Submission to the Committee on Justice on the Dying with Dignity Bill 2020

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Age Action firmly believes that broad consultation with a wide range of stakeholders is necessary to allow for an informed discussion where all voices are heard.

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Age Action recognises the inherent dignity of the individual and the importance of this concept in underpinning human rights protections. We recognise that a person may achieve a dignified and peaceful end in many different ways and that this is not the exclusive jurisdiction of assisted dying. Age Action recommends that the short and long title of this Bill be reviewed.

Section 2 Interpretation
To accurately understand the impact on the doctor-patient relationship it is necessary to hear the views of all parties affected. It is only through broad engagement that a true picture of perceptions and attitudes can be discerned.

Section 8 Terminally ill
Age Action recommends that the definition for terminal illness be reviewed, particular attention should be paid to the reasons why a person might seek assisted dying. Age Action would welcome an opportunity for a meaningful discussion about the concept of 'qualifying person' more generally.

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Section 9(3) Dying with Dignity Bill: Age Action recognises the importance of safeguards as part of any possible liberalisation of the law on assisted dying. It is essential that persons that are considered vulnerable are effectively protected and steps to prevent and identify coercion and duress are implemented. It should however be emphasised that the voice of vulnerable persons should be facilitated to inform the debate on end of life policy practices.
Section 9(4) Dying with Dignity Bill: Age Action calls for strengthened and better access to palliative care on an equitable basis throughout the country. Central to this is adequate and secure resourcing by Government of palliative care teams and hospices. Each person should have access to palliative care appropriate to each stage of their illness trajectory.

Section 10 Assessment of capacity
Age Action calls for the full commencement of the Assisted Decision-Making (Capacity) Act 2015. Any move towards the introduction of assisted dying in this jurisdiction must necessarily be preceded by the commencement of the 2015 Act so as to ensure that people have the best opportunity to exercise their autonomy.

Section 11 Assistance in dying
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Section 11(6) Dying with Dignity Bill: This section requires far greater scrutiny in order to resolve issues of ambiguity and ensure appropriate safeguards for the benefit of all parties.

Section 15 Establishment of Assisted Dying Act Review Committee

Age Action recommends that the composition and function of any review committee for assisted dying be set out in detail by the relevant legislation. The functions and composition should then be further shaped through an open consultation process.

1. Introduction

Age Action is the leading advocacy organisation on ageing and older people in Ireland. Age Action supports and advocates for equality and human rights for all older people. Everything we do is based on a recognition of the diversity of identity and situation among older people and a concern for equality. In addressing ageing, our work includes a concern to influence perspectives on and responses to ageing. This pursuit of equality and human rights is underpinned by our work to promote ageing in place, life-long learning, and health and wellbeing for older people, empowering them to live as active citizens.

Age Action believes that the discussion of choice in regard to end-of-life care, and control of one's own end-of-life care should be encouraged and supported. We know from our daily work that there is much confusion around end of life choices and legal instruments such as advance healthcare directives. Furthermore, we are aware that conversations about death and dying can cause anxiety for many people. Yet, it is important that such conversations take place in society and that the voice of the older person can contribute to shaping and informing the development of the law. Age Action welcomed the publication of the Dying with Dignity Bill 2020 and the discussion it prompts about assisted dying

In terms of discussion it is our view that there has not been a sufficiently detailed discussion that captures and reflects the multitude of viewpoints that exist in Irish society on the issue of end of life care and assisted dying. Broad consultation with a wide range of stakeholders is essential to allow for all voices to be heard. The right to participate in political and social discourse is fundamental to Human Rights; the right to participate in decisions that impact on our lives is core to enabling us to fully realise our rights.

While the primary focus of this submission is the Dying with Dignity Bill 2020, the provision of palliative care will also be referenced. It is important to recognise the comfort and essential supports that palliative care brings to many each day, both those with progressive illnesses and persons nearing the end of life. Age Action remains committed to calling for strengthened and better access to palliative care on an equitable basis around the country. Central to this is adequate and secure resourcing of palliative care teams and hospices by Government.

It is hoped that this submission by Age Action will contribute to a broader conversation on how best to ensure that the rights of each person are respected at the end of life and how people can be supported in making choices about their life and death. This submission first articulates the legislative and policy context for the Dying with Dignity Bill 2020. Second, significant sections in the legislation are closely examined and commented upon.

2. Policy and Legislative Context

In 1993, the enactment of the Criminal Law (Suicide) Act 1993 decriminalised the act of suicide, but made it a criminal offence in Ireland if a person 'aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide'.[1] The prosecution of a person under this section is subject to the discretion of the Director of Public Prosecutions.[2] However, there are currently no specific guidelines outlining what factors will be taken into account in exercising this discretion.

In 2013, the first case to address the ban on assisted dying arose. In *Fleming v Ireland*[3] Marie Fleming, who was suffering from multiple sclerosis, brought a case to the High Court to seek an order that the ban on assisted dying in section 2(2) of the 1993 Act was unconstitutional and contrary to the ECHR and if this was not found, to seek that the DPP produce 'guidelines stating the factors that will be taken into account in deciding…whether to prosecute' a person who provides assistance to those who wish to end their lives.[4]

In the High Court, it was accepted that the personal rights of Ms Fleming under Article 40.3.2° of the Irish Constitution and under Article 8 of the ECHR, and her right to equality under Article 40.1 and Article 14 of the ECHR were engaged by the ban on assisted dying. However, the Court held that the state has a 'profound and overwhelming interest in safeguarding the sanctity of all human life' and the ban on assisted dying was not unconstitutional or in violation of the ECHR as it was 'rationally connected to this fundamental objective of protecting life'. The Court also held that it was not within the remit of the DPP to provide such guidance and her case was dismissed. Ms Fleming appealed to the Supreme Court. Denham CJ, who delivered judgment on behalf of the Supreme Court, held that there is 'no explicit right to commit suicide, or to determine the time of one's death, in the Constitution'[5] and that the ban on assisted dying was 'neutral' and did not infringe upon the right to equality under Article 40.1.[6] She also held that the State was 'entitled to regulate activities which are detrimental to the life and safety of persons' and the State had not violated the ECHR.[7] On the basis of these findings, the case was dismissed.

The first prosecution for assisted dying under the 1993 Act was the trial of Gail O'Rorke.[8] Gail O'Rorke was accused of assisting her friend, Bernadette Forde, in her wish to end her own life and faced three charges under the 1993 Act for attempting to assist in a suicide by making arrangements for Ms Forde to travel to Switzerland, for aiding and abetting a suicide by helping to secure and administer a toxic substance, and for procuring a suicide by making funeral arrangements before Ms Forde's death. Judge McCartan ordered the jury to acquit Ms O'Rorke of ordering a lethal dose of barbiturates, and to find her not guilty of procuring a suicide by

[1] Criminal Law (Suicide) Act 1993, Sections 2(1) and 2(2).
[2] Criminal Law (Suicide) Act 1993, Section 2(4).
[3] *Fleming v Ireland* [2013] IEHC 2; *Fleming v Ireland* [2013] IESC 19.
[4] *Fleming v Ireland* [2013] IEHC 2 [1]-[24].
[5] *Fleming v Ireland* [2013] IESC 19 [47], [99]-[115].
[6] *Fleming v Ireland* [2013] IESC 19 [116]-[139].
[7] *Fleming v Ireland* [2013] IESC 19 [141]-[165].
[8] Although, statistics produced by Dignitas indicate that there have been 9 individuals from Ireland who have availed of their assisted dying services between 1998 to 2019 in spite of the legislative ban. See 'Accompanied Suicides per Year and Country of Residence' (Dignitas) <http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2019.pdf> accessed 09 January 2021.

helping organise the funeral.[9] On the remaining charge, a jury found her not guilty in April 2015.[10]

In the aftermath of these cases, the first attempt to introduce more liberal legislation was initiated by John Halligan TD, who proposed the first Dying with Dignity Bill in 2015. The intention for this Bill was to realise 'the right of clearly consenting adults who are enduring intolerable physical suffering to seek medical help to end their lives', whilst also ensuring the safety of 'vulnerable people' who may face risk under this Bill.[11] This Bill eventually lapsed with the dissolution of the Dáil and Seanad.[12]

In November 2017, assisted dying was considered by the Joint Committee on Justice and Equality as a part of their discussion on the 'right to die with dignity'.[13] They heard submissions from a number of academics and interest groups regarding the introduction of legislation to allow for assisted dying. The Joint Committee outlined a number of broad recommendations stemming from these hearings. These included referring the issue to the Citizen's Assembly, the improvement of palliative care provision across the country, ensuring care and support encompasses vulnerable groups including the disabled and those suffering from mental illness or chronic physical conditions. Furthermore, a number of guiding questions were identified that might assist the legislature when considering the legalisation of some form of assisted dying.[14]

It is against this backdrop that the Dying with Dignity Bill 2020 was proposed. The intention behind this Bill is to 'give to a person the legal and medical right of the authorisation of assisted dying where that person is suffering from a terminal illness'.[15] In introducing the Bill, Gino Kenny TD stated that 'in the most profoundly difficult circumstances people should have a choice to have a dignified and peaceful end to their lives on their own terms when the pain and suffering become unbearable'.[16] This submission is prepared by Age Action as part of the Committee scrutiny of the Bill.

[9] Conor Gallagher, 'Gail O'Rorke acquitted on two of three charges against her' *The Irish Times* (Dublin, 24 April 2015).
[10] Mark Hilliard, 'Gail O'Rorke found not guilty of helping friend take her own life' *The Irish Times* (Dublin, 28 April 2015).
[11] Dáil Deb 15 December 2015, vol 901, no 1.
[12] See 'Dying with Dignity Bill 2015' (Oireachtas.ie, 03 February 2016) <https://www.oireachtas.ie/en/bills/bill/2015/125/> accessed 10 January 2021.
[13] Joint Committee on Justice and Equality, *Report on the Right to Die With Dignity* (32/JAE/18, 2018).
[14] Joint Committee on Justice and Equality, *Report on the Right to Die With Dignity* (32/JAE/18, 2018) 56-58.
[15] Explanatory Memorandum to the Dying with Dignity Bill 2020.
[16] Dáil Deb 15 September 2020, vol 997, no 3.

3. Dying with Dignity Bill 2020

The following sections in the Dying with Dignity Bill 2020 are examined:

- Title / Long Title
- Section 2 Interpretation
- Section 8 Terminally ill
- Section 9 Declaration
- Section 10 Assessment of capacity
- Section 11 Assistance in dying
- Section 15 Establishment of Assisted Dying Act Review Committee

This discussion places a particular focus on possible legal policy implications, issues of ambiguity, and matters related to the prospective implementation of this Bill. In parts, the discussion also draws attention to some of the key ethical debates that arise in the context of assisted dying.

Title / Long title

> Dying with Dignity Bill 2020
> 'An Act to make provision for assistance in achieving a dignified and peaceful end of life to qualifying persons and related matters'

The reference to dignity in the title of the Bill and the reference to a 'dignified and peaceful end of life' may prove problematic and raise questions of interpretation. Dignity is a complex concept that has special relevance for a wide range of end of life issues including palliative care, the withdrawal or withholding of life sustaining treatments, and in this instance, assisted dying. The concept is therefore not solely linked to one end-of-life practice. Furthermore, the ethical concept is subject to many differing interpretations that can lead to diametrically opposing arguments.

It is a concept that is invoked equally by proponents and opponents of assisted dying. Those in favour of a liberalisation of the law may claim that assisted dying gives control over the end of life thereby serving a person's dignity.[17] In contrast, opponents maintain that a practice such as assisted dying is a direct violation of the dignity of a human being.[18] This inconsistency reflects the fact that distinct interpretations of dignity are being called on in support of a particular argument. For those in favour of assisted dying, dignity may be closely linked to respect for autonomy, self-determination, or 'quality of life'. In response, opponents of assisted dying understand dignity as being intrinsic. Adorno explains this position as follows: 'From this point of view, our right to life, which is a direct consequence of our dignity, is not something we can freely dispose or abdicate. Taken in its intrinsic sense, killing oneself can be

[17] Jeff McMahan, 'Human dignity, Suicide and Assisting Others to Die' in S Muders (ed) *Human dignity and Assisted Death* (Oxford University Press 2017).
[18] Christopher Kaczor and Robert George, 'Death with Dignity' in S Muders (ed) *Human dignity and Assisted Death* (Oxford University Press 2017).

taken to entail a denial or rejection of one's inherent dignity.'[19] The use of 'dignity' in the title sets up a point of conflict as debates about the ethical concept of dignity are not easily resolved.

As noted above, forms of care such as palliative care are also associated with dignity.[20] Yet, the title of the Bill serves to closely tie the concept of dignity to assisted dying. Age Action recognises the importance of palliative care and this should not be diminished in any way. While some jurisdictions make reference to 'dignity' in the title of their legislation,[21] there are many others which do not; this includes the likes of the Netherlands,[22] Australia,[23] New Zealand,[24] and Canada.[25]

Age Action recognises the inherent dignity of the individual and the importance of this concept in underpinning human rights protections. We recognise that a person may achieve a dignified and peaceful end in many different ways and that this is not the exclusive jurisdiction of assisted dying. **Age Action recommends that the short and long title of this Bill be reviewed.**

Section 2 Interpretation

> "attending medical practitioner" is the registered medical practitioner from whom a qualifying person has requested assistance to end their life

For many people, the medical practitioner will be the first point of contact in accessing assisted dying under this Bill. This is a significant element in the organisation and implementation of this legislation. It will lead to broader questions about the effect that assisted dying might have on the doctor-patient relationship.

There is a significant concern expressed amongst some members of the medical community that the legalisation of assisted dying will result in an irreparable change in the relationship between doctors and patients. The role of doctors has traditionally been shaped by ethical principles such as beneficence and non-maleficence, which require them to 'act in the best interest of the patient' and to 'do no harm'.[26] The legalisation of assisted dying is seen to conflict with these principles, and it has been argued that it 'moves beyond the nature of the healing relationship and the social contract by which physicians are given power over persons

[19] Roberto Andorno, 'Dignity' in N Emmerich et al (eds) *Contemporary European Perspectives on the Ethics of End of Life Care* (Springer 2020) 153.
[20] John Lombard, *Law, Palliative Care and Dying* (Routledge 2018) Chp 3.
[21] See the Oregon Death with Dignity Act, the Washington Death with Dignity Act, or the Maine Death with Dignity Act.
[22] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.
[23] Australia (Victoria), Voluntary Assisted Dying Act 2017; Australia (Western Australia), Voluntary Assisted Dying Act 2019; Australia (Tasmania), End-of-Life Choices (Voluntary Assisted Dying) Bill 2020.
[24] End of Life Choice Act 2019, <https://www.legislation.govt.nz/act/public/2019/0067/latest/DLM7285905.html> accessed 21 January 2021.
[25] Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), <https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent> accessed 21 January 2021.
[26] Andreas Fontalis, Efthymia Prousali and Kunal Kulkarni, 'Euthanasia and assisted dying: what is the current position and what are the key arguments informing the debate?' (2018) 111(11) Journal of the Royal Society of Medicine 407, 410-411.

in need'.[27] By way of contrast, there is an argument that at a certain point the 'duty to relieve suffering' should take priority over the 'fight against death'[28] and that a person should be allowed to die. Such arguments are grounded in ideas of compassion and beneficence, and suggests that for a patient whose suffering is untreatable that a medical practitioner may be acting beneficently by assisting in their death.[29]

Individual medical practitioners may opt not to participate in assisted dying. Age Action supports the inclusion of conscientious objection at section 13 of the Dying with Dignity Bill 2020. Nonetheless, we recognise that a change in the law would alter the broader landscape of end-of-life care in this country. On this point Søren Holm stated:

> Conscientious objection to PAD [physician-assisted death] is often assumed as 'the solution' to assuage the concerns of doctors and other healthcare professionals who do not want to participate in PAD or do not want PAD to be part of medical practice … The concerns doctors have may not only be personal or fully captured by 'I do not want to perform PAD'; they are often about a wider set of actions than direct performance, and often about changes in healthcare that will inevitably follow the introduction of PAD, and can perhaps be more accurately expressed as 'introducing PAD will inevitably make it part of the context of my professional life, and that worries me because it will change that life'.[30]

Such nuanced concerns must be teased out through meaningful engagement with healthcare professionals.

A further argument advanced is that the perceived fundamental alteration of the role of the doctor would weaken 'trust' between patients and their doctors.[31] In response, it may be argued that trust could be fostered by clarifying the law and by upholding 'patient choices at the end of life'.[32] 37% of respondents in a Dignity in Dying Poll conducted by Populus across Great Britain in 2015 suggested that the legalisation of assisted dying would increase their trust in doctors. 50% of respondents indicated that it would not make a difference, while 12% stated that it would reduce their trust in doctors.[33]

To accurately understand the impact on the doctor-patient relationship it is necessary to hear the views of all parties affected. It is only through broad engagement that a true picture of perceptions and attitudes can be discerned.

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[27] David C Thomasma, 'Assessing the Arguments for and against Euthanasia and Assisted Suicide: Part Two' (1998) 7 Cambridge Quarterly of Healthcare Ethics 388, 391.

[28] Rolf Ahlzen, 'Suffering, authenticity, and physician assisted suicide' (2020) 23 Medince, Health Care and Philosophy 353, 353-354.

[29] Gary Seay, 'Do Physicians Have an Inviolable Duty Not to Kill?' (2001) 26(1) Journal of Medicine and Philosophy 75, 87.

[30] Søren Holm, 'The debate about physician assistance in dying: 40 years of unrivalled progress in medical ethics?' (2015) 41 Journal of Medical Ethics 40.

[31] Wendy N Weigand, 'Has the Time Come for Doctor Death: Should Physician-Assisted Suicide Be Legalized?' (1993) 7(2) Journal of Law and Health 321, 343; Sarah Mroz, et al, 'Assisted dying around the world: a status quaestionis' (2020) Annals of Palliative Medicine, <https://pubmed.ncbi.nlm.nih.gov/32921084/> accessed 21 January 2021.

[32] Samia A Hurst and Alex Mauron, 'The ethics of palliative care and euthanasia: exploring common values' (2006) 20 Palliative Medicine 107, 108.

[33] Populus, 'Dignity in Dying Poll' <https://yonderconsulting.com/poll-archive/dignity-in-dying.pdf accessed> 26 January 2021.

Section 8 Terminally ill

Among the requirements for a person to be considered a qualifying person for the purposes of this Bill is that he or she is terminally ill. Under section 8 of the Bill, a person is defined as terminally ill if that person:

> (a) has been diagnosed by a registered medical practitioner as having an incurable and progressive illness which cannot be reversed by treatment, and the person is likely to die as a result of that illness or complications relating thereto ("a terminal illness"), and
> (b) treatment which only relieves the symptoms of an inevitably progressive condition temporarily is not to be regarded for the purposes of paragraph (a) as treatment which can reverse that condition.

The failure to specify a prognosis is notable as the current definition facilitates a broad interpretation of qualifying person. In other jurisdictions where reference is made to a terminal illness it is usually linked to a timeframe within which the person's death is expected.

> Oregon Death with Dignity Act: "Terminal disease" means an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months.
>
> New Zealand End of Life Choice Act 2019: In this Act, person who is eligible for assisted dying or eligible person means a person who— (c) suffers from a terminal illness that is likely to end the person's life within 6 months
>
> Victorian Voluntary Assisted Dying Act 2017: For a person to be eligible for access to voluntary assisted dying— (d) the person must be diagnosed with a disease, illness or medical condition that— (iii) is expected to cause death within weeks or months, not exceeding 6 months.

The Dying with Dignity Bill 2020 also does not make specific reference to a requirement of 'suffering', 'unbearable suffering', or 'enduring physical or psychological suffering'. This requirement is seen in jurisdictions such as Oregon, New Zealand, Victoria, and Canada. The absence of such a criterion further facilitates a broad interpretation of qualifying person.

In the absence of a terminal illness, a person is not considered a qualifying person if they are suffering from any form of mental disorder or mental illness, has some form of disability, or is of an advanced age.

Age Action recommends that the definition for terminal illness be reviewed, particular attention should be paid to the reasons why a person might seek assisted dying. Age Action would welcome an opportunity for a meaningful discussion about the concept of 'qualifying person' more generally.

Section 9 Declaration

> 9(3) Before countersigning a person's declaration under subsection (1), the attending medical practitioner and the independent medical practitioner, having separately examined the person and the person's medical records and each acting independently of the other, must be satisfied that the person—
> (a) is terminally ill,
> (b) has the capacity to make the decision to end his or her own life, and
> (c) has a clear and settled intention to end his or her own life which has been reached voluntarily, on an informed basis and without coercion or duress.

Age Action recognises the importance of safeguards as part of any possible liberalisation of the law on assisted dying. It is essential that persons that are considered vulnerable are effectively protected and steps to prevent and identify coercion and duress are implemented**. It should however be emphasised that the voice of vulnerable persons should be facilitated to inform the debate about end of life policy and practices.**

On both sides of the debate, there are concerns surrounding the risks posed to vulnerable people. From the point of view of those opposed to the relaxation of the ban on assisted dying, the concerns raised are that vulnerable individuals may be coerced or encouraged to avail of assisted dying[34] or may consider assisted dying when they otherwise would not have considered it due to the perception that they are placing 'social, emotional, or financial strains' on their relatives.[35] These concerns are especially heightened for individuals with disabilities and older persons, as there is a fear that a change within the law may alter perceptions regarding illness and aging, and impact how they are treated by society.[36]

Studies published in recent years have suggested that categories of vulnerable people (including older persons and individuals with disabilities) are not more likely to avail of assisted dying when it is legalised.[37] Conversely, research on the operation of law in other jurisdictions indicates that the categories of people most likely to avail of assisted dying are 'older, white and well-educated'.[38] In this respect, those who are in favour of assisted dying argue that there is a greater risk to vulnerable individuals in keeping assisted dying a hidden practice[39] and that vulnerable individuals can be protected by introducing safeguards within

[34] R J D George, I G Finlay and David Jeffrey, 'Legalised euthanasia will violate the rights of vulnerable patients' (2005) 331 British Medical Journal 684.
[35] Jeffrey Stephenson, 'Assisted dying: a palliative care physician's view' (2006) 6(4) Clinical Medicine 374, 375.
[36] Andreas Fontalis, Efthymia Prousali and Kunal Kulkarni, 'Euthanasia and assisted dying: what is the current position and what are the key arguments informing the debate?' (2018) 111(11) Journal of the Royal Society of Medicine 407, 410.
[37] Margaret P Battin, et al, 'Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ''vulnerable'' groups' (2007) 33 Journal of Medical Ethics 591. See also discussion in Roddy Slorach, 'Assisted dying: the search for a good death' (2016) 4(1) Critical and Radical Social Work 93, 99 and Ben White and Lindy Willmott, 'Future of assisted dying reform in Australia' (2018) 42 Australian Health Review 616, 618.
[38] Ezekiel J Emanuel, et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe' (2016) 316(1) Journal of the American Medical Association 79, 83. See further, Emily Jackson, 'Legalizing Assisted Dying: Cross Purposes and Unintended Consequences' (2018) 41(1) Dalhousie Law Journal 59, 84.
[39] Margaret P Battin, et al, 'Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ''vulnerable'' groups' (2007) 33 Journal of Medical Ethics 591.

legislation.[40] However, the process of legalising assisted dying should not be rushed as insights from other jurisdictions such as Victoria indicate that a careful balance must be struck when introducing safeguards within legislation between having too few safeguards and too many safeguards that either permit or restrict individuals excessively.[41]

> 9(4) In deciding whether to countersign a declaration under subsection (3), the attending medical practitioner and the independent medical practitioner must be satisfied that the person making it has been fully informed of the palliative, hospice and other care which is available to that person.

Palliative care is defined by the World Health Organization as '… an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.'[42] The standard of palliative care in Ireland has traditionally been of a high standard.[43] It is important to recognise the comfort and essential supports that palliative care brings to many each day, both those with progressive illnesses and towards the end of life.

Section 9(4) of the Dying with Dignity Bill 2020 is framed in such a manner that the medical practitioners must be satisfied that the qualifying person has been fully informed of the palliative, hospice and other care which is available to that person. Regardless of any change in the law on assisted dying, **Age Action calls for strengthened and better access to palliative care on an equitable basis throughout the country. Central to this is adequate and secure resourcing by Government of palliative care teams and hospices. Each person should have access to palliative care appropriate to each stage of their illness trajectory.**[44]

The importance of palliative care is illustrated by the 'First Annual Report on Medical Assistance in Dying in Canada'. In Canada in 2019, 263 patients who had submitted a written request for medical assistance in dying subsequently withdrew it. Of these, 26.2% withdrew their request as palliative measures were sufficient. Under the medical assistance in dying legislation, the Government of Canada committed to improving access to palliative and end-of-life care. Moreover, the legislation requires a government committee to review the state of palliative care in Canada and report on any change that the committee recommends. This review is to take place five years after the legislation received Royal Assent. A similarly robust approach in supporting palliative care provision in this jurisdiction should be explored.

[40] David Leaf, 'Safe laws on assisted dying are working worldwide' (2012) 345 British Medical Journal 30.
[41] Rosalind McDougall and Bridget Pratt, 'Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation' (2020) 21 BMC Medical Ethics 38.
[42] World Health Organization, 'Palliative Care' <https://www.who.int/news-room/fact-sheets/detail/palliative-care> accessed 17 January 2020.
[43] The Economist Intelligence Unit, 'The 2015 Quality of Death Index: Ranking palliative care across the world' (EIU 2015) 15.
[44] See recommendations of the Joint Committee on Justice and Equality, *Report on the Right to Die With Dignity* (32/JAE/18, 2018).

Section 10 Assessment of capacity

Section 10 of the Dying with Dignity Bill 2020 largely mirrors Section 3 of the Assisted Decision-Making (Capacity) Act 2015. The Assisted Decision-Making (Capacity) Act 2015 was signed into law by President Michael D Higgins on the 30 December 2015. Yet, the majority of the 2015 Act remains to be commenced. The ADM(C) Act applies to persons whose capacity is called into question or may shortly be called into question. Key elements of the 2015 Act include recognition of the functional approach to capacity, the use of guiding principles in place of best interests, the establishment of the Decision Support Service, the formalisation of decision-making supports, the abolition of the Ward of Court system, changes to enduring power of attorney, and the provision of a statutory framework for advance healthcare directives. These are changes which will reshape the framework for decision-making in Ireland.

The law on enduring powers of attorney were set out by the Powers of Attorney Act 1996. The powers provided under the 1996 Act did not extend to healthcare decisions. This has been addressed by the 2015 Act. Section 59 of the Assisted Decision-Making (Capacity) Act 2015 describes an enduring power of attorney as an arrangement whereby a donor may appoint another person on whom he or she confers general authority to act on the donor's behalf in relation to all or a specified part of the donor's property and affairs, and/or authority to do specified things on the donor's behalf in relation to the donor's personal welfare or property and affairs. An enduring power of attorney does not enter into force until such time as the donor lacks capacity in relation to one or more of the relevant decisions which are the subject of the power, and the instrument creating the enduring power of attorney has been registered in accordance with Section 69 of the Act. At the time of writing (January 2021) this section is yet to be commenced.

Advance healthcare directives are provided for by Part 8 of the Assisted Decision-Making (Capacity) Act 2015. An advance healthcare directive means 'an advance expression made by the person, … of his or her will and preferences concerning treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity'.[45] At the time of writing (January 2021) this part of the 2015 Act is yet to be commenced.

In an Age Action report titled 'Healthcare Decision-Making and the Older Person' it was recommended that steps be taken to promote the commencement and awareness of the Assisted Decision-Making (Capacity) Act 2015.[46] The Report called for the discussion of end-of-life care to be encouraged and supported. It also illustrated the level of uncertainty and confusion surrounding the role and function of advance healthcare directives. For instance, 60.53% of respondents did not know what an advance healthcare directive is, and 17.29% were not sure.

In order to fully support and realise human rights at the end of life, there must be greater clarity and awareness of these legal instruments. **Age Action reiterates the call for full commencement of the Assisted Decision-Making (Capacity) Act 2015. Any move towards the introduction of assisted dying in this jurisdiction must necessarily be preceded by the commencement of the 2015 Act so as to ensure that people have the best opportunity to exercise their autonomy.**

[45] Assisted Decision-Making (Capacity) Act 2015, s 82.

[46] John Lombard, 'Healthcare Decision-Making and the Older Person' (Age Action 2020) <https://ulir.ul.ie/bitstream/handle/10344/8738/Healthcare_DecisionMaking_Report.pdf?sequence=1> accessed 27 January 2021.

Section 11 Assistance in dying

> 11(2) Such assistance may be provided by the attending medical practitioner to a qualifying person in the following circumstances: …
> (c) in the case that it is not possible for the self-administer then the substance or substances may be administered;
> with the purpose of enabling that person to end his or her own life.

Section 11(2) of the Dying with Dignity Bill presents the self-administration of substances as the primary way in which assisted dying will occur. However, section 11(2)(c) and section 11(5)(d) make it clear that the medical practitioner may administer the substance(s) in situations where self-administration is 'not possible'. This condition represents a dividing line between self-administration and administration by medical practitioner. Yet, no detail is provided on why it may not be possible to self-administer. For instance, would this be limited to physical limitations or would it extend to psychological issues such as anxiety. The manner in which this term is interpreted would therefore have a significant influence on the implementation and organisation of assisted dying. **The interpretation of this dividing line requires further attention and greater clarity.**

> 11(3) Any substance or substances prescribed under *subsection (1)* shall only be delivered to the person for whom they are prescribed— …
> (b) after the attending medical practitioner has confirmed that the person has not revoked and does not wish to revoke their declaration …

Section 11(3) is framed in the negative but could be reworded to strengthen the safeguard. Under section 241(3)(h) of the Canadian Criminal Code it states: 'immediately before providing the medical assistance in dying, give the person an opportunity to withdraw their request and ensure that the person gives express consent to receive medical assistance in dying'. This provides a space to reassess the declaration and to confirm the validity of the qualifying person's consent. In some cases, the consent process may trigger a capacity assessment. A decision to end one's life through assisted dying will require a high level of capacity. **A person's capacity may fluctuate in the period after signing the declaration and appropriate safeguards are needed to account for this.**

> 11(6) The attending medical practitioner or assisting health care professional must remain with the person until the person—
> (a) self-administered the substance or substances or have it or them administered,
> (b) decided not to self-administer the substance or substances or have it or them administered,
> for the purpose of this subsection the attending doctor or healthcare professional is to be regarded as remaining with the person if the attending doctor or assisting healthcare professional is in close proximity to, but not necessarily in the same room as, the person.

A crucial term for the interpretation of section 11(6) is 'remain with the person'. As drafted, this does not require the attending medical practitioner or assisting healthcare professional to be in the same room as the qualifying person but they should be in close proximity. This section raises a multitude of issues that are not resolved by the Bill. First, the attending medical practitioner or assisting healthcare professional do not need to be in the same room as the qualifying person when the substance is self-administered or a decision not to self-administer is made. Second, there is no indication of whether a third party or parties may be present. If the medical practitioner is elsewhere at the time, this leaves open the possibility of coercion or the involvement of a third party in administering the substance(s). Third, the qualifying person may vomit after self-administering the substance(s) but medical assistance may not be immediately available. The final point to highlight is that the section effectively means that the attending medical practitioner or assisting healthcare professional does not need to witness the death of the qualifying person. **Section 11(6) requires far greater scrutiny in order to resolve issues of ambiguity and ensure appropriate safeguards for the benefit of all parties.**

Section 15 Establishment of Assisted Dying Act Review Committee

> 15(2) On the establishment day there shall stand established a body to be known as the Assisted Dying Act Review Committee

The following points can be highlighted in relation to Section 15 of the Dying with Dignity Bill 2020: the name of the committee; composition; and function.

First, there is a discord between the title of the Bill and the title of the review committee. The Assisted Dying Act Review Committee suggests that the legislation is the 'Assisted Dying Bill' rather than the 'Dying with Dignity Bill'. This is a relatively minor point but stands to be reviewed. In contrast, question of composition and function are of far greater significance.

The Dying with Dignity Bill provides no detail on the likely composition of the Assisted Dying Act Review Committee. This is a point addressed by legislation in jurisdictions such as New

Zealand and the Netherlands (see below). The Victorian Voluntary Assisted Dying Act 2017 also provides substantial detail on membership and procedure.[47]

> New Zealand, End of Life Choice Act 2019, s 26(1) The Minister must appoint an end-of-life Review Committee consisting of—
> (a) a medical ethicist; and
> (b) 2 health practitioners, one of whom must be a medical practitioner who practises in the area of end-of-life care.
>
> Netherlands, Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, s 3(2) A committee is composed of an uneven number of members, including at any rate one legal specialist, also chairman, one physician and one expert and one expert on ethical and philosophical issues. The committee also contains deputy members of each of the, categories listed in the first sentence.

The final point to underline is the absence of detail on the proposed role and functions of the Assisted Dying Act Review Committee. Bodies of this nature provide a critical oversight role for the operation and implementation of assisted dying in a jurisdiction. Potential functions include monitoring assisted dying practices, reviewing safeguards, reporting on the operation of the legislation, referring issues for further review, promoting standards of quality and safety, conducting research, consulting with various groups and organisations, advising on legislative reform etc. It is therefore regrettable that no such detail is provided.

Age Action recommends that the composition and function of any review committee for assisted dying be set out in detail by the relevant legislation. The functions and composition should then be further shaped through an open consultation process.

[47] Voluntary Assisted Dying Act 2017, ss 94-102.

4. Key Recommendations

Process
Age Action firmly believes that broad consultation with a wide range of stakeholders is necessary to allow for an informed discussion where all voices are heard.

Title / Long Title
Age Action recognises the inherent dignity of the individual and the importance of this concept in underpinning human rights protections. We recognise that a person may achieve a dignified and peaceful end in many different ways and that this is not the exclusive jurisdiction of assisted dying. Age Action recommends that the short and long title of this Bill be reviewed.

Section 2 Interpretation
To accurately understand the impact on the doctor-patient relationship it is necessary to hear the views of all parties affected. It is only through broad engagement that a true picture of perceptions and attitudes can be discerned.

Section 8 Terminally ill
Age Action recommends that the definition for terminal illness be reviewed, particular attention should be paid to the reasons why a person might seek assisted dying. Age Action would welcome an opportunity for a meaningful discussion about the concept of 'qualifying person' more generally.

Section 9 Declaration
Section 9(3) Dying with Dignity Bill: Age Action recognises the importance of safeguards as part of any possible liberalisation of the law on assisted dying. It is essential that persons that are considered vulnerable are effectively protected and steps to prevent and identify coercion and duress are implemented. It should however be emphasised that the voice of vulnerable persons should be facilitated to inform the debate on end of life policy practices.
Section 9(4) Dying with Dignity Bill: Age Action calls for strengthened and better access to palliative care on an equitable basis throughout the country. Central to this is adequate and secure resourcing by Government of palliative care teams and hospices. Each person should have access to palliative care appropriate to each stage of their illness trajectory.

Section 10 Assessment of capacity
Age Action calls for the full commencement of the Assisted Decision-Making (Capacity) Act 2015. Any move towards the introduction of assisted dying in this jurisdiction must necessarily be preceded by the commencement of the 2015 Act so as to ensure that people have the best opportunity to exercise their autonomy.

Section 11 Assistance in dying
Section 11(2) Dying with Dignity Bill: The phrase 'is not possible' represents a dividing line between self-administration and administration by a medical practitioner. It requires further attention and greater clarity.
Section 11(3) Dying with Dignity Bill: A person's capacity may fluctuate in the period after signing the declaration and appropriate safeguards are needed to account for this.
Section 11(6) Dying with Dignity Bill: This section requires far greater scrutiny in order to resolve issues of ambiguity and ensure appropriate safeguards for the benefit of all parties.

Section 15 Establishment of Assisted Dying Act Review Committee

Age Action recommends that the composition and function of any review committee for assisted dying be set out in detail by the relevant legislation. The functions and composition should then be further shaped through an open consultation process.

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