduct of clinical care. The practice of medicine in Ireland, as in most other European countries, is governed by the principle of ‘do no harm’, which requires that doctors must not, in advising or treating their patients, deliberately bring harm to them. The Irish Medical Council, the body which regulates the practice of medicine in the country, tells doctors in its Guide to Professional Conduct and Ethics that “you must not take part in the deliberate killing of a patient”³.

Notwithstanding this, the bill seeks not only to license assisted suicide and administered euthanasia but also to embed these practices within clinical care. Apart from the ethical issue, this would bring significant problems. In the first place, the majority of doctors in Ireland would be unlikely to be willing to participate in PAS or PAE. The bill includes provision⁴ for a doctor with a conscientious objection to refuse to engage in such practices, but that does not resolve the difficulty. The conscientious objection section is accompanied by another⁵ requiring an objecting doctor to connect the applicant with a willing colleague, which

³ Irish Medical Council, Guide to Professional Conduct and Ethics (8th Edition 2019), Section 46.9

⁴ Section 13(1)

⁵ Section 13(3)

many doctors would see as simply engaging in PAS or PAE at one remove and therefore as a violation of conscience.

More important still is the fact that, with a majority of doctors refusing to engage, requests for PAS/PAE would have to be considered by a minority of referral doctors with no first-hand knowledge of applicants as patients. Such ‘doctor shopping’ is what has happened in Oregon, where multiple prescribing of lethal drugs by a small number of referral doctors is common. In 2019 one of these doctors wrote no fewer than 33 such prescriptions⁶.

The committee may therefore wish to consider whether, if the bill were to proceed, its implementation should be separated from clinical practice. This would mean that requests for PAS or PAE would be examined and decided on, not by doctors, but by a senior court, with the involvement of doctors limited to the provision of a medical report on the strictly clinical facts of a request. The decisions involved in such cases are predominantly social rather than medical. They are about balancing rights for some against protection for others and, as such, are the natural province of the courts, not of the consulting room.

The Provisions of the Bill⁷

In the above paragraphs we have sought to explain why in our view the existing law is not in need of change. We move now to examine how the sponsors of the bill believe the law should be changed.

Briefly, the bill seeks to offer PAS (or in some circumstances PAE) to people who have been diagnosed as terminally ill and who appear to be of sound mind, have a settled wish to end their lives, and to be making a request for lethal drugs voluntarily and on an informed basis.

Terminal Illness (Section 8)

The bill’s definition of terminal illness is wide-ranging. It defines terminal illness as “an incurable and progressive illness which cannot be reversed by treatment” and from which the person “is likely to die as a result of that illness or complications relating thereto”. However, it contains no requirement for a prognosis of life expectancy as a result of the illness concerned. As a result its ambit is significantly wider than

⁶ Oregon Death with Dignity Act, 2019 Data Summary, Oregon Health Authority, Page 7

⁷ Oireachtas Framework for Committee Scrutiny of PMBs, Questions 8, 10, 15, 17, 19

Oregon's PAS law, which requires not only a diagnosis of terminal illness but also a prognosis of six months or less. It also differs in this respect from recent parliamentary bills at Westminster and Holyrood which have included a similar prognosis condition – and have been rejected as unsafe.

The bill as drafted would bring within its ambit not only people who had been diagnosed with a terminal illness in the normally understood sense of that term but also others with chronic illnesses, such as multiple sclerosis, Parkinson's disease, heart disease and even diabetes, which are incurable, progressive and irreversible but can be – and are – managed by appropriate medication or treatment and with which those concerned can live for many years, often decades. There can scarcely be a street in Ireland where there are not people who might qualify for lethal drugs under the terms of the bill as presented. For this reason, as noted above⁸, the estimate of some 161 assisted suicide deaths annually in Ireland resulting from the bill is likely to be an under-estimate, as it is based on the death rate from Oregon's more restricted PAS law. Contrary to what the bill's title implies, its ambit goes well beyond dying.

Settled Intent (Sections 7(b), 9(1)(a) and 9(3)(c))

Clause 9(1)(a) of the bill requires a person seeking lethal drugs to make a declaration that he or she “has a clear and settled intention to end his or her own life”. Clause 9(3) requires doctors considering such a request to be “satisfied” that this is the case. In making this requirement the bill is presumably aiming to separate people with a firm and determined wish to end their lives from others who may be acting as a result of transient depression.

Two questions arise from this – what is a “clear and settled intention” to take one's own life? And how is that intention to be ascertained? The bill is silent on both these questions. It would appear from the bill that a “clear and settled intention” is whatever the applicant for lethal drugs says it is and that it is up to the assessing doctors to decide whether that is so. The ability of a doctor to make an assessment of this nature depends to a large extent on how well and for how long the doctor has known the patient and what discussions of the issue have taken place. The bill has nothing to say on this.

⁸ See Page 4

Moreover, as noted above, with a majority of doctors unwilling to participate in PAS or PAE, in many cases applicants would have to be assessed by doctors who are not their regular practitioners but to whom they had been introduced solely for the purpose of receiving lethal drugs and who would have no prior knowledge of them as patients. This provides no basis on which to make knowledge-based judgements.

If applicants for lethal drugs were required to have made a declaration, say, twelve months before making a request for PAS to the effect that, if they were at a future date to find themselves eligible for what the bill is proposing, they might wish to consider it, that might possibly provide an indication to an assessor of a request that the possibility of seeking PAS in certain circumstances had been considered. Such a declaration would carry no obligation to seek PAS and could be withdrawn at any moment. It is not uncommon to hear people say that they would not want to go on living in certain clinical situations. Such statements are in most cases not seriously intended but the ability to make an advance declaration of interest could provide a helpful means at a future date of separating serious requests for lethal drugs from others resulting from acute emotional turmoil resulting from a terminal diagnosis.

Whether this would provide sufficient grounds on which to identify a “clear and settled intention” is debatable. It is clear, however, that the bill as it stands falls well short of the requirement to protect vulnerable people.

Of sound mind (Sections 9(3)(b) and 10)

The bill sets out various steps to confirm assessment of capacity. While these are unobjectionable as far as they go, they are insufficient. They treat capacity assessment as a purely mechanistic process of establishing whether or not an applicant’s thinking and comprehension processes are intact. For a decision of this nature it is necessary to have regard also to a person’s state of mind.

It is possible to have all our thinking processes sufficiently intact to understand the nature a decision and to be able to communicate our wishes, but nonetheless to have our judgement impaired by depression or personal circumstances. A terminal diagnosis can be a shattering experience. Depression is understandably widespread at such times and patients need time and support to come to terms with their mortality.

They can also be seriously worried about the impact that their illness will have on their families and others around them. It is common for terminally ill people to veer between wanting to live and wanting to die. The bill is, in effect, placing serious and irreversible decisions before people at a highly stressful time of their lives.

The bill does not reflect an awareness of this. It presents assessment for PAS or PAE as a straightforward process for people who know exactly what they are doing and who have no pressures on them as they are doing it. In the real world most seriously ill people are focused on coping with their lives as they are and with preparing for dying as best they can rather than on asserting their will and making autonomous decisions.

Nor does the bill require that capacity assessment should be carried out by a specialist in that field. The assessment is left entirely in the hands of the assessing doctor, who may or may not have any expertise in this area. For all these reasons, the bill's provisions in the field of capacity assessment are insufficient to protect vulnerable people.

Voluntary Request (Section 9(3)(c))

A request for lethal drugs from a terminally ill person may appear on the face of it to imply a voluntary act. We all make decisions every day which are to a greater or less extent voluntary. Decision-making rarely proceeds from a clean sheet of paper. However, for a decision of such gravity and with an irrevocable outcome, positive evidence is needed that it is voluntary. The bill as it stands requires no such evidence, simply a subjective assessment by a doctor.

Why would someone request lethal drugs if the decision to do so were less than voluntary? To answer this question we need look no further than Oregon. The 2019 official report of the Oregon Health Authority stated that six out of ten of those who took their own lives with legally-supplied lethal drugs had stated that one of their concerns related to being a "burden on family, friends/caregivers"⁹.

There is also the issue of external coercion. It may be hard to imagine that relatives would put pressure on sick family members to end their

⁹ Oregon Death with Dignity Act, 2019 Data Summary, Oregon Health Authority, Page 12

lives as this is not the way we ourselves would behave. But, sadly, there are people out there who are capable of such behaviour. In many western countries elder abuse is on the rise, much of it within families. External pressure need not take the form of overt threats or demands. It can occur in the form of disparaging treatment or neglect and can make a terminally ill relative feel that death is their only option.

The bill does not recognise these situations. It requires that an assessing doctor should simply be “satisfied” that a request is voluntary and “without coercion or duress”, but it mandates no minimum steps that the doctor must take in order to ensure that this condition is met. This is a particularly serious deficiency in view of the fact that many such requests would fall to be considered by referral doctors with no prior knowledge of the person making the request or of his or her family situation. In this respect too the bill falls well short of what is required.

Fully Informed Decision (Sections 9(3)(c) and 9(4))

The bill states that an applicant for lethal drugs must be “fully informed of the palliative, hospice and other care which is available”. But it does not require that such information should be imparted by a specialist in palliative/hospice care rather than by the doctor who happens to be assessing the request and who may or may not be up to speed with developments in this branch of medicine.

Nor is there any requirement in the bill that a person seeking lethal drugs should have experienced the care which specialist palliative care can provide. In 2004 the organisation Help the Hospices¹⁰ told a Westminster parliamentary committee 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” and that “patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed”¹¹.

Doctors who specialise in palliative care encounter patients from time to time who are referred to them and who say they want to end their lives but who, once they have experienced modern palliative care, change their minds. This begs the question whether, if PAS/PAE were to be legalised, there should be a requirement for the applicant to have

¹⁰ Now known as Hospice UK

¹¹ House of Lords Report 86-I (Session 2004-05), Paragraph 258)

experienced specialist palliative care before confirming a request. In this area, as in others, the bill falls to address the real-world issues.

Northern Ireland (Section 7(c)(2))

The bill states, as one of its qualifying conditions for PAS/PAE, that an applicant must have been “resident on the island of Ireland” for at least a year. It is for others to comment on the constitutional issue which this provision may raise. Our interest is in the practical problems which it could present. As PAS/PAE are unlawful in Northern Ireland, we are assuming that a person residing there who may wish to seek lethal drugs would need to cross the border for the purpose.

This raises some questions. What would be the legal position of a doctor in (say) Belfast who referred a patient to another doctor in (say) Dublin or provided the patient’s medical history to a doctor practising south of the border in order that the patient may seek PAS or PAE? Or, to take another example, what would be the legal position of a patient who received lethal drugs from a doctor south of the border and brought those drugs back home across the border to Northern Ireland? These and other situations could present serious cross-border difficulties for patient care.

Conclusion

We submit that, before the bill could be responsibly enacted into law, clear evidence is needed that the existing law is in need of change and, if (and only if) that is so, that the bill is fit for purpose. On neither count in our view can an affirmative answer be given.

It is natural to empathise with assistance to end life being given in highly exceptional cases and to say that such cases should not be exposed to prosecution. However, changing the law to license in advance the supply or administration of lethal drugs for groups of people is a completely different matter. Such legislation, however well intended, sends a potentially dangerous social message. If the existing law were dysfunctional or oppressive, there might be a case for change. But no serious evidence has been produced that that is so. It is not sufficient to say that the law does not meet the wishes of some people. No law does that. The primary purpose of the law is to protect the vulnerable.

Even if it were to be considered that the law is in need of change, the bill as it stands falls well short of what is required for that purpose. Its deficiencies are so numerous and serious that it is in our view beyond simple amendment. Its provisions contain no safeguards worthy of the name to protect the vulnerable. They are little more than idealistic statements of what ought to happen in a perfect world and they are not designed for the real world of serious illness, clinical care and complex family dynamics.

The bill, moreover, is very widely drawn. It offers both assisted suicide and administered euthanasia not only to people who are terminally ill in the generally understood sense of that term but also to large numbers of people with common chronic illnesses which can be, and generally are, managed successfully for many years. The experience of jurisdictions that have gone down this road should serve as a salutary warning.

And, finally, the bill places responsibility for decision-making on the shoulders of doctors. While some doctor involvement is inevitable where such a law is linked to designated clinical states, the main issues underlying requests for lethal drugs are personal or social rather than medical. The subject with which the bill deals is essentially about balancing rights for some against protection for others. Such decisions are the province of the courts – and given the gravity of what is involved of a senior court – rather than the consulting room.

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