

THE COMMITTEE ON JUSTICE: DEATH WITH DIGNITY BILL 2020.

A RESPONSE FROM MY DEATH, MY DECISION.

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About us

My Death, My Decision is a grassroots not-for-profit campaign group, which advocates for a change in the law to allow those who are terminally ill or incurably suffering the option of a legal, safe, and compassionate assisted death.

We were founded to represent the interests of those facing constant and unbearable suffering, at a time when no other right to die organisation would, and to advocate on their behalf to secure a lasting change in the law. We have quickly become one of the leading assisted dying organisations in England and Wales. We are advised by an expert medical group, are a founding member of the UK Assisted Dying Coalition, and at the forefront of social change: nearly 90% of the public now favours a change in the law to allow assisted dying for those who are incurably suffering or terminally ill.¹

Summary of our response

We welcome the opportunity to respond to the House of the Oireachtas consultation on the Death with Dignity Bill 2020. A defining feature of modern and enlightened societies, such as in Ireland, has long been the freedom of self-determination such societies afford to their citizens. In view of this, we believe the ability to choose how, where, and when we die should be given equal recognition and protection under the law, because arguably the most important expression of autonomy is choosing whether one continues to live or not.

The Death with Dignity Bill 2020, if enacted, would therefore represent a signature piece of rights protection for Irish and Northern Irish citizens. Since, subject to the robust safeguards it envisages, it would enable those who wish to avoid the prospect of a painful or undignified death, the choice to end their life on their own terms; we strongly endorse these principles. In our response, we focus upon discussing the implications of the bill for our members and supporters in Northern Ireland, as Section 7(c)(ii) of the bill would have implications for their rights and freedoms.

In brief our views are as follows:

- Although palliative medicine is a vital form of healthcare, there are some forms of suffering that cannot be adequately alleviated by palliative means alone. In these instances, people deserve the reassurance of knowing they have a right to choose how, when, and where they die.
- The Death with Dignity Bill would comply with Ireland's international obligations under the European Convention on Human Rights, and in its current form conforms to the emerging global consensus on regulating assisted dying.
- Extending access to all citizens on the island of Ireland is a sensible and modest proposal, in line with the precedent set by abortion rights.
- Although My Death My Decision campaigns for the introduction of legislation which is inclusive of both the terminally ill and the incurably suffering, we strongly endorse the Death with Dignity Bill 2020's definition of terminal illness. This is because it avoids the challenges of defining terminal illness in an arbitrary manner; adopts an ethically sustainable basis upon which to base a right-to-die; and avoids the risk of unintended discrimination.

¹ My Death, My Decision, 'New research finds up to 93% of people consider assisted dying acceptable in at least some situations, even if rarely.' (2019). Accessible at: <https://www.mydeath-mydecision.org.uk/wp-content/uploads/2019/03/Briefing-on-NatCen-assisted-dying-poll.pdf>

Response to consultation questions

1. Define the problem/the policy issue which the Bill is designed to address; to what extent is it an issue requiring attention? What is the scale of the problem and who is affected? What is the evidence base for the Bill?

Despite the best efforts of palliative medicine, it is a sad but inescapable fact that around the world, including in Ireland and Northern Ireland, many people continue to die in painful, undignified, and less than desirable circumstances. In some cases, this is due to a simple lack of high-quality palliative support. However, more often than not, it is also because palliative solutions have been unable to keep pace with modern medicines' ability to extend the length – but not quality – of someone's life. A paradigm example of this would be adults who are of sound mind, but suffering from cancer, progressive neurological conditions such as motor neurone disease or multiple sclerosis, or conditions such as irreversible tetraplegia.

According to the Office of Health Economics, at least 3000 people per year in Northern Ireland suffer due to an unmet palliative need. However, according to the same report even if everyone in Northern Ireland had access to the best possible palliative relief available, at least 161 people would be in pain with no relief at all and 1,381 people would suffer with only partial relief.² This reflects the experience of jurisdictions where assisted dying is already legal, such as Canada where 82.1% of people who had an assisted death were reported to have received palliative care,³ and Oregon where 89.9% of people who received assistance were enrolled in a hospice;⁴ since it implies the majority of people who seek an assisted death have already exhausted their palliative options and nevertheless continue to endure unrelieved physical or existential suffering.

Presently, there are three options which would be available to such people in this situation in Ireland and Northern Ireland. The first would be to do nothing and face the prospect of a distressing and sometimes drawn-out death. The second would be to break the respective laws of Ireland and Northern Ireland by travelling to Switzerland for an illegal assisted death. The third would be the inhumane prospect of lawfully ending one's life through the refusal of food & nutrition or the tragic prospect of suicide. In Northern Ireland, this problem is particularly acute, since there is a lack of commercial flights travelling from Northern Ireland to Zurich. When defining the scale of the problem it is important to bear in mind that if the law were to change to enable legal assisted dying for the terminally ill, it is probable a tiny minority of the population would seek to end their life via this means. For example, according to data from Oregon and Canada, assisted deaths account for between 0.5% and 2% of the total death rate. This would appear to be confirmed by statistics from the Swiss organisation Dignitas, which states 56 Irish citizens are presently members of an assisted death facility abroad.⁵ Nevertheless, it is important to bear in mind that whilst this may only impact a minority of the population, the impact upon that population is devastatingly severe. Moreover, the small number of people who choose to avail themselves of this option, does not account for those who applied for an assisted death, but then possibly changed their mind as the mere presence of a choice was enough to alleviate their concerns, as is the case with more than a third of people in Oregon.⁶

3. Is there a wider EU/international context?

It is well established within the jurisprudence of the European Court of Human Rights that a human right exists to control the manner and timing of one's own death. However, this right is subject to the margin of appreciation and thus its realisation is at the discretion of each member state.⁷

Assisted dying is legal in Austria, Belgium, Italy, Germany, Luxembourg, the Netherlands, and Switzerland for both the terminally ill and the incurably suffering. It is also specifically permitted for those with fewer than six months left to live in Colombia, ten US jurisdictions, the Australian state of Victoria, and will soon become legal in Western Australia and New Zealand. In Canada, assisted dying is also permitted along lines similar to the Death with Dignity Bill 2020 for those with a 'reasonably foreseeable death' (although this criterion on life expectancy is expected to be removed by legislation due to be passed by 26th February 2021); this takes into account all of someone's medical circumstances and even as currently enacted does not require a specific prognosis as to how long they have left to live.

As mentioned above it is our understanding based on 7(c)(ii) of the Death with Dignity Bill that if enacted, assisted dying would be available to residents in Northern Ireland as well as the Republic of Ireland.

2 Zamora et al, 'Unrelieved Pain in Palliative Care in England', Office of Health Economics (2020). Available at: <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england>

3 Health Canada, 'First Annual Report on: Medical Assistance in Dying in Canada 2019', (2020). Available at: <https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf>

4 Oregon Health Authority, 'Oregon Death with Dignity Act: 2019 Data Summary' (2020). Available at: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year22.pdf>

5 Dignitas, 'To die with dignity members as of 31 December 2019, Countries of Residence' (2019). Available at: <http://www.dignitas.ch/images/stories/pdf/statistik-mitglieder-wohnsitzstaat-31122019.pdf>

6 Ibid no. 4

7 *Hass v Switzerland* (Application no. 31322/07) (2011), para 51

4. How is the approach taken in the Bill likely to best address the policy issue?

In our view, the Death with Dignity Bill 2020 strikes a sensible balance between respecting the wishes of those who are terminally ill, and ensuring a robust system of safeguards exists to protect the most vulnerable. Moreover, in extending assistance to all Irish citizens, we believe this Bill emulates the approach taken by the Republic of Ireland to abortion rights on the island of Ireland and echoes the spirit of the Good Friday Agreement.

Beyond this, we wish to draw the Committee's attention to one specific aspect of the Bill which we strongly endorse: the definition of 'terminal illness' under Section 8. Internationally, there are two predominant models of assisted dying law. The first, found in some parts of the United States and Australia, and due this year in New Zealand, only provides assistance to those who are terminally ill, in the sense of meaning they have six or fewer months left to live; whereas the second, found in most other jurisdictions does not limit a choice on the basis of a specific prognosis. Instead, in jurisdictions such as Canada, a more holistic assessment of an individual's condition is used to determine if someone is incurably and irreversibly suffering, and the likelihood of their death as a result of their illness or associated complications. Although the aspirations of My Death, My Decision extend beyond a Bill solely for the terminally ill in England and Wales, we strongly support the model currently envisaged within the Death with Dignity Bill 2020 for three reasons:

First, we are concerned that a rigid six-month requirement would prove arbitrary and unworkable in practice. This is because there is no principled basis upon which someone can be said to be more deserving of a choice to end their life when they have six months left to live, rather than seven or eight etc. In other words, if the Death with Dignity Bill was amended to include a six-month limitation, it would be unclear why the line was drawn at six rather than any other cut-off point. Additionally, we are anxious that a six-month limitation would prove ineffective since doctors freely admit they cannot accurately predict when someone has six or fewer months left to live. If anything, imposing this restriction would add an additional burden upon a doctor and make it their choice whether someone had an assisted death or not, rather than placing ultimate authority within the individual themselves. In practice, we believe the best any medical professional can do when asked to provide a terminal prognosis, is to make an educated assessment and estimate. Therefore, if a six-month rule in practice merely invites a medical professional to make an assessment of someone's health, we think it follows a fortiori that an assessment which considers factors beyond someone's mere life expectancy would be more robust and effective.

Second, we believe there is a strong moral case not to impose a six-month restriction. We do not think a person's life span, in and of itself, tells us anything about their quality of life. And if anything, a short quantity hides the fact that someone with more than six months left to live, may face the unenviable prospect of many more months of suffering. This being said, we acknowledge that any legislation on assisted dying must draw a line somewhere. Thus, we suggest the most ethical basis upon which to do so, is to focus on 'quality' rather than 'quantity'. Indeed, as the philosopher and patron of My Death, My Decision, Professor A.C. Grayling, has persuasively argued:

'The 'right to life' cannot mean a right to merely bare existence. It must at least mean a right to a certain minimum experienced quality of life. For example: if someone were confined to a small cage and provided with nothing more than bread and water in perpetuity, this would scarcely be to afford him a life in any acceptable sense.'

'The right to a minimum quality of life, that is, to a minimum quality of experience in any living act, ipso facto applies to the experience of dying. 'Life' in the phrase 'the right to life' is not mere existence. It is existence with at least a minimum degree of quality and value. It means a life in which an individual is protected from arbitrary power and threat, is free to seek opportunities and exercise choice, to enjoy the rewards of endeavours in peace, and to seek and foster personal relationships - and which, to the degree reasonably possible for anyone in this world, is free from distress and pain.'

'As this implies, mere existence is not automatically a good. If it were, no-life support machine would ever be switched off, and contraception would be outlawed because it limits the sheer accumulation of human numbers... Shortening the dying process, and making it easy and peaceful, expresses consideration for what is meant by a 'right to life' in the fullest sense.'⁸

Finally, in the event a six-month amendment was to be included, we are concerned it would fall foul of Ireland's international obligations to prohibit discrimination. Put simply, a six-month restriction would create a two-tier system in Ireland, whereby those who had six months or fewer left to live would have a greater range of dignified end of life options than those who had more than six months to live. In view of this, we strongly support the wording of Section 8 which would define terminal illness as whether someone has 'an incurable and progressive condition which cannot be reversed by treatment, and the person is likely to die as a result of that illness or complications relating thereto.'

8 A.C. Grayling, 'Choosing to have the life and its end that belongs to you', (2018). Available at: <https://www.mydeath-mydecision.org.uk/info/lectures/oct-2018-acgrayling-lecture/>