

**Submission To
Justice Committee**

Dying With Dignity Bill 2020

End of Life Ireland



**END OF
LIFE
Ireland**



Executive Summary

- a) **End of Life Ireland** supports the Dying With Dignity Bill 2020 as being compassionate, humane and in tune with both popular opinion and the State's movement to a rights-based model for services provision.
- b) Ireland has ratified the UN Convention on the Rights of Persons with Disabilities. The Department of Health has set up the HSE National Office for Human Rights & Equality Policy and the Health Information Quality Authority (HIQA) has adapted the principles of fairness, respect, equality, dignity and autonomy. This Bill is in the spirit of those policies.
- c) The Assisted Decision-Making (Capacity) Act 2015 seeks to enable all individuals to give a considered decision about their lives, even where there may be reduced capacity. The Act is awaiting full commencement and a public consultation is ongoing. Part of this consultation includes the concept of advance healthcare directives provided for in the Act and it deals for the first time in Ireland with decisions touching on how we may determine how we should die. The Dying with Dignity Bill is another step towards the recognition of the autonomy of the person as a human right.
- d) It is within almost everyone's experience that many people have a 'bad death'. That is, their death may be painful and degrading, depriving them of dignity and autonomy. This Bill gives hope to those with terminal illnesses and choice — for those who wish to avail of it — in the manner of their dying. And dying is an inescapable part of life.
- e) International experience of about two decades shows that the provision of Voluntary Assisted Dying promotes good, constructive end-of-life discussions with doctors and with family members. Such discussions often do not lead to a request for assisted dying.
- f) When a request for assisted dying is successful, not all patients go on to avail of it. However, they have 'emotional insurance' and the quality of their remaining life is improved both for them and for their loved ones. Further, the discussion about the decision and recognition of the individual's autonomy all contribute to greater acceptance of the death and a much easier grieving process for the bereft.

- g) The international experience shows that the safeguards work: ‘vulnerable’ groups are not coerced into seeking assisted dying. Ireland can draw on that experience to quickly formulate appropriate safeguards.
- h) ***End of Life Ireland* recommends that the implementation of the Bill be based on the Dutch model, which uses the professional skills of general practitioners, It also has efficient, rigorous monitoring and transparent reporting.**
- i) ***End of Life Ireland* recommends that the Bill be passed to the Committee stage. The Supreme Court has determined that there is no constitutional objection to such a provision and the international experience provides material to work with.**

Dedication.

This submission is dedicated to the memory of Gaynor Ffrench, who, during her own last illness, campaigned tirelessly for [Dying with Dignity](#). Gaynor died in 2018.¹

¹ Irish Examiner (2018).

Introduction

This submission has been compiled by *End of Life Ireland (EOLI)*, a voluntary advocacy group which seeks to foster conversations about *End of Life* matters. **EOLI** is open and compassionate and argues that individuals should have *choices* about the end of life, just as they have choices about living. The members of **End of Life Ireland** have diverse professional backgrounds, from nurses to psychotherapists, who have experience of working with people at the end of life, a solicitor, an academic and representatives of commerce and the public service.

John Halligan, TD, originally presented this Bill in 2015. Since that time Ireland has continued to become more diverse and more inclusive. A 2020 poll on the issue of dying with dignity showed that overall 52% agreed that “It should be legal for people to be given medical assistance to end their lives if that is their wish”, with only 17% rejecting the proposition outright.²

The changing views in Ireland reflect those taking place elsewhere in the developed world³. In the last year or so similar legislation has been approved or is extremely likely to be approved in some Australian states (e.g. Victoria, NSW, Tasmania), Austria, Spain and New Zealand. Such legislation has existed for many years in Oregon USA, Belgium and The Netherlands.

The purpose of this submission is to support the Dying With Dignity Bill 2020. The approach is to consider some of the arguments for the Bill and also place the debate in the context of rights-based service provision and individual autonomy. The submission will also draw on the results of good research on international practice, especially in Oregon (USA) and The Netherlands. The submission also discusses how the Bill might be implemented and ensure that proper safeguards are in place. There is international experience going back 20 years on which Ireland can draw.

Throughout this submission the term *Voluntary Assisted Dying* (VAD) is used because it emphasises that the decision to end one’s life is **voluntary**, that is, a **considered, free decision** on the part of an **individual**.

² Irish Times/Ipsos/MRBI Poll.8th October 2020.

³ Wikipedia (2020). List of jurisdictions where voluntary assisted dying is legal.

‘Assisted suicide’ and ‘Euthanasia’⁴ are generally used as pejoratives and in our view should only be used where it is necessary to distinguish between cases where the individual takes the lethal dose (‘assisted suicide’; ‘physician-assisted dying’ might be preferable), and cases where the physician administers it (‘euthanasia’).

Benefits of the Bill

1. **Human Rights.** Ireland has ratified the UN Convention on the Rights of Persons with Disabilities. This and the Assisted Decision-Making (Capacity) Act 2015 have created a new context for the provision of services, including medical services, namely, that individuals have the right to be fully involved in decision-making about services and — in the context of this Bill — the provision of health care. This is a major shift in attitude from much more paternalist models that pertained in the past.

The Department of Health has set up the HSE National Office for Human Rights & Equality Policy⁵. In implementing its policy it has adopted the FREDA principles of *fairness, respect, equality, dignity and autonomy*. (The same principles have been adopted by HIQA.⁶) This Bill is consistent with those objectives.

2. **Choice.** The Bill is essentially compassionate and seeks to provide choice to individuals who are terminally ill and wish to end their lives in order to avoid intolerable suffering. The Bill provides strict grounds for qualification.
3. **Autonomy.** Individuals have personal autonomy, that is the ability to make decisions concerning themselves and their treatment. However, this autonomy is never ‘unfettered’. Individuals live within societies and have obligations, not least the obligation not to cause harm to others. Autonomy is the sign that respect is given to the individual, and with respect comes dignity. Dying is part of life and a measure of

⁴ ‘Euthanasia’ is not seen as pejorative in some jurisdictions and in the Netherlands it is the preferred term.

⁵ HSE National Office for Human Rights and Equality Policy Office

⁶ Health Information Quality Authority (HIQA) (2019). Draft Guidance on a Human Rights-Based Approach to Care and Support in Health and Social Care Settings

control is required to retain autonomy and dignity. Individual autonomy is thrown into sharp relief in the context of medical 'paternalism'.⁷

4. **Mitigation of Intolerable Suffering.** As a general principle, the reduction of suffering is a social good. Personal testimony shows that it is not uncommon to have witnessed a death that was not a 'good death'. Such deaths may be long-drawn out, with loss of autonomy and dignity and possibly in the unfamiliar surroundings of an intensive care or palliative care unit. We do not extend to our fellow-citizens the same compassion and relief of suffering that we extend to the animals in our care.

5. **Relief of Mental Suffering and Early Deaths/Suicides.** International experience and personal testimony from Ireland⁸ and elsewhere⁹ confirm that when citizens have the choice to end their intolerable suffering in a terminal condition, the 'fear of a bad death'¹⁰ is removed. Reassurance about the end of life by qualification for VAD provides relief of stress and enables individuals to enjoy the time that remains to them without the extreme fear of pain and indignity and the fear of being the cause of anguish to their loved ones. Further, 'around 35% who qualify and are given a prescription choose not to use it. ... they have the prescription as "emotional insurance."¹¹ In short, there is an increase in the *quality* of life.

Where VAD is not available, individuals with intolerable illnesses may seek to travel to another jurisdiction to end their lives — a process which is both difficult and expensive and so only available to the privileged. In order to be able to do this, they will have to travel while they are still relatively healthy, thereby depriving themselves of a significant period of satisfying life.

Alternatively, individuals may be tempted to commit suicide, which is likely to have serious emotional consequences for their loved ones and also carries the risk that the attempt will not be successful, leaving them worse off both physically and emotionally.¹²

⁷ Grayling, AC (2003). For a useful brief discussion of autonomy, respect and paternalism; medical ethical dilemmas see p199 ff.

⁸ 2018 Report, p43; O'Shaughnessy, 2018.

⁹ De Jong (2020).

¹⁰ Oireachtas Library & Research Service, 2020.

¹¹ 2018 Report, p5.

¹² *ibid.* (p43) 'This argument supports the idea that it is not really death that people are seeking; rather, they wish to alleviate the fear of a 'bad death' - a drawn-out dying process in great pain, for instance.'

6. **Ethical and Moral Distinctions.** Medical treatment may shorten life, even though that is not the intention. This is known as the *doctrine of double effect*¹³, described by the humanist philosopher, AC Grayling, as a ‘conceptual convenience’¹⁴, meaning that there is no significant moral distinction between death as a consequence of medical treatment given primarily to relieve physical and psychological distress¹⁵ and giving a drug which is intended to shorten or end the patient’s life.

Similarly, it can be argued that there is no significant moral distinction between withdrawing treatment and other vital supports and allowing the patient to die (‘passive euthanasia’) and assisting a patient to die by providing or administering a lethal medication (‘active euthanasia’). *On the contrary, enabling an individual to escape from intolerable suffering for which there is no prospect of relief may be seen as a moral good.*

That said, the Bill provides a ‘conscience clause’ so that no doctors are obliged to assist in the provision of VAD.

6. **Promotion of Constructive Discussions about End of Life.** An important consequence of legislation such as the Dying With Dignity Bill 2020, is the promotion of much better discussions about end-of-life issues. If an individual is considering a voluntary assisted death, it will be necessary to have a serious discussion with a medical adviser and also with family and close social circle. The benefits of these discussions were borne out in the Oregon report reviewing 20 years’ experience with the Death with Dignity Act 1997. Indeed, that report showed that such conversations ‘reassure a dying person rather than direct them towards making a request for medical aid-in-dying. The vast majority of people who raise the possibility of assisted dying with their doctor will not go on to make a formal request.’¹⁶ These discussions are an essential step in the Dutch practice (see *Implementation and Appendix*).
7. **Doctor-Patient Relationship.** The international experience also supports the view that the provision of VAD enhances the doctor-patient relationship by fostering the doctor’s appreciation of the patient’s wishes and circumstances. This places

¹³ IAPC Palliative Sedation Discussion Paper (2011).

¹⁴ Grayling, AC (2003). p 207.

¹⁵ IAPC Palliative Sedation Discussion Paper (2011). Palliative Care uses ‘deep sedation’ to control otherwise intractable physical and psychological distress and it is often accompanied by withdrawal of nutrients and water, resulting in death within days.

¹⁶ Dignity in Dying ‘Oregon Report 2017’, p10.

emphasis on the doctor as more centrally involved with the patient and using all her/his clinical and personal knowledge, not only to inform the patient of all options, but also to form a considered opinion of the patient. This opinion is critical to the judgement of the patient's qualification for VAD. In particular, it will be critical to the assessment that the patient is making a free decision and is not coerced by anyone.

It is worth making the point that not all doctors share the view that their first duty is 'to do no harm'. Some doctors see relief of extreme suffering as a primary duty. In some jurisdictions doctors in palliative care work closely with colleagues who are involved in providing VAD.¹⁷

8. **Enhancement of the Value of Human Life.** Many people do not share the view that it is *always* wrong to end a life; indeed the state itself sanctions lethal force in certain circumstances. Many consider that we have just the one life and it should be valued all the more for that reason. (There is an implied duty to attempt to fulfil each individual, not merely for selfish reasons, but for the betterment of society, the species and our whole environment of which we are, in effect, the custodians.) This view means that *all* lives are valued and that specifically includes those described as 'vulnerable' in earlier discussions about Dying with Dignity: namely the frail elderly and those with physical or intellectual impairments.

The Bill is about providing *choice* for those who do not share the absolutist view that it is always wrong to end a life. The ability to make decisions about end-of-life issues is as important as the ability to make decisions about other aspects of life. Retaining a measure of control over the circumstances of death retains the individual's dignity and reflects the value of the quality of a human life.

9. **Coercion of Individuals to End their Lives.** This is properly a matter of concern. It is critically important that the decision to seek VAD is considered and free from coercion of any kind. It must be a decision for the individual in full knowledge of the possible outcomes and alternatives. There is no evidence of coercion in international practice (some of it of more than 20 years' duration). The safeguards include evaluation of an individual's decision and best practice is to consider the individual in the context of family and social circumstances (see *Implementation*).

It is important to remember that this Bill limits VAD to those with an illness which is either directly terminal or its consequences will prove terminal. The commonly

¹⁷ Gerson, SM et al. (2020).

expressed desire not to be a burden to family and loved ones is *not* a qualifying ground and nor is physical or intellectual impairment.

10. **'Slippery Slope'**. This is the argument that, once enacted, there is a serious risk that there will be a gradual widening of the qualifying criteria which will threaten the vulnerable. There is no evidence in international practice of a 'slippery slope', that is, of unintended consequences or overuse or abuse. Oregon's Act is unchanged for over 20 years; there has been no widening of the criteria. In other words, the framing of the laws and the safeguards have been successful. No jurisdiction has ever repealed Dying with Dignity legislation. There has been increasing acceptance of the practice, both in the population as a whole (Oregon, 73%¹⁸, Netherlands 90%¹⁹) and amongst health-care professionals and, indeed, among active church-goers. The Oireachtas and State are able to produce laws and regulations which carry out the intentions precisely and prevent unwanted actions.

11. **Decision-Making Capacity**. It is critical that individuals seeking VAD have legal capacity, that is they understand the decision they are making and its consequences, as well as the alternatives. The Assisted Decision-Making (Capacity) Act 2015 seeks to enable every individual to give a considered decision of this kind, even where there may be reduced capacity. Not all of this Act has yet been commenced but it has established the Office of Decision Support Services. An important aspect of the Act is that it supports the individual's decision-making, even when the decision may not be considered to be in the individual's 'best interests'. The stated intention of the legislators in passing this legislation was to create an environment at the highest level to work with all citizens to enhance their capacity, to facilitate them so that they may exercise their right to make decisions about themselves.

In the specific context of the Bill, we argue that only the individual can decide whether her/his suffering is intolerable. The context described above suggests that the individual's view should be respected.

12. **Terminal Illness**. End of Life Ireland approves of the definition of terminally illness in the Bill. In other jurisdictions, the demand for a medical opinion that life expectancy is less than six months has had the undesirable effect of excluding those with neurodegenerative conditions, such as motor neuron diseases and multiple sclerosis.

¹⁸ Oregon Report, p6.

¹⁹ Roest, B *et al.* (2019).

13. **Advance Healthcare Directives.** At present these directives have no force in law and health-care professionals may or may not choose to be guided by them. The Assisted Decision-Making (Capacity) Act 2015 is awaiting full commencement and a public consultation is ongoing. Part of this consultation includes the concept of advance healthcare directives provided for in the Act and it deals for the first time in Ireland with decisions touching on how we may determine how we should die.
14. **Implementation.** There is a great deal of ‘practice wisdom’ available from the implementation of similar legislation. In some jurisdictions VAD has been available for about 20 years. And, especially in the case of the Netherlands, the practice has been extensively discussed within the Netherlands and also in international studies. This submission suggests that that experience can be drawn on and adapted to suit our specific circumstances in Ireland. Implementation should be efficient and take into account the needs of individuals and society as a whole.

Here, we outline the Dutch system as providing efficient oversight and safeguarding which is essential if society is to have trust in the system.²⁰

- a) **Implementation and Oversight in the Netherlands.** The Dutch practice places great emphasis on the trustworthiness and professionalism of physicians. The reporting is detailed and transparent. In the Netherlands there has been long and detailed discussion over many years about the individual, dying and its social context, as well as the operation of the relevant act. This means that the ideas are well-developed and respected. Guidelines are occasionally amended in response to detailed cases. The Act and its operation have received almost 90% approval in recent surveys.²¹

b) The Procedure in The Netherlands

- i. A request for VAD is made by the patient. The GP, who knows the patient well, assesses the nature and validity of the request. The GP will have several conversations with the patient, family members and significant others (if the patient agrees). If the GP supports the request, a second, independent, specially trained (SCEN) physician will be asked to carry out an assessment (see *Appendix* for qualification and role of SCEN doctors).

²⁰ The Netherlands (2019 a, b).

²¹ In Roest *et al.* (2019).

- ii. The SCEN physician carries out a formal interview; specific questions must be covered and he/she must be sure that all criteria for eligibility and due care have been met; then a report is written for the Regional Oversight Committee. SCEN consultations must be rigorous and about 30% of requests are denied (mostly because the relevant criteria have not been met).
- iii. The procedure is performed by the GP in a prescribed way. The GP reports to the municipal coroner, and s/he makes separate reports to the Regional Oversight Committee. The Oversight Committees each consists of a lawyer (chair), a physician and an ethicist. The committees scrutinise all stages to ensure compliance with every detail of the prescribed procedure. They have the options of reprimanding the GP, sending the case to the Medical Disciplinary Committee or recommend prosecution. The Medical Disciplinary Committee can suspend the doctor. Only in one case has there been prosecution of a doctor and the doctor was acquitted of all charges and the code of practice was amended to give greater clarity.

Recommendations

1. *End of Life Ireland recommends* that the Dying With Dignity Bill be moved to the Committee Stage. The Supreme Court determined in the Marie Fleming case that there is no constitutional barrier to introducing a law on assisted dying. The international experience and research is available to assist in the framing of the guidelines for implementation. Public opinion is ready for this change. This is an opportunity for legislators to reduce the amount of suffering in Ireland.
2. *End of Life Ireland recommends* that the implementation and safeguards be based essentially on the Dutch practice. That practice emphasises the position of trust of the GP (the 'attending physician') and has oversight by an independent physician; both report to a Regional Committee which rigorously checks that all aspects of the law and procedure have been complied with. Reporting is annual and open.

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Appendix

Definitions of a second independent physician consulted in relation to Dutch applications for Voluntary Assisted Dying²²

'SCEN physician (Support and Consultation on Euthanasia in the Netherlands) is consulted as second independent physician. The SCEN project is a programme of the Royal Dutch Medical Association (RDMA) with the aim to improve the quality of consultation and thereby the quality of EAS. SCEN physicians receive a 3-day training programme in which their tasks and the Dutch Euthanasia Act are discussed. When active as SCEN physician, they are expected to attend intervision²³ three times per year in their SCEN region. Both training and intervision are considered important to maintain the quality of consultation.'

'SCEN physicians differ from attending physicians with regard to three aspects. First, they are specifically trained in assessing the due care criteria and have the most experience. Therefore, they are the best to provide information on complexities. Second, they have a different relationship with the patient. Whereas an attending physician has a long-term relationship with the patient, the SCEN physician often consults the patient once to assess the due care criteria. Third, they fulfil another role in the process of EAS compared to the attending physician. They assess the criteria based on the law, and thus, unlike attending physicians, they do not have to take their personal boundaries into consideration.'

²² Bergman et al. (2020).

²³ **Intervision** is an 'intercollegial' learning method in a group of equals guided by a chairperson, focusing either on improving personal functioning of staff or on improving treatment/care work. [Source: United Nations Office on Drugs and Crimes]