CAMPAIGN FOR DIGNITY IN DYING.

Dignity in Dying

Submission to the Select Committee on Justice

Dying with Dignity Bill 2020

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Introduction

Dignity in Dying is a not-for-profit membership organisation based in the United Kingdom and is the leading campaign group for the legalisation of assisted dying throughout the UK. Our membership is drawn from across the UK and includes over 3,000 supporters in Northern Ireland. As the Dying with Dignity Bill would, if enacted in its current form, permit terminally ill, mentally competent residents of the island of Ireland to access assisted dying, we would like to lend our support to the Bill on behalf of our members in Northern Ireland.

Assisted dying internationally

Dignity in Dying campaigns to allow terminally ill, mentally competent adults to have the option to end their life with medical assistance. The bills we have supported in the UK have been based on those laws first adopted by the US State of Oregon in 1997 and now present across 10 US States, covering 1 in 5 Americans. More recently, similar laws have been enacted in the Australian States of Victoria and Western Australia, and nationwide in New Zealand.

The Dying with Dignity Bill fits with the US, Australian and New Zealand models. These laws have been shown to work well – for over 20 years in Oregon's case. They also command huge popular support: in New Zealand, the End of Life Choice Act was approved by a nationwide referendum in October by 65% of voters. Some assisted dying laws in the USA were also introduced via state-wide referendums and the most recent such example, in Colorado in 2016, also received 65% support from voters. When implemented, these laws have not been expanded beyond their strict remits and have not been repealed, demonstrating that they are stable, safe and supported by citizens and healthcare professionals alike. For example Oregon's Hospice Association "supports the rights of Oregonians to choose or not to choose any and all legal end-of-life options, and supports hospice and palliative care programs in development of their own policies around the Oregon Death With Dignity Act and Physician-Assisted Death (PAD)"[1].

There are a number of other jurisdictions around the world that provide choice at the end of life to a broader category of people, including Canada, the Netherlands, Belgium, Luxembourg and Switzerland. Legislative efforts are also under way in both Spain and Portugal, which are both likely to change their laws in the coming year. The Supreme Court of Austria in December found that the prohibition on assisted dying was incompatible with human rights and so legislation is likely to be forthcoming in Austria soon. Assisted dying legislation is likely to be brought to the Scottish Parliament following their elections later this year, while a Citizens Jury is currently being set up on the Channel Island of Jersey to discuss assisted dying.

It is clear that internationally there is a growing desire across the world to grant dying people the option to choose the manner and timing of their deaths.

The case for assisted dying

The Bill would provide dying people with the option to end their own lives, with medical assistance. This would ensure that people suffering from a terminal illness could choose the manner and timing of their deaths, subject to medical assessments and strict safeguards, including the requirement that they have the mental capacity to make that decision.

Without assisted dying, the options available to a terminally ill person are limited. Those options are insufficient for the following reasons.

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[1] https://oregonhospice.org/hospice-and-dwd/

While palliative and hospice care can relieve the vast majority of suffering, it is undoubtedly the case that it cannot cure or relieve all suffering. Research in the UK has shown that even if every person had access to the very best palliative and hospice care, 17 people would die in pain every day[2]. Beyond that, there are also physical and emotional symptoms of terminal illnesses that are impossible to relieve, causing distress and indignity to the dying person themselves, their families and their carers. One such example is that of malignant fungating wounds, a consequence of some cancers, which are likely to cause pain as well as emotional and psychological suffering, not just for the dying person but for those who care for them[3].

For those who would wish to avoid the risk of dying in pain, suffering, or without dignity (as they personally would define it), assisted dying presents an opportunity to take control of the dying process. Where it is legal, it provides dying people with the assurance that they can take the decision to die on their own terms at a time that is right for them. Annual reports from Oregon[4] suggests that 30-40% of those who have requested assistance to die and passed the strict safeguards and eligibility criteria do not go on to use this option under Oregon's Death with Dignity Act but die from their underlying illness. This demonstrates that for many, simply knowing they have the option can be enough to grant peace of mind, and does not commit anyone to using the law until and unless they wish to do so[5].

Under the existing laws in Ireland and in the UK, those who wish to take control of their deaths are left with few options. Some may be able to request palliative or terminal sedation, though this is not always an appropriate option and denies the dying person the chance to say goodbye to their families. Depending on the health of the dying person, this can take many days and cause anguish and stress to their families as they die over a longer period of time. Studies have shown a disconnect between the views of dying people and healthcare professionals in regard to the use of sedation at the end of life[6].

Similarly, a person can choose to voluntarily stop eating and drinking (VSED). This is a legal healthcare option and is often supported by end-of-life care practitioners. As with palliative sedation, it can be a drawn-out process and may cause great suffering to the dying person and their families as they are effectively starving and dehydrating themselves to death.

Some dying people choose to travel to other countries in order to end their lives. The most well-known example of this is Switzerland, which through organisations like Dignitas and Life Circle permit non-Swiss nationals and non-Swiss residents to end their own lives with medical assistance. Dying people from Ireland, as EU citizens, may theoretically be able to

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[2] Dignity in Dying commissioned the Office of Health Economics (OHE) to carry out a review of literature on pain relief at the end of life. The OHE then used the available and most reliable quantitative data to estimate the current extent of unrelieved pain in end-of-life care in the UK. The OHE also extrapolated the data to estimate the frequency of unrelieved pain that would be present even if every dying person who needed it had access to high quality palliative care. Further information can be found in our research report, 'The Inescapable Truth', accessed at: https://www.dignityindying.org.uk/wp-content/uploads/DiD_Inescapable_Truth_WEB.pdf

[3] A full discussion of these can be found in our research report, 'The Inescapable Truth', under section 3: Uncontrollable Symptoms. Accessed at: https://www.dignityindying.org.uk/wp-content/uploads/DiD_Inescapable_Truth_WEB.pdf

[4] Oregon Death with Dignity Act, Data summary, 2019, accessed at: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx

[5] Interest in physician-assisted suicide among Oregon cancer patients, Journal of Clinical Ethics 17:27-38, Ganzini L, Beer TM, Brouns M et al, 2006

[6] Engstrom et al., Palliative sedation at end of life – a systematic literature review, European Journal of Nursing Oncology, February 2007

make use of the Belgian, Dutch and Luxemburgish laws (and may soon be able to do so in Spain, Portugal and Austria as well) although it's unclear to what extent this is possible without registration with local healthcare services. The financial cost of accessing assisted dying at Dignitas is around £10,000 or €11,300, putting the option out of the financial reach of many individuals and families. There is also the additional risk that accompanying family members could be in breach of the prohibition on assisting a suicide.

Finally, there are also dying people who end their own lives. Research from other countries would suggest that suicides of terminally ill people could constitute up to 10% of suicides; in England, Freedom of Information requests conducted by Dignity in Dying found that 7.36%[7] of suicides were of terminally ill people, while in Victoria, Australia, the Coroners Court of Victoria put that figure at 8.3%[8]. These suicides are clearly distressing for the dying person, but also to their families and to police and healthcare professionals who must respond to these cases. We also know that those who have ended their lives in other ways have often attempted suicide previously, though there is little data on the extent of this.

Faced with the options of potentially unbearable suffering, sedation, starvation, suicide or travelling to Switzerland, it is difficult to justify the ongoing prohibition of assisted dying, which is unsafe and unjust. This is particularly the case when tried and tested models exist in other jurisdictions that are culturally not dissimilar to Ireland (or to the UK). The Dying with Dignity Bill provides a strong foundation for a legal, safe and compassionate approach to assisted dying.

End-of-life care

Assisted dying and end-of-life care can and should work hand-in-hand. In countries and states where assisted dying has been legalised, they operate alongside one another as part of the spectrum of options available to people reaching the end of life. They are not mutually exclusive alternatives but complementary provisions available to the dying person. In Oregon for example, 90% of those who have made use of the Death with Dignity Act are enrolled in hospice care[9].

Those who oppose assisted dying will frequently argue that it would be unnecessary if only universal, high-quality palliative care were available to all. But even the most passionate advocates of palliative care do not argue that it is a panacea, and acknowledge that there will always be a group of people whose suffering cannot be relieved by even the best palliative care. Even people who die in high-quality palliative and hospice care settings can experience unrelieved pain, uncontrollable symptoms and a lack of dignity in their final days[10].

We advocate for greater funding of hospice and palliative care and indeed in recent years where assisted dying has been legalised, it has been accompanied by a major investment in palliative care. For example when the Victorian Parliament passed assisted dying legislation, the State Government reviewed palliative care services and provided an extra $72 million (AUD) to increase palliative care beds and access to homebased palliative care[11]. We welcome this approach: instead of treating them as mutually exclusive or discrete options they must both be available to dying people to enable them to make the choice that is right for them. For a small but significant number of dying people, assisted dying will be the

[7] https://cdn.dignityindying.org.uk/wp-content/uploads/Research_FOI_Suicides.pdf
[8] https://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_1037_-_Coroners_Court_of_Victoria_further_submission.pdf
[9] Oregon Death with Dignity Act, Data summary, 2019
[10] As in note 3, above.
[11] https://www.premier.vic.gov.au/boost-for-palliative-care-providers/

preferred option. For many more, it will be a welcome reassurance that grants great peace of mind.

There are additional benefits to the legalisation of assisted dying for end-of-life care. Evidence from Oregon and California for instance shows that the introduction of the option of assisted dying encourages fuller and franker conversations between terminally ill people and their doctors as well as more appropriate palliative care training of physicians and greater efforts to increase access to hospice care[12] [13] [14] [15]. The vast majority of those who discuss assisted dying with their doctors do not go on to have an assisted death, but it provides an opportunity for them to explore their health and care options and for doctors to signpost their patients to services they may not have been aware of previously.

The Dying with Dignity Bill

As outlined above, we believe there are significant reasons why the legalisation of assisted dying is necessary to provide terminally ill people with a genuine choice at the end of life. There is also a wealth of evidence from the growing number of progressive, liberal democracies that assisted dying laws are safe, compassionate and popular.

As to the content of the Dying with Dignity Bill, most of the provisions are based on laws that work well in other jurisdictions. The qualifying persons under section 7 are similar to those in other jurisdictions with the notable exception of a time frame for defining a person as terminally ill. Our preference for legislation in the UK would be to include within this definition an expected prognosis to determine eligibility to access assisted dying. The US laws[16] use an expected prognosis of six months, whereas the assisted dying law in Victoria[17] is accessible to those with a prognosis of six months or less, or twelve months or less for those with a terminal neurodegenerative condition.

It is also worth being aware though that other assessments of whether someone is terminally ill do not include a specific timeframe or prognosis. Since the passage of the Social Security (Scotland) Act 2018[18] for example a person's eligibility for terminal illness benefits in Scotland has been assessed by medical practitioners' clinical judgment[19]. Guidance for this is published by the Chief Medical Officer for Scotland, informed by the Short-Life Working Group on Terminal Illness for Disability Assistance[20].

On behalf of our members in Northern Ireland, we welcome the provision that the law will be accessible by residents of the island of Ireland. We would also hope that professional

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[12] Legal regulation of physician assisted death – the latest report cards, New England Journal of Medicine 356:1911-1913, Quill TE, 2007
[13] Oregon physicians' attitudes about and experiences with end of life care since passage of the Oregon Death with Dignity Act, Journal of the American Medical Association 285:2363-2369, Ganzini L, Nelson HD, Lee MA et al, 2001
[14] Characteristics and proportion of dying Oregonians who personally consider physician assisted suicide, Journal of Clinical Ethics 15:111-118, Tolle SW, Tilden VR Drach LL, et al, 2004
[15] Oregon physicians' responses to requests for assisted suicide: a qualitative study, J. Palliat Med. Dobscha et al, 2004
[16] See, eg, Oregon's Death with Dignity Act, accessed at: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ors.aspx
[17] Voluntary Assisted Dying Act, accessed at: https://www.legislation.vic.gov.au/in-force/acts/voluntary-assisted-dying-act-2017/004
[18] https://www.legislation.gov.uk/asp/2018/9/section/31/enacted
[19] https://www.gov.scot/policies/social-security/terminal-illness/
[20] https://www.gov.scot/groups/short-life-working-group-on-terminal-illness-for-disability-assistance-slwg/

medical bodies with responsibility for medical practice in Northern Ireland would produce guidance for their members so that all residents of the island of Ireland are able to make use of the law.

In section 9, the safeguards of two doctors independently assessing the eligibility of the person requesting assisted dying are very similar to safeguards in the USA and Australia (and soon to come into effect in New Zealand) that have been demonstrated to work well. We particularly support the inclusion at section 9(4) that the person making the request "has been fully informed" of their care options. Similarly we welcome the provision at section 9(3) that the medical practitioners must be satisfied that the decision has been reached voluntarily. In preparation for the implementation of assisted dying in Victoria, Australia, the Department of Health and Human Services published information and training modules to support healthcare professionals to be able to detect possible coercion around decisions relating to assisted dying. The information acknowledged that 'doctors should already be alert to coercion in a range of healthcare decision scenarios'[21].

The capacity assessment in section 10 is an important safeguard to ensure the voluntariness of the person's decision to end their own life. The question of capacity to understand important decisions about one's care is one that is used extensively throughout modern medicine, including for instance the refusal of life-sustaining treatment. If it is possible to assess a person's capacity to make decisions about life-sustaining treatments – or indeed treatments that carry a large risk of mortality – it is certainly possible to assess a person's capacity to make a decision about choosing the end of his or her life.

In section 11 the provision to allow the direct administration of life-ending medications in the event that the person is unable to self-administer them is similar to that in the Australian and New Zealand laws. This is a key difference to the US legislative model for assisted dying and may require further attention; it is not clear whether this would currently be an offence under the Criminal Law (Suicide) Act 1993 or an offence of homicide. If the latter, a further amendment may be required. For clarity, Dignity in Dying only supports legislation that permits self-administration of life-ending medication as we believe there to be an important ethical difference between allowing someone to take their own life and allowing a medical professional to end another's life.

We strongly support the conscientious objection provisions under section 13, particularly 13(3), which would ensure that healthcare professionals' consciences can be respected – those who do want to participate in the law and those who do not – while ensuring that patients are not abandoned.

We also support sections 14 and 15, which will allow close monitoring of the assisted dying law and allow transparency and accountability for the operation of assisted dying. The methodologies for monitoring and learning lessons from the operation of the law could very easily be adapted from Victoria, where there is a very comprehensive system in place[22].

[21] https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/medical-practitioner-training
[22] https://content.legislation.vic.gov.au/sites/default/files/2020-06/17-61aa004%20authorised.pdf