



**Tithe an  
Oireachtais  
Houses of the  
Oireachtas**

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An Comhchoiste um Dhlí agus Ceart agus Comhionannas

Tuarascáil maidir leis an gCeart chun Bás Dínitiúil a fháil

Meitheamh 2018

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## **Houses of the Oireachtas**

Joint Committee on Justice and Equality

Report on the Right to Die With Dignity

June 2018

**32/JAE/18**





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## Chairman's Preface

As part of its Work Programme for 2017, the Joint Committee identified the Right to Die with Dignity as a priority issue for consideration. It is an important, emotive and at times divisive topic, which has generated a broad range of literature spanning multiple fields.

During November 2017, the Joint Committee examined the issue by meeting with stakeholders and academic experts both in favour of, and against, introducing legislation to regulate assisted dying in some form. The engagements were extremely informative and brought home the gravity of the issue and its complexity to Committee members.

This report has been sent to the Minister for Justice and Equality, **and the Minister for Health**, and the Committee recommends that the **respective** Ministers give due consideration to the report and its recommendations at **their** earliest convenience.

On behalf of the Committee, I would like to thank all those who engaged in this review and assisted us in our deliberations.

Finally, I would like to express my gratitude to the staff of the Oireachtas Library & Research Service, and to the Committee Secretariat, who assisted the Committee in the preparation of this report.



A handwritten signature in black ink, which appears to read 'Caoimhghín Ó Caoláin'.

Caoimhghín Ó Caoláin T.D.  
Chairman  
June 2018





## Glossary of terms and use of language

**Table 1: Glossary of terms**

<b>Assisted Dying / Aid-in-Dying</b>	<p>Assisted dying is a term for helping someone else to die, and includes euthanasia and assisted suicide.</p> <p>Aid-in-Dying is a synonymous term. Medical-aid-in-dying would be a doctor assisting someone to die.</p>
<b>Euthanasia</b>	<p>Euthanasia is an intervention undertaken with the intention of ending a life to relieve suffering.</p> <p>The European Association for Palliative Care (EAPC) Ethics Task Force has defined euthanasia as <b>"A doctor intentionally killing a person by the administration of drugs at that person's voluntary and competent request."</b><sup>1</sup></p> <p>Literally, euthanasia means an easy or gentle death.</p> <p><u>Voluntary euthanasia</u> occurs at the request of the person killed.</p> <p><u>Involuntary euthanasia</u> occurs in the absence of a request by the person killed, although that person is competent.</p> <p><u>Non-voluntary euthanasia</u> occurs where the wishes of the person killed are not known (for instance if they are unconscious or unable to communicate).</p> <p>Crucially, in euthanasia, <b>the doctor or other person involved 'acts last'</b>; it is their action that causes death (giving a lethal dose of medication for instance).</p>
<b>Assisted Suicide</b>	<p>Assisted suicide is the act of intentionally assisting a person to take their own life. Importantly, in assisted suicide <b>the person seeking to die 'acts last'</b>; they take the medicine / use whatever means selected that results in death. The assistance allows them to do so.</p>

<sup>1</sup> [Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force](#) (2003)

<b>Physician Assisted Suicide (PAS)</b>	PAS is the act of a doctor intentionally assisting a person to die by providing them with the means to kill themselves. This is commonly a prescription for a lethal drug(s).
<b>Physician Assisted Death</b>	This would include euthanasia and assisted-suicide where a doctor was instrumental.
<b>Palliative Care</b>	<p>Palliative care is described by the World Health Organisation (<b>WHO</b>) as an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness through the prevention and relief of suffering. This is achieved by means of early identification, impeccable assessment and treatment of pain and other symptoms that may be physical, psychosocial and spiritual.<sup>2</sup></p> <p>While it may generally be associated with terminal care (especially cancer care), it can be applied more broadly, at earlier stages of disease and for many serious conditions.</p>

### The use of language

In the literature on assisted dying, it is clear that those with different views employ language differently. This appears to be done to make a particular viewpoint sound more convincing and reasonable, or to make another sound less convincing and less reasonable. In parallel, the terms used by professionals and the public may differ. **The recent report of New Zealand Parliament's Health Committee on this topic (discussed below) noted that in the public's submissions to it:**

**"Submitters wanting a law** change [to allow for assisted dying] used terms such as medically assisted dying. Those opposed tended to

<sup>2</sup> Irish Hospice Foundation (2009) [\*Palliative Care for All - Integrating Palliative Care into Disease Management Frameworks\*](#);

use the technical terms including suicide, assisted suicide and euthanasia.”<sup>3</sup>

New Zealand Parliament’s Health Committee also noted that palliative care professionals were reluctant to use terms such as “assisted dying” as they view their current work as assisting people to die without it being euthanasia or assisted suicide.

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<sup>3</sup> New Zealand Parliamentary Health Committee (2017) *Petition 2014/18 of Hon Maryan Street and 8,974 others – Report of the Health Committee*. Fifty-first parliament. Presented to the House of Representatives. August 2017 p.7.

## Introduction

The issue of assisted dying is long-debated, highly controversial and frequently emotionally charged. It is a challenging and complex area requiring the consideration of a myriad arguments spanning the fields of medicine, law, theology, ethics and morality. Parliaments and other official bodies that have conducted public consultations on this topic have obtained very high levels of engagement.

Voluntary euthanasia, or physician-assisted suicide, is permitted in only a small number of jurisdictions. Some jurisdictions are more permissive than others. The Netherlands and Belgium, for instance, allow both euthanasia (where the physician **'acts last'**) and physician-assisted suicide (where the person seeking to die **'acts last'**); while US jurisdictions allow only for physician-assisted suicide.

Suicide is not a crime in Ireland, and competent patients may refuse or decide to stop treatment, including feeding and hydration, even when this will result in their death. Assisting suicide is illegal, however, with a penalty of up to fourteen **years imprisonment**. **Deliberately ending another's life** can be prosecuted as murder or manslaughter.

A recent Supreme Court judgement did not preclude the Oireachtas from legislating in this area. The *Right to Die with Dignity Bill 2015*<sup>4</sup> was moved by Deputy John Halligan as **a Private Members' Bill in the last Dáil**. However, as a Minister Deputy Halligan cannot progress the Bill himself.

The reasons people request assisted dying varies. The following table was created by Dr. Louise Campbell, Medical Ethicist and a Lecturer in Medical Ethics in National University of Ireland, Galway (NUIG):<sup>5</sup>

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<sup>4</sup> <https://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2015/12515/document1.htm>

<sup>5</sup> Dr. Campbell appeared before the Committee in November 2017.

**Table 2: Reasons for seeking assisted death**

<b>Illness-related experiences</b>	<ul style="list-style-type: none"> <li>• Feelings of weakness, tiredness, discomfort</li> <li>• Loss of function</li> <li>• Pain or unacceptable side-effects of medication</li> </ul>
<b>Threats to sense of self</b>	<ul style="list-style-type: none"> <li>• Loss of sense of self</li> <li>• Desire for control</li> <li>• Long-standing beliefs in favour of hastened death</li> </ul>
<b>Fears about the future</b>	<ul style="list-style-type: none"> <li>• Fears about future quality of life and dying</li> <li>• Negative past experiences of dying</li> <li>• Fear of being a burden on others</li> <li>• Fear of loss of independence</li> </ul>
<b>Source:</b> Campbell, L (2013) <i>Assisted dying: arguments for and against</i> . Presentation to the Irish Medical Organisation, 4 <sup>th</sup> April 2013.	

A 2016 review of practice in a range of jurisdictions that allow assisted dying found that more than 70% of cases involved patients with cancer. Patients were typically older, white and well-educated. Pain is mostly not reported as the primary motivator.<sup>6</sup>

The debate often focuses on adults with terminal disease, but this is not the only circumstance in which the topic of assisted dying arises:

- It has been suggested that assisted dying may be relevant to very old individuals, those with chronic or degenerative illnesses, people with mental health problems and society as a whole;<sup>7</sup>
- Assisted death has also been sought (sometimes successfully) by people **that are 'tired of life'**;<sup>8</sup>
- Euthanasia has also been debated in relation to the care of very premature babies.<sup>9</sup>

Both sides of the debate invoke moral arguments. These place differing levels of value on personal autonomy versus broader social considerations. The arguments are set out in brief below and considered in [section 8](#) of this Report.

<sup>6</sup> Emanuel, EJ, *et al* (2016) 'Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada and Europe'. *Journal of the American Medical Association* (JAMA), July 5; 316 (1):79-90.

<sup>7</sup> [Irish Council for Bioethics \(year unknown\) Euthanasia – your body, your death, your choice?](#)

<sup>8</sup> <http://www.worldrtd.net/news/exit-considers-assisted-dying-people-who-are-tired-life>

<sup>9</sup> [Irish Council for Bioethics \(year unknown\) Euthanasia – your body, your death, your choice?](#)

Arguments **in favour** of permitting assisted dying include:

- The importance of personal autonomy and choice; that competent people, in certain conditions (with terminal illnesses or in great pain, for instance) should have the right to decide on the manner and timing of their death;
- The uselessness of pain and suffering – that people should not have to endure pain when this could be ended;
- There is no moral distinction between withholding care/palliative care (that may hasten death) and a purposeful action to end life, yet the former is permitted and the latter is not;
- Assisted dying happens anyway and should be regulated;
- Having the drug and the option to choose your time of death may be enough;
- Some people travel to other jurisdictions to avail of assistance to die, and having this assistance available closer to home would relieve the stress and possible prematurity of such a decision. The expense of such a choice also makes it inaccessible to many people; **and**
- There is a lack of evidence to support the contention that vulnerable members of society will be endangered by legislation in the area.

Arguments **against** permitting assisted dying include:

- Human life has intrinsic value. It is not up to an individual or their doctor to decide when it should end;
- Individual autonomy must be balanced with the implications for society and is not a good enough reason given the potential negative effects;
- Doctors should not assist people to die – this is the opposite of their role, and incompatible with it. To do so would injure the trust relationship between doctors and patients;
- Intent is very important in end of life care. There is a significant moral distinction between acts that aim to alleviate symptoms (though they may have the side-effect of hastening death) and those that aim to cause death;
- Allowing assisted dying in certain circumstances may result in pressure on those in those circumstances to choose death over continued care, for reasons such as to alleviate stress on families or contain spending;

- A de-valuation of the lives of those with disabilities is likely to occur if assisted dying is allowed with potential for the worth put on lives that are not free from pain or dependence, for instance, to be decreased; **and**
- **A 'slippery slope' argument contends that even tightly written laws that** seek to limit the applicable circumstances for assisted dying would be subject to pressures to allow for more people and more situations to be included, eventually resulting in a regime that might be very different than that imagined by its instigators.

## Stakeholder engagement

In November 2017, the Joint Oireachtas Committee on Justice and Equality (hereinafter referred to as 'the Committee') held hearings with a number of witnesses. The witnesses and links to the transcripts of the debates are detailed in the following table:

<b>Table 3: Witnesses and Official Report</b>		
<b>Witness</b>	<b>Organisation</b>	<b>Date of hearing and link to the official report</b>
Dr. Regina McQuillan	Irish Association for Palliative Care (IAPC)	<a href="#">Official Report, 22 November, 2017</a>
Mr. Tom Curran & Mr. Michael Nugent	Right to Die Ireland	
Professor Penney Lewis	<b>King's College London</b>	
Professor Desmond O'Neill	Tallaght Hospital and Trinity College Dublin	<a href="#">Official Report, 29 November, 2017</a>
Ms. Karen Hall	Disability Action (Northern Ireland)	
Dr. Louise Campbell	National University of Ireland, Galway	



## Current legal context in Ireland

This section gives an overview of the legal context in Ireland to debates about assisted dying. It looks at the current legislation, some relevant case law and a recent Bill brought forward to change the law.

### Current legislation

Both euthanasia and assisted suicide are illegal under Irish law. However, attempting to commit suicide is not a criminal act in itself. The [Criminal Law \(Suicide\) Act 1993](#) decriminalised suicide, and made it a criminal offence to assist another person to take their own life with the possibility of a fourteen year prison term on conviction.

#### **Box 1: Section 2 of the [Criminal Law \(Suicide\) Act 1993](#):**

2.—(1) Suicide shall cease to be a crime.

(2) A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be guilty of an offence and shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years.

(3) If, on the trial of an indictment for murder, murder to which [section 3](#) of the [Criminal Justice Act, 1990](#) applies or manslaughter, it is proved that the person charged aided, abetted, counselled or procured the suicide of the person alleged to have been killed, he may be found guilty of an offence under this section.

(4) No proceedings shall be instituted for an offence under this section except by or with the consent of the Director of Public Prosecutions.

Patients do have the right to refuse life-sustaining treatment. They may refuse clinical assistance with nutrition and hydration, even though without these the person may die.<sup>10</sup>

### Selected Case Law

In common with other jurisdictions, in Ireland, the law banning assisted dying has been subject to legal challenge and legal cases have generated a high level

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<sup>10</sup> Campbell, L (2013) *Assisted dying: arguments for and against*. Presentation to the Irish Medical Organisation, 4<sup>th</sup> April 2013.

of interest. Two recent cases stand out as important legal background to the issue of assisted dying. The first is the Marie Fleming case, which is considered a landmark legal action testing the law on assisted suicide. The second is the **prosecution of Gail O'Rorke** for allegedly assisting/attempting to assist her friend to die. The facts of these cases provide a large part of the current legal context in this area. Thus they warrant some detailed examination when considering any proposed changes to the law.

### Marie Fleming case

In 2012, Marie Fleming took a legal action to be allowed assistance with dying. The case (*Marie Fleming v Ireland and the Attorney General*) was first heard in the High Court and subsequently, on appeal, in the Supreme Court. Ms. Fleming (the plaintiff) challenged the law criminalising assisted suicide.

The proceedings turned on the question of whether the plaintiff - in the final stages of multiple sclerosis and physically incapable of ending her own life - had a right to assisted suicide if this was the conscious decision she made. She claimed that the blanket ban on assisted suicide breached her constitutional rights and her rights under the European Convention on Human Rights (ECHR).<sup>11</sup> Both courts rejected her claim. Ms. Fleming died in December 2013.

As part of this case, Ms. Fleming sought assurance that her partner, Tom Curran, could so assist her without fear of prosecution. The High Court refused to issue an order requiring the Director of Public Prosecutions (DPP) to clarify policy on the factors in favour of or against prosecution for the crime of assisted suicide. This was not appealed, and therefore not considered by the Supreme Court.<sup>12</sup> The decision of the Supreme Court is detailed below.

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<sup>11</sup> Her key argument was that Section 2(2) of the [Criminal Law Suicide Act 1993](#) should be declared invalid under the Constitution and incompatible with the ECHR.

<sup>12</sup> Spain, E. (2013) '[Fleming and the Right to Die](#)' (blogpost), on [humanrights.ie](#) [accessed 18/09/2017]

## Box 2: The Supreme Court decision in the Marie Fleming case

The first important decision of the Supreme Court in this case was the finding that the right to die was not a corollary of right to life under Art 40.3.2, nor was **the right to commit suicide or to have one's life terminated to be read into any** other articles of the constitution. Specifically, the court held that the right to life does not entail a right to terminate life or have life terminated. Indeed,

*[in] the social order contemplated by the Constitution, and the values reflected in it, that would be the antithesis of the right rather than the logical consequence of it.*

In coming to this conclusion, the court affirmed the distinction drawn by the Supreme Court in 1996 (In Re a Ward of Court (withholding medical treatment) No 2) between positive steps to end life and allowing nature take its course. In that case the court held that the right to life included a right to die a natural death; and it consented to the withdrawal of all artificial nutrition and hydration of a patient in a near persistent vegetative state. The actions proposed by Marie Fleming would have amounted to positive action to end her life rather than dying a natural death, and are therefore not within the boundaries of Art 40.3.2.

The Court also rejected the argument that s2(2) of the **Criminal Law (Suicide) Act 1993** was incompatible with the constitution on the ground of equality, as it had the effect of indirectly discriminating against those who are unable to commit suicide without assistance. It was held that the fact that an objectively neutral provision affects able bodied and disabled bodied individuals differently does not amount to a breach of the constitutional principle of equal treatment under Art 40.1. This differs from the reasoning of the High Court, which found that this failure to differentiate between able bodied and disabled people amounted to unequal treatment, but that such treatment was a proportionate interference given the necessity to safeguard the lives of others.

Finally, the court was called upon to decide upon the compatibility of s2(2) of the 1993 Act with the European Convention on Human Rights, particularly Article 8 of the Convention, with the court again finding against Ms Fleming. The court relied heavily on a decision of the European Court of Human Rights in a case taken by Diane Pretty (Pretty v United Kingdom), a woman suffering from motor neuron disease. The Court held it was primarily for individual States to assess whether an interference with the right to private life under Article 8 was proportionate, bearing in mind the risks of abuse if the law on assisted suicide was relaxed.

**Adapted from:** Spain, E. (2013) '[Fleming and the Right to Die](#)' [blogpost], on [humanrights.ie](#) [accessed 18/09/2017]

A central theme arising in the Fleming case and that of similar cases in other jurisdictions is how the autonomy of the individual who is seeking help to die can be balanced against the rights of vulnerable persons to the protection of the state.<sup>13</sup>

### **Gail O'Rorke case**

Another notable case is that of Gail O'Rorke.<sup>14</sup> In 2014, Ms. O'Rorke was arrested and charged in relation to attempting to assist the suicide of her friend, Bernadette Forde. Ms. Forde killed herself in 2011 using drugs (barbiturates) obtained for this purpose. Prior to this she had planned to go to Switzerland to avail of assisted suicide. However, the travel agent used to book this trip alerted An Garda Síochána as it **suspected Gail O'Rorke had booked flights in order to travel for a suicide.**

Ms. O'Rorke was accused of assisting Bernadette Forde's suicide by obtaining barbiturates for the purpose of taking an overdose, and also with making funeral arrangements with Ms. Forde.

In April 2015, the judge ruled there was insufficient evidence on these charges, and Ms. O'Rorke was found not guilty of attempting to assist in the suicide of her friend by arranging for her to travel to Switzerland.

It was the first case of its kind under the 1993 legislation which decriminalised suicide but made it a criminal offence to assist or attempt to assist a person to take their own life.

### **Possible legislative and policy options**

Maintaining the current law as it stands is one course for the future in Ireland.

Another possibility is the enactment of legislation to allow for some form of assisted dying (the Bill described below, for example). The Supreme Court has made clear that the Oireachtas is not precluded by the Constitution from

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<sup>13</sup> Campbell, L (2016) 'The limits of autonomy: an exploration of the role of autonomy in the debate about assisted suicide,' in M Donnelly and C Murray (Eds.) *Ethical and Legal Debates in Irish Healthcare*. Manchester: Manchester University Press, p.56.

<sup>14</sup> Sources: Irish Times, '[Despite recent cases law on assisted suicide unlikely to change](#)'; MS Ireland (2017) *Treatment and Care Decisions in Advanced Multiple Sclerosis (MS) - Briefing Document and Position Paper*, BBC, '[Gail O'Rorke: Dublin woman found not guilty of assisted suicide](#)'.

legislating to decriminalise assisted dying in limited circumstances, and subject to appropriate safeguards.<sup>15</sup>

In addition, the Supreme Court noted that the State is not under any obligation to use all necessary means to prevent individuals in circumstances such as Marie Fleming's from ending their own lives.

In terms of policy, in the Fleming case, both the Supreme and High Courts emphasised that the Director of Public Prosecution (DPP) maintains the authority to decide whether or not to prosecute in an individual case.<sup>16</sup>

It is possible that the DPP may produce guidelines on factors to be considered in deciding on such prosecutions. This is the approach that has been taken in England and Wales (see below). However, during her appearance before the Justice and Equality Committee on 22 November 2017, Professor Penney Lewis - co-director of the Centre of Medical Law and Ethics at King's College London - raised considerable reservations regarding this approach.<sup>17</sup>

### **Recent legislative attempt – Right to Die with Dignity Bill 2015**

In 2015, Deputy John Halligan introduced the *Right to Die with Dignity Bill 2015*.<sup>18</sup>

The long title of this Bill describes it as follows:

"Bill entitled an Act to make provision for assistance in achieving a dignified and peaceful end of life to qualifying persons and related matters."

This Private Members' Bill passed first stage and order was made for Second Stage in Dáil Éireann. However, Second Stage debate has not yet taken place. As a Minister, Deputy Halligan cannot progress the Bill himself. Deputy Halligan indicated that the Bill is intended to assist those that are:

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<sup>15</sup> [Fleming -v- Ireland & ors, 2013, para. 108.](#)

<sup>16</sup> However, the High Court expressed confidence that the DPP would exercise her discretion to prosecute in that case in a humane and compassionate way.

<sup>17</sup> [Official Report of The Justice and Equality Committee, 22 November 2017](#)

<sup>18</sup> <https://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2015/12515/document1.htm>

**"...in their most desperate moment of life ...being deprived of their humanitarian rights."**

The Deputy argued that other European countries are legislating to allow for assisted dying and that with increased life expectancy there is an increase in the rate of chronic illness. **The Deputy stated that the Bill provided for "clear protection for vulnerable people" as follows:**

**"[Under the provisions of the Bill] Two separate medical practitioners are required to examine the qualifying person and sign a valid declaration that their decision is voluntary and they have an incurable and progressive illness which cannot be reversed by treatment and which is likely to lead to their death. A third independent witness, who is not a beneficiary of their estate, must also testify that the person has a clear and settled intention to end their own life when their illness becomes too much to bear. At all times safeguards must be met to show the terminally ill person has reached their decision on an informed basis and without coercion or duress. Furthermore, no doctor will be obliged to participate in an assisted death if he or she has a conscientious objection."**<sup>19</sup>

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<sup>19</sup> [Dáil Éireann, 15 December 2015.](#)

## Palliative care in Ireland

The World Health Organisation defines palliative care as:

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Traditionally, palliative care has been associated with the care of terminally ill cancer patients. However, it is now widely accepted that palliative care should not be limited to terminal conditions or end-of-life care, and has a much wider role to play. The Irish Hospice Foundation states:

“Palliative care is appropriate at any stage for people with a life limiting illness including advancing neurological illnesses, heart, circulatory and respiratory disease. Palliative Care can be provided with curative treatment. It is not designed to replace treatment; rather it complements the treatment received.”<sup>20</sup>

The need to ensure the provision of timely, effective and accessible palliative care services was raised on numerous occasions during the Committee hearings. On 22 November 2017, Dr. Louise Campbell of the National University of Ireland, Galway, stated that palliative care providers, in particular, feel that “effective and accessible palliative care support can reduce or eliminate demand for assisted dying.”

The *Palliative Care Services Three Year Development Framework (2017 to 2019)*<sup>21</sup> was launched in November 2017. It aims to direct and inform the development of palliative care services in Ireland, improve care for people with a life-limiting condition and enhance collaboration in palliative care provision.

Government policy on palliative care stems from the *2001 National Advisory Committee on Palliative Care (NACPC) Report*, which will be reviewed

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<sup>20</sup> <http://hospicefoundation.ie/aboutus/hospice-palliative-and-end-of-life-care/what-is-palliative-care/>  
<sup>21</sup> [Palliative Care Services Three Year Development Framework \(2017 to 2019\)](#)

and updated as part of the Framework. At the launch of the Framework, Minister for Health, Simon Harris TD, said:

"Palliative care is a key part of our health service and it is essential that when it comes to end of life people are treated with dignity and respect. These values must be enshrined in the quality of care which is provided to patients and their families. We must also work to ensure that palliative care services are accessible across the country and that there is an integrated pathway across in-patient, homecare, nursing home, acute hospital and day care services. As Minister for Health I welcome the publication of this important three year Framework and I am assured that my Department will continue to work closely with the HSE on the implementation of its recommendations and actions."<sup>22</sup>

Some notable aspects of the Framework include:

- Its acknowledgement of the need to continue to expand palliative care provision:

**"Full access to palliative care services for patients with non-malignant disease is now the norm in the sector, with service providers accepting referrals based on need rather than condition. While the work of embedding palliative care in the disease trajectory for non-cancer conditions must continue, attention should now extend to the needs of vulnerable populations."**<sup>23</sup>

- The need to address regional discrepancies in the provision of palliative care:

"regional variations still exist in access to specialist palliative care in inpatient units, day care services, acute hospitals,

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<sup>22</sup> <https://www.hse.ie/eng/services/news/media/pressrel/hse-launches-new-palliative-care-development-framework.html>.

<sup>23</sup> *Palliative Care Services Three Year Development Framework (2017 to 2019)* p.14.



and community-based services, both in infrastructure and staffing levels.”<sup>24</sup>

- As articulated in the foreword from the Chairperson of the Framework Steering Group, it is financially prudent to invest in palliative care:

“The economic case for investment in palliative care is well established, evidence-based and firmly grounded. It demonstrates that fully developed inpatient hospice services alongside properly resourced community services, can substantially reduce the level of acute admissions for patients with both malignant and non-malignant diseases, particularly in the last three months of life – in these instances the number of people being cared for at home significantly increases. This leads to cost savings within acute hospitals, as well as a reduction in inappropriate hospital admissions, a more appropriate care pathway, and an improved experience for patients and their families.”

As noted in the Framework, the number of those over 65 years of age is projected to increase from 532,000 in 2011 to 991,000 in 2031, while the number of deaths of persons over 65 years of age is projected to increase from 28,000 to 36,000 in the same period.<sup>25</sup> This will be accompanied by an increase in fatalities from neurodegenerative diseases and cancer, and will increase demand for palliative care.

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<sup>24</sup> [Palliative Care Services Three Year Development Framework \(2017 to 2019\)](#) p.34.

<sup>25</sup> Source: CSO (2013), *Regional Population Projections 2016 -2031*.

## Other jurisdictions

### Key points:

- Most jurisdictions, including those in the Western liberal tradition, do not allow for any form of legal assisted dying;
- Policy makers in a number of jurisdictions have engaged in debate around assisted dying;
- In most jurisdictions where assisted dying is allowed, this is a relatively new phenomenon;
- Jurisdictions that do allow some form of assisted dying vary to some degree in what is permissible (assisted suicide or assisted suicide and euthanasia) and who is eligible (just those with a terminal disease with less than six months to live or including those with non-terminal unbearable suffering, which may include psychiatric conditions);
- They also vary in many other regards, such as age limits, degrees of safeguards, oversight etc. In general, the laws seem to allow for **'conscience clauses'** so that health professionals who do not wish to take part in assisted dying can opt out.

### Overview of legal context in other jurisdictions

Relatively few jurisdictions allow for any form of legal assisted death. Nonetheless, the issue has some currency, and in most jurisdictions where it is allowed, this is the result of a relatively recent change (see the recent legislative changes in the Australian State of Victoria (below), for example). In other jurisdictions (such as New Zealand (again, see below)) the topic has been debated but assisting someone else to die remains illegal. The table below indicates key jurisdictions (as highlighted in the (English language) literature) in which some form of assisted death is allowed by law.

Following this are descriptions of laws in some jurisdictions, and debates and proposals in others. For reasons of brevity, these descriptions seek to highlight some key aspects, and do not attempt to paint a comprehensive picture of the policies or debates, or the implementation infrastructure/regulatory regimes.

**Table 4: Jurisdictions where assisted death is legally permitted<sup>26</sup>**

Physician Assisted Suicide	Euthanasia or Physician Assisted Suicide
<ul style="list-style-type: none"><li>• US States / Territories of:<ul style="list-style-type: none"><li>◦ Oregon</li><li>◦ Colorado</li><li>◦ California</li><li>◦ Washington</li><li>◦ Montana</li><li>◦ Vermont</li><li>◦ Washington D.C.</li></ul></li><li>• Switzerland (person assisting need not be a doctor though a prescription will be necessary)</li></ul>	<ul style="list-style-type: none"><li>• Netherlands</li><li>• Belgium</li><li>• Luxembourg</li><li>• Colombia</li><li>• Canada (Quebec since 2014, nationally since June 2016)</li></ul>

## Belgium<sup>27</sup>

The *Belgian Euthanasia Act 2002* permits doctors to perform euthanasia (understood as the termination of life on request). Assisted suicide is not specified separately, though the oversight body (Federal Control and Evaluation Commission) has accepted that this is included in the law's provisions.

### *Notable aspects of Belgian law:*

- A terminal illness is not necessary to avail of euthanasia or assisted suicide. Rather, the **individual must have a 'medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious or incurable disorder caused by illness or accident'**;
- More stringent procedures apply where the patient is not expected to die of natural causes in the near future;
- The **individual making the request must be 'legally competent'** and the request must be voluntary, not the result of external pressure;

<sup>26</sup> Adapted from: [Emanuel EJ](#), [Onwuteaka-Philipsen BD](#), [Urwin JW](#), [Cohen J](#) (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe'. *JAMA*. (Journal of the American Medical Association) 2016 Jul 5;316(1):79-90.

<sup>27</sup> Adapted from Lewis & Black (2012) Effectiveness of Legal Safeguards in jurisdictions that allow assisted dying. reproduced in SPICe – The Information Centre, Scottish Parliament briefing on Assisted Suicide (Scotland) Bill, 08 January 2015 (15/02), by Robson, K and Harvie-Clark, S.

- The doctor is required to inform patients of their condition and possible therapeutic and palliative courses of action and their likely consequences;
- **The patient's request must be in writing (and may be made in advance** though conditions are in place regarding how this is applied – for instance, it would not apply to future diagnosis of dementia).

### *Age eligibility*

The law applies to all ages, although children require approval of their parents and counselling by doctors and a psychiatrist / psychologist. They must have rational decision-making capacity and be in the final stages of a terminal illness.

### Notable Belgian case

A notable case that is often cited in the literature is that of Belgian twins Marc and Eddy Verbessem. They were born deaf, and had heart and spinal problems. They were both losing their sight, and requested euthanasia for fear of being deaf-blind. Though they had their first request refused, they eventually died of lethal injection on 14 December 2012, aged 45.<sup>28</sup>

## **The Netherlands<sup>29</sup>**

In the Netherlands, both euthanasia (termination of life on request) and assisted suicide are legal when performed by doctors in keeping with the statutory criteria. The relevant law is the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*.

### *Notable aspects of law in the Netherlands:*

- To be eligible, **a person's attending physician must be satisfied that the patient's suffering is unbearable with no prospect of improvement.** Only physicians may perform euthanasia.

<sup>28</sup> Campbell, L (2013) as before. and BBC, '[Deaf Belgian twins end lives as they start going blind](#)'.

<sup>29</sup> Adapted from Lewis & Black (2012) Effectiveness of Legal Safeguards in jurisdictions that allow assisted dying. reproduced in The Information Centre, Scottish Parliament briefing on Assisted Suicide (Scotland) Bill, 08 January 2015 (15/02), by Robson, K and Harvie-Clark, S.

- This need not be related to terminal illness, and is not limited to physical illness or symptoms.
- No reasonable alternative must be available, and the disease must be incurable.
- The request must be made in “full consciousness” by the patient.

### *Age eligibility*

The law applies to adults but minors aged between 12 and 18 must also have their requests considered. In the case of 16-18 year olds, where individuals are capable of making a reasonable appraisal of their own interests, their request will be considered, and parents / guardians must be consulted but do not have a veto. The same capacity test applies to 12-15 year olds, but **parents’ or guardians’ consent is required.**

### *Consultation and referral*

An independent physician must see the patient and give an opinion (in writing) on whether the due care criteria are met. **Tighter rules apply where a person’s** suffering is due to a psychiatric disorder. The majority of reported euthanasia cases involve a consultant from the state-funded programme Support and Consultation on Euthanasia in the Netherlands (SCEN). The doctor involved must take due medical care and attention and, generally, this means being continuously present during the euthanasia or assisted suicide.

## **Switzerland**

In Switzerland, assisted suicide is not punishable, so long as the motives of the assistant are not selfish. The person need not have a terminal condition.<sup>30</sup> Assistance does not necessarily have to be from a doctor, though the need for a prescription for the necessary medication means that a doctor must be involved to some extent. Euthanasia is not permitted in Switzerland.

Dignitas is a particularly well-known organisation that facilitates assisted suicide in Switzerland (it is reported that there are four such organisations -

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<sup>30</sup> New Zealand Parliamentary Health Committee (2017) *Petition 2014/18 of Hon Maryan Street and 8,974 others – Report of the Health Committee*. Fifty-first parliament. Presented to the House of Representatives. August 2017.

though not all accept non-residents<sup>31</sup>). It has been documented that many people travel to Switzerland to avail of these services.

It can be seen in the laws in some other jurisdictions (and in the discussions of the most recent Scottish Bill for instance), that they appear to be drafted to **exclude the possibility of attracting 'suicide tourism'**. This has been provided for by way of requirements around minimum duration of residency etc. In 2011, a **proposal to ban 'suicide tourism' to Switzerland was rejected** by Swiss voters (by way of referendum).<sup>32</sup>

## USA

In the USA, **there is no federal law on assisted dying or a 'right to die'**; rather, those laws are generally made at state level. The states / territories of Oregon, Colorado, Washington, Vermont, California, and Washington D.C. have laws allowing people to seek a doctor's help in ending their life.<sup>33</sup> These are known as the **'Oregon-model states'**.

However, the issue remains controversial in the USA, with many states maintaining specific laws banning assisted-dying, and others prohibiting it by way of common law. These laws have been subject to challenges (though some states have no specific laws on assisted suicide).<sup>34</sup> In early September 2017, the **state of New York's highest court (the Court of Appeals) ruled that the legislature's ban on physician-assisted death was not unconstitutional**.<sup>35</sup>

### *Features of laws in US jurisdictions that allow Physician-Assisted Suicide*

The following gives an overview of some of the stipulations made in assisted suicide laws in the USA. While there is quite a degree of commonality between laws in different US jurisdictions (e.g. all apply only to adults aged 18 or over expected to live six or fewer months), there is also some variety. The following is an attempt to demonstrate the types of conditions that apply.

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<sup>31</sup> New Zealand Parliamentary Health Committee (2017), *as before*.

<sup>32</sup> Source: Reuters, ['Zurich voters reject ban on "suicide tourism"'](#).

<sup>33</sup> <https://www.nytimes.com/aponline/2017/09/09/us/ap-us-right-to-die.html>

<sup>34</sup> Produced by [ProCon.org](#), a USA based source seeking to provide objective information on contentious issues.

<sup>35</sup> <http://abcnews.go.com/Health/wireStory/top-york-court-rules-physician-assisted-suicide-49678435>

**Table 5: Features of US laws allowing Physician Assisted Suicide**

<b>Patient</b>	<ul style="list-style-type: none"> <li>• Age 18 years or older;</li> <li>• Be resident in the jurisdiction;</li> <li>• Be competent to make and communicate the relevant decision;</li> <li>• Must be physically and mentally capable of self-administering the “aid-in-dying” drug.</li> </ul>
<b>Physician Protocol</b>	<ul style="list-style-type: none"> <li>• Physician must be registered in the jurisdiction;</li> <li>• Diagnosis must be for a terminal illness with a life expectancy of 6 months or less;</li> <li>• A second opinion is generally required – on terminal diagnosis and on mental competence;</li> <li>• Required to inform patient of alternatives (such as palliative / hospice care);</li> <li>• May be required to make a mental health referral in all cases or for psychological assessment if physician has concerns over the patient’s concern (depending on the jurisdiction);</li> <li>• May be required to request patient to inform their next-of-kin of their request.</li> </ul>
<b>Patient Request Timeline</b>	<ul style="list-style-type: none"> <li>• Each jurisdiction has waiting time periods that <b>must be served before a patient’s request can proceed</b> (cooling-off periods);</li> <li>• Generally, two oral requests are required, some time apart (e.g. at least 15 days apart) and a further request in writing.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• Generally, the use of assisted dying laws can not be used to affect life assurance, health insurance or annuity policies;</li> <li>• Physicians or healthcare systems are not obliged to participate;</li> <li>• Pharmacists filling prescriptions may also be protected from prosecution.</li> </ul>

**Source:** Adapted from source material in ‘[State-by-State Guide to Physician-Assisted Suicide](#)<sup>36</sup>’.

## England and Wales

The legislative situation in the UK is similar to that in Ireland in that suicide and attempted suicide are not in themselves criminal offences. However, under the *Suicide Act 1961* it is an offence for one person to encourage or assist the suicide (or attempted suicide) of another.

<sup>36</sup> [ProCon.org](#), as before.

Again, in common with other jurisdictions, there have been several legal cases regarding the offence of assisted suicide, particularly in the context of disabled or terminally ill people who are unable to end their lives without assistance. Some notable cases are outlined below.

### **Box 3: Notable legal cases in the UK re Assisted Suicide**

Of particular relevance is the case of Debbie Purdy, who in July 2009 obtained a House of Lords ruling ordering the Director of Public Prosecutions (DPP) to formulate an offence-specific policy setting out the public interest factors the Crown Prosecution Service will consider when deciding whether to prosecute assisted suicide offences. **The DPP's policy was published in February 2010 following a public consultation (see below).**

In June 2014, the Supreme Court revisited the issue of assisted suicide in the cases of Tony Nicklinson, Paul Lamb and AM, who were seeking a declaration that the current law on assisted suicide was incompatible with their right to a private life under Article 8 of the European Convention on Human Rights. The Supreme Court decided against making such a declaration by a majority of seven to two. It took the view that Parliament was the most appropriate forum for considering changes to the law on this particular issue. Following the Supreme Court decision, in July 2015, the European Court of Human rights dismissed applications from Jane Nicklinson and Paul Lamb.

**Source:** [House of Commons Briefing Paper \(2015\)](#)

In 2010, the UK Director of Public Prosecutions, Keir Starmer QC, launched the *Policy for Prosecutors in respect of cases of Encouraging or Assisting Suicide* (it was subsequently updated in 2014).

This policy provides guidance to prosecutors on the public interest factors to take into account in reaching decisions in cases of encouraging or assisting suicide. It is designed to give public confidence in the Crown Prosecution Service's (CPS) policy and followed an extensive public consultation.<sup>37</sup>

At the time of publication, the (then) Director stated:

"The policy is now more focused on the motivation of the suspect rather than the characteristics of the victim. The policy does not

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<sup>37</sup> Nearly 5,000 responses were received by the Crown Prosecution Service (CPS) following the consultation exercise launched in September 2009. Source: Crown Prosecution Service page: [http://www.cps.gov.uk/publications/prosecution/assisted\\_suicide.html](http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html)



change the law on assisted suicide. It does not open the door for euthanasia. It does not override the will of Parliament. What it does is to provide a clear framework for prosecutors to decide which cases should proceed to court and which should not.

Assessing whether a case should go to court is not simply a question of adding up the public interest factors for and against prosecution and seeing which has the greater number. It is not a tick box exercise. Each case has to be considered on its own facts and merits.

As a result of the consultation exercise there have been changes to the policy. But that does not mean prosecutions are more or less likely. The policy has not been relaxed or tightened but there has been a change of focus."

**The policy identifies factors that may 'tend' for and against prosecution (the entire DPP policy can be read [here](#)).<sup>38</sup> It is very clear that this policy applies only in cases of assisted suicide where a person takes their own life. "It is murder or manslaughter for a person to do an act that ends the life of another, even if this is at the latter's express wish."<sup>39</sup>**

The victim being under 18 years of age is amongst the factors tending in favour of prosecution. Those tending against prosecution are set out in **Box 4** below.

**Box 4: DPP's policy on prosecution of assisting or encouraging suicide - England and Wales [extract]**

A prosecution is less likely to be required if:

1. the victim had reached a voluntary, clear, settled and informed decision to commit suicide;
2. the suspect was wholly motivated by compassion;
3. the actions of the suspect, although sufficient to come within the definition of the offence, were of only minor encouragement or

<sup>38</sup> Crown Prosecution Service page

[http://www.cps.gov.uk/publications/prosecution/assisted\\_suicide\\_policy.html](http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html)

<sup>39</sup> House of Commons Briefing Paper (2015) *The Assisted Dying (No. 2) Bill 2015*. [accessed 28/09/2017].

assistance;

4. the suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide;
5. the actions of the suspect may be characterised as reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide;
6. the suspect reported the victim's suicide to the police and fully assisted them in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing encouragement or assistance.

**Source:** [Crown Prosecution Service](#).

This policy has been debated on at least two occasions (House of Commons, March 2012; and House of Lords, March 2014). An attempt to compel the government to consult on putting the guidance on a statutory basis failed.<sup>40</sup>

As previously mentioned, during her appearance before the Justice and Equality Committee on 22 November 2017, Professor Penney Lewis raised a number of reservations regarding this approach. Professor Lewis stated:

"My concerns about the specifics of the policy are that there are no **requirements or even factors related to the patient's condition**. This means one does not have to be terminally ill and there is no requirement that one be suffering unbearably. In many ways, this regime is more liberal than the Dutch or Belgian regimes."<sup>41</sup>

### ***Stats on Assisted Suicide Cases***

Cases of assisted suicide (England and Wales) are recorded centrally by the Crown Prosecution Service (CPS) Headquarters and are dealt with in the Special Crime and Counter Terrorism Division in the CPS. The latest figures (July 2017) show the following:

- From 1 April 2009 up to 7 July 2017, there have been 136 cases referred to the CPS by the police that have been recorded as assisted suicide;
- Of these 136 cases, 85 were not proceeded with by the CPS. 28 cases were withdrawn by the police;

<sup>40</sup> House of Commons Briefing Paper (2015), as before.

<sup>41</sup> [Official Report of The Justice and Equality Committee, 22 November 2017](#)

- There are currently eight ongoing cases. One case of assisted attempted suicide was successfully prosecuted in October 2013, one case of assisted suicide was charged and acquitted after trial in May 2015 and seven cases were referred onwards for prosecution for homicide or other serious crime.

### ***Legislative attempts***

It has been argued that a change to the law is needed as, amongst other things, **the current law is not fit for purpose (evidenced by the DPP's guidance on when it will not be prosecuted)**. Indeed, there have been a number of legislative attempts at Westminster – both in the House of Lords and House of Commons and **by way of specific Private Members' Bills and by amendment to other proposed legislation**. These occurred in 2004, 2008-09, 2013, 2014 and 2015. Details are available in a House of Commons Briefing Paper on: [The Assisted Dying \(No. 2\) Bill 2015](#).

## **Australia**

Previously, controversially, and for a short period of time (in 1995-1997), assisted suicide was legal in the Northern Territory of Australia.<sup>42</sup> In November 2017, the state of Victoria passed legislation that will legalise assisted dying from 2019, and a legislative proposal is to be considered in New South Wales.

## **Victoria**

In 2016, the Victorian Parliament's Legal and Social Issues Committee published its final report on its '[Inquiry into End of Life Choices](#)'. The Committee recommended changes in a number of areas such as advance care planning and palliative care. Included was a recommendation to allow for assisted dying in some, limited, circumstances. This was put in the context of broader reforms aimed at giving "greater prominence" to end of life care.

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<sup>42</sup> This was the first jurisdiction in the world to pass a law (*Rights of the Terminally Ill Act 1995* (NT)) allowing a doctor to end the life of a terminally ill patient at the patient's request. The Act was subsequently constitutionally overridden by the Commonwealth of Australia. See: Parliament of Australia Research Service (1997) [Euthanasia - the Australian Law in an International Context- Research Paper - Research Paper 4 1996-97 \(for contemporary information\)](#) and Australian Human Rights Commission (2016) [Euthanasia, Human Rights and the Law – Issues Paper](#). (covering this and subsequent developments).

In November 2017, the [Voluntary Assisted Dying Bill 2017](#)<sup>43</sup> was controversially passed. It will legalise assisted dying in the state of Victoria from 2019. The law is designed for patients who are in severe pain. Safeguards include:

- A patient must make three requests to specially trained doctors in order to end their life;
- They must be suffering in a way that cannot be relieved in a manner the person deems tolerable;
- Patients must be of sound mind;
- Coercion of patients into ending their life will be a crime;
- A special board must review all cases;
- Patients must have lived in Victoria for at least 12 months.

Patients must administer the drug themselves unless they are physically unable to do so, in which case a doctor can deliver the lethal dose. Patients must be terminally ill with less than six months to live (or 12 months for those with neurodegenerative illnesses such as multiple sclerosis or motor neurone disease).<sup>44</sup>

## **New South Wales**

The Parliament of New South Wales in Australia is due to debate the [Voluntary Assistance with Dying Bill 2017](#).<sup>45</sup> This cross-party Private Members' Bill, reportedly prepared by a Working Group over a two-year period<sup>46</sup>, is expected to be subject to a conscience vote when it comes before the Assembly.

## **New Zealand**

The Health Committee of the New Zealand parliament recently reported having considered a petition on the topic of 'medically assisted dying'.<sup>47</sup>

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<sup>43</sup> Source: <http://www.legislation.vic.gov.au>.

<sup>44</sup> Sources: BBC, '[Australian State legalises assisted dying in national first](#)'; The Guardian, '[Crossing the threshold: How Victoria's assisted dying law finally made history](#)'; ABC, '[Euthanasia: Victoria becomes the first Australian state to legalise voluntary assisted dying](#)'.

<sup>45</sup> [Link to Bill page with further details \(sponsors, debates etc.\)](#): [accessed 27/09/2017].

<sup>46</sup> [Hawke, S \(2017\) 'Nationals MPs Trevor Khan makes emotional plea on assisted dying bill', ABC news](#). [accessed 27/09/2017]

<sup>47</sup> New Zealand Parliamentary Health Committee (2017), *as before*.

The Committee's work spanned two years. It received approximately 22,000 submissions on this topic (1,000 were heard in person), demonstrating a high level of public interest. The majority of these expressed opinions opposed to legislating for assisted dying. However, the Chair (Simon O'Connor MP<sup>48</sup>) stated that he did not think it was a 'numbers game', and he recommended that people read the Committee's report<sup>49</sup> to gain a deeper understanding of the arguments.

The Committee did not recommend changing the New Zealand legislation (which is similar to Irish legislation in that assisting anyone to take their own life is a crime punishable by up to fourteen years in prison). Mr. O'Connor said the main argument against introducing a legal system of assisted dying was public safety, and on this ground it was "not a prudent step to make".<sup>50</sup> He said:

"It is very difficult to see how there could be sufficient safeguards to actually protect vulnerable people in New Zealand. And that's been the experience overseas as well. It probably comes down to the simple question of 'How many errors would Parliament be willing to accept in this space?'"<sup>51</sup>

The NZ Green Party health spokeswoman, Julie-Anne Genter, said the Committee could not reach a consensus on changing the law. The Green Party supports voluntary euthanasia, and Genter is quoted as saying that it was a consolation that the Committee did not make a formal recommendation against a law change.<sup>52</sup>

It has been argued in New Zealand that any change in law should be put to a referendum rather than a parliamentary vote (including a conscience vote).<sup>53</sup>

## Scotland

Changes to the law to allow assisted suicide have also been rejected in Scotland, with Bills being defeated in 2010 and 2015 (the most recent being the *Assisted*

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<sup>48</sup> Of the New Zealand National Party.

<sup>49</sup> Available [here](#).

<sup>50</sup> Cited in Davison, I (2017) '[Major inquiry on voluntary euthanasia does not recommend law change](#)', *New Zealand Herald*, 2 August 2017. [accessed 29/08/2017]

<sup>51</sup> Cited in Davison, I (2017) as before.

<sup>52</sup> Cited in Davison, I (2017) as before.

<sup>53</sup> New Zealand First political party cited in Davison, I (2017) '[Major inquiry on voluntary euthanasia does not recommend law change](#)', *New Zealand Herald*, 2 August 2017. [accessed 29/08/2017]

*Suicide (Scotland) Bill*). After debate, the motion to agree the general principles of this Bill was disagreed to by division: For 36, Against 82, Abstentions 0.<sup>54</sup>

The principal provisions of this Bill are outlined below.

#### **Box 5: Key provisions of the *Assisted Suicide (Scotland) Bill***

To be eligible to receive assistance to commit suicide under the Bill, an individual would require to:

- be diagnosed with an illness or progressive condition that was terminal or life-shortening;
- have come to the conclusion that his or her quality of life was unacceptable and that there was no prospect of any improvement;
- be aged 16 or over;
- be registered with a Scottish medical practice; and
- have the legal capacity to make such a decision.

The Bill did not specify what means of death would be available to an eligible individual but the accompanying documents to the Bill envisaged what would constitute “physician assisted suicide”, whereby a doctor would provide a prescription for a drug that would end the person's life painlessly. The Bill envisaged the cause of death being the result of the individual's own act and no-one else's.

**Source:** [Scottish Parliament Information Centre note.](#)

## **Debate**

It is clear that similar lines of reasoning regarding assisted dying are employed over time and in different jurisdictions. The arguments presented here are distilled from the very broad literature on this topic,<sup>55</sup> and the discussions of the Joint Committee on Justice and Equality on 22 and 29 November, 2017.

<sup>54</sup> Minutes of proceedings are available [here](#). Details of the Bill's background and progress can be found [here](#).

<sup>55</sup> There is an extensive literature on this topic in the fields of medicine, law, philosophy, theology etc. This paper seeks to summarise key arguments but does not explore this literature in depth.

## Arguments in favour of permitting assisted dying

There is some variation in arguments in favour of assisted dying in terms of what the proponent favours – some would argue for euthanasia as well as assisted suicide, and some would prefer more restrictive eligibility criteria than others. This variation is borne out in the differences between laws in jurisdictions that have introduced some form(s) of assisted dying (as discussed above).

Some of the key arguments put forward in favour of allowing assisted dying (in some form) are set out below.

### The importance of personal autonomy and choice

This is a key, common argument in favour of assisted dying. It contends that competent people, in certain conditions (with terminal illnesses or in great pain, for instance) should have the right to decide on the manner and timing of their death. Loss of dignity due to the inability to carry out daily functions as a result of advanced disability is also cited as a reason why people would choose to and be allowed to die. The importance of autonomy and patient-centred practice in other healthcare decisions and practice is cited as part of the context for the primacy of autonomy in end of life decisions. Such arguments support freedom of choice for individuals:

**"Having considered themselves autonomous, self-determining adults throughout their life, supporters [of physician-assisted suicide] believe that they should continue to be autonomous, self-determining adults at the end."**<sup>56</sup>

During the Committee debate on 22 November 2017, Deputy Clare Daly stated:

**"From a personal point of view the right to die at a time or in a manner of one's own choosing is something I found to be an incredibly compelling argument. The challenge for us is to balance that with any unintended consequences from legislation."**<sup>57</sup>

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<sup>56</sup> New Zealand Parliamentary Health Committee (2017), as before.

<sup>57</sup> [Official Report of The Justice and Equality Committee, 22 November 2017](#)

In her submission to the Committee, Professor Penney Lewis **of King's College London** cited empirical data from Oregon, which states that:

**"In every single year the most frequent reasons for requesting assistance are loss of autonomy, loss of dignity and a loss of ability to participate in the activities that made life worth living for that person. It is not about not receiving enough pain control, symptom alleviation or feeling like a burden on others. It tends to be about control, autonomy and dignity."**

Addressing the Committee on 29 November 2017, Dr. Louise Campbell, of the National University of Ireland Galway, stated:

**"Properly defined, autonomy refers to a person's interest in making and acting on choices of momentous significance in that person's life according to that person's most cherished values and beliefs. It is not just about having a range of choices and choosing between them."**

Dr. Campbell also discussed the perception that the regulation of assisted dying would reinforce negative attitudes towards disability, given that the predominant reasons for requesting assisted dying include loss of dignity, mobility and independence - impairments that those with chronic disabilities live with on a daily basis. Dr. Campbell felt that:

**"It is not the case that the person who is requesting assistance in dying on the grounds of the same functional impairments is making a value judgment about the life of a person with a disability. There are two separate ways of enacting autonomy."**

Dr. Campbell also referred to Baroness Hale's **comments in the** context of the 2009 Debbie Purdy case (see Box 3 above), where she stated:

**"If we are serious about protecting autonomy we have to accept that autonomous individuals have different views about what makes their lives worth living."**

### **The futility of suffering and the limits of palliative care**

It is contended that pain and suffering are useless and that people should not have to endure pain (or other severe suffering) when this could be ended. It is



also contended that there is moral good in helping someone in need. British journalist and retired nurse Andrew Heenan has made the point that some of the language used in these debates conceals what suffering means:

**“Poorly managed pain will inevitably lead to a wretched life, and the expression ‘poor quality of life’ is weasel words for the appalling reality experienced by many.”<sup>58</sup>**

Related to this are arguments that point out limitations in the effectiveness of palliative care. They highlight that despite good quality palliative care being available (in many places) it cannot relieve all pain. The Irish Council for Bioethics provides an estimate that in about 5% of cases, pain cannot be eased with palliative drug treatment.<sup>59</sup> It has been argued that:

**“The fear of protracted, painful, undignified death is very real for many people, whether or not they have been diagnosed with a terminal illness or condition. Despite all the advances in medical technology in recent years, and the high-quality palliative care that is available in many places, not everyone can be assured of a ‘good death’ in which pain is kept at bay and a reasonable quality of life is maintained until the end. For some, their final months or years are dominated by pain or discomfort and the inability to experience or enjoy those things that previously gave their life meaning and which most of us take for granted.”<sup>60</sup>**

The fact that pain and suffering are subjective concepts has also been raised. Addressing the Committee on 22 November 2017, Mr. Tom Curran of Right to Die Ireland stated:

**“While one can say a toothache is very difficult, it is only the individual who can decide, not what he or she is capable of, but what he or she is prepared to tolerate. What right have we to say to them that they should continue to live in that discomfort and pain past the point where they find it unacceptable?”**

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<sup>58</sup> Hennan, A (2014) ‘A nurse’s perspective on end of life care’, in Close L and Cartwright J (Eds.) *Assisted Dying – Who makes the final decision? The case for greater choice at the end of life*. London: Peter Owen Publishers.

<sup>59</sup> Irish Council for Bioethics (year unknown), as before.

<sup>60</sup> [Policy Memorandum](#) to the *Assisted Suicide (Scotland) Bill* (SP Bill 40) as introduced in the Scottish Parliament on 13 November 2013.

## **There is no moral distinction between some current end of life care and assisted dying**

Elements of this debate consider current end-of-life care and practices. One contention arising in this regard is that there is no moral significance to the distinction between acts (action taken to end life) and omissions (withholding/withdrawing care). It is also commonly raised in relation to the giving of drugs at the end of life for the purpose of relieving symptoms, but that have the effect of hastening death (this is known as **the** Principle of Double Effect (PDE)). It has been argued that:

**"there ... [is] no morally significant distinction between assisted suicide on the one hand and withholding or withdrawal of life-sustaining treatments and potentially life-shortening care on the other. Thus if the latter were permitted (as they are), then so too should be the former."**<sup>61</sup>

This was raised by Deputy Colm Brophy during the course of the hearing on 29 November 2017:

"The right of a patient to refuse treatment, which in a number of instances will lead to a more painful death, is an issue. Everybody has personal experiences and knowledge of such things. Medication for pain is a key part of palliative care for many people. The removal of that particular aspect would cause a person more pain and distress. If we respect the right to refuse treatment as an absolute, how is there not an automatic right to choice in such circumstances?"

## **Euthanasia or assisted suicide happens anyway and should be regulated**

In other jurisdictions, the argument has been made that doctors do purposely hasten death by deliberately administering higher doses of medication than necessary to dying patients in order to end their suffering. However, as this is illegal such practices are covert and unregulated – with no consistency, transparency or safeguards. This presents risks both for patients (being subject

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<sup>61</sup> View of Canadian legal-ethicist, Jocelyn Downie, presented in Storch, J (2011) 'Editorial comment', *Nursing Ethics*, 18 (6), 753-755.

to euthanasia against their wishes) and for doctors (who may jeopardise their reputations or risk imprisonment in order to do what they perceive to be in their **patient's best interests**).<sup>62</sup>

There is also evidence to suggest that people end their lives earlier than they would have preferred in jurisdictions where assisted dying is unregulated. Addressing the **Victorian Parliament's Legal and Social Issues Committee**, Caitlin English of the Coroner's Court in the Australian state of Victoria stated:

"These are people who are suffering from irreversible physical terminal decline or disease, and they are taking their lives in desperate, determined and violent ways."<sup>63</sup>

The **Victorian Parliament's Legal and Social Issues Committee** published its final report on its '[Inquiry into End of Life Choices](#)', and felt that:

"The evidence is conclusive that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying **does not.**"

However, it should be noted that concerns were raised by witnesses and Committee members regarding the adequacy of safeguards, particularly in cases of psychological illness. On 22 November 2017, Senator Frances Black stated:

"I have huge reservations about the psychological model in the whole area of assisted dying. No matter how rational one might be, depression is a kind of self-destruction. This aspect of the issue worries me."

Notwithstanding this, during the same hearing, Mr. Tom Curran of Right to Die Ireland was of the opinion that:

"No safeguards that we bring in are going to be perfect ... Just because something is illegal does not prevent people from doing it, just as making assisted dying illegal is not preventing people from doing it. People are doing it all the time. We need a more regulated

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<sup>62</sup> [Policy Memorandum](#) to the *Assisted Suicide (Scotland) Bill* (SP Bill 40), as before.

<sup>63</sup> Available [here](#).

basis on which they do it. There is more likely to be abuse in an unregulated situation than there is in a regulated situation.”

Similarly, Professor Penney Lewis of **King’s College London** advised:

“The evidence does not show that euthanasia is only practised in jurisdictions that have legalised it. This practice exists. The question is whether one wants to regulate it. The answer to that must be that it is certainly better to regulate it. That would be the way to avoid having people pressured or killed without valid requests. If we do that, at least then we bring the practice into the open, we will know what is happening and if there are people behaving outside the legal regime, we can deal with them appropriately.”

### **Some people travel to avail of assistance to end their lives – they should not have to do so**

Support for assisted dying closer to home may develop as it is known that some people travel abroad for this purpose. A well-known destination is Switzerland (where assisted suicide is permitted), with people travelling to gain the assistance of, for example, the Dignitas organisation.

In such a case, a person will need to be well enough to travel abroad and also be capable of taking the prescribed medicine themselves. As above, it has been argued that this results in people travelling sooner than they may wish (ideally) to end their lives, for fear of becoming incapable of doing so. As a result, they may shorten their lives unnecessarily.

Professor Penney Lewis offered the opinion to the Committee that:

“Exporting suicide to Switzerland is not fair, as it results in people either travelling earlier than they would have wished or being prevented from travelling because they are too unwell or do not have money to travel. It is expensive to have an assisted suicide at Dignitas. The figure that is most often circulated is approximately **€10,000** which is a significant burden for people approaching the end of life who may well have other financial difficulties.”

## **The ban on assisted suicide discriminates against people with disabilities**

This argument maintains that the law discriminates against people with disabilities because able-bodied people may be able to take their own lives but (some of) those with physical limitations cannot. This argument was rejected by the Supreme Court in the Marie Fleming legal case noted above.

## **Having the drug may be enough**

Terminally ill patients who wish to have control over their dying may be comforted by just having the medication available to them should they feel the need to end their own lives. Data from the US state of Oregon appear to support this theory, as many patients fill their prescription but do not take the medicine.<sup>64</sup>

The Committee also heard evidence to this effect in relation to Marie Fleming (see the Marie Fleming legal case noted above). Mr. Tom Curran of Right to Die Ireland, **Marie Fleming's** partner, informed the Committee that once Marie had the drugs in her possession, her whole demeanour brightened and she started to live again. Mr. Michael Nugent, also of Right to Die Ireland, spoke similarly of his late wife Anne:

"Anne died naturally, as do most people who make these preparations. It is not about the act of dying, it is about the peace of mind one has while one is still alive of knowing one can avoid unnecessary suffering at the end if one has to. Once we had made **those preparations, Anne's quality of life soared for its remainder.** She had a quality of life that she would not have had if she had not made those preparations."

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.

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<sup>64</sup> Buckley, T (2016) 'Physician Assisted Suicide - An End of Life Care option that should be available to all dying patients', Law School Student Scholarship. 943 (Seton Hall University).

Legislation would also provide for regulation of the drugs used. In Oregon, for example, each prescription and each resulting death must be reported to the Oregon Department of Human Services.

### **There is a lack of evidence to support the contention that vulnerable groups are endangered when legislation permitting assisted dying is enacted**

Available evidence suggests that vulnerable groups are not disproportionately endangered when assisted dying is permitted. In jurisdictions where assisted dying is regulated, those that avail of the practice tend to be white, educated and living with a diagnosis of terminal cancer. A study by Professor Margaret Battin et al found:

**"the available data ... shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges."**<sup>65</sup>

A 2016 study in the journal of Social Science and Medicine found euthanasia was:

**"performed** less often among the elderly, women, less-educated individuals and unmarried patients and [that] there was no clear evidence for a slippery slope."<sup>66</sup>

Empirical evidence also suggests that current end-of-life decisions to withdraw or withhold treatment are far more susceptible to abuse than assisted dying. On 22 November 2017, **Professor Penney Lewis of King's College London** informed the Committee that regardless of whether a jurisdiction has legislated for assisted dying, the proportion of end-of-life decisions that are to withhold or withdraw treatment far outweigh the proportion of cases of euthanasia, assisted suicide and termination of life without request. As such, the perceived threat that certain sections of society might feel pressure to end their lives prematurely

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<sup>65</sup> Battin M et al (2007). "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups ". *Journal of Medical Ethics* 33:591–597.

<sup>66</sup> Rietjens J et al (2012). "Medical end-of-life decisions: does its use differ in vulnerable patient groups? A systematic review and meta-analysis". *Social Science and Medicine* 74 (8): 1286. See also Dierickx et al (2016).

is far more likely to be an issue in terms of the much more prevalent end-of-life decision to withhold or withdraw treatment.

Reviewing evidence from the Netherlands and Oregon in *Carter v Canada*<sup>67</sup> (2012), Smith J found there was no evidence to support the claim that assisted dying posed a greater risk to socially vulnerable populations, stating:

“it is possible for a state to design a system that both permits some individuals to access physician-assisted death and socially protects **vulnerable individuals and groups.**”

In her submission to the Committee, Dr. Louise Campbell of the National University of Ireland Galway concurred with this view:

“The benefits of establishing a properly-regulated system of assisted dying with genuine oversight and robust safeguards outweigh the risk of harm to vulnerable persons. However, not until vast improvements are made in the provision and organisation of services to support those living with disability, mental illness or chronic physical conditions and in the provision of accessible, effective palliative care services should any legal changes be implemented.”

## Arguments against permitting assisted dying

Some of the key arguments put forward by those who oppose any form of assisted dying are set out below:

### Human life has innate value

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<sup>67</sup> *Carter v Canada (Attorney General)* [2012] BCSC 886 at 666-7. See also Battin M et al, as before.

This argument contends that it is not up to an individual or his or her doctor to decide when life should end. It holds that the fundamental social value of respect for life should be maintained, and killing is intrinsically wrong. While **proponents of assisted dying may argue for 'death with dignity'** those opposed respond that dignity may not be seen in this private, individualised way and cannot be lost through disease, disability, dependency or suffering. This is argued as follows:

**"Instead, human dignity is inherent – it is an irreducible, immeasurable and necessary quality that belongs equally to all members of humanity and can never be lost. Thus, any attempt to end the life of a person through euthanasia and assisted suicide would be a denial and violation of this kind of inherent dignity which is the basis of all civilised societies. It would also mean that there is such a thing as a life unworthy of life."**<sup>68</sup>

In his opening statement to the Committee on 29 November 2017, Professor **Desmond O'Neill of Trinity College Dublin, stated:**

**"I come back to dignity. It is about realising that people often talk about how undignified it is for a patient but it usually is how undignified the care setting is. Our role as sentient, aspirational human beings is to improve care."**

The contention is made that there is a line that must not be crossed (often referred to as a Rubicon) to allow for intentional killing. The argument goes that regardless of how sympathetic individual cases may be, by crossing such a line:

**"We could begin to erode the very foundation on which tolerance and care are based. We could be in danger also of changing the whole ethos of medicine and law....In other words, there are deep moral structures in our society with which we tamper at our peril."**<sup>69</sup>

The arguments about the innate value of human life are often made by those who hold religious beliefs, who may argue that it is wrong to interfere with the divine prerogative to determine the moment of death. However, many non-

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<sup>68</sup> MacKellar Calum (2011) [‘End of Life Assistance \(Scotland\) Bill heavily defeated as Scots count cost and reappraise ‘dignity’](#), *Christian Medical Fellowship News Review*.

<sup>69</sup> [Archbishop of York \(UK\) in evidence to the House of Lords Select Committee on Medical Ethics, 9 May 1994.](#)



religious people also oppose assisted dying on the same ground (value of human life). (There are also religious groups and notable people of faith who support assisted suicide.<sup>70</sup>)

### **Individual autonomy must be balanced with the implications for society**

Autonomy is rejected by opponents as a factor in favour of assisted dying for a **number of reasons including that it is in fact 'mere choice' and that individual autonomy must be balanced against the broader needs of society.** This view sees people in relation to others, and was articulated by Dr. Regina McQuillan of the Irish Association for Palliative Care during her appearance before the Committee on 22 November 2017:

"The IAPC recognises very much the patient idea of personal autonomy but we are aware that autonomy, as such, is qualified as we are all members of a society."

Deputy Jim **O'Callaghan** noted that legislators have an obligation to take into account the implications for society and the broader groups within it.

In evidence to a Scottish parliamentary committee on the subject, Dr. Stephen Hutchinson of Highland Hospital argued that:

**"We function as a relational and interdependent society....Therefore we need to look at choice with responsibility. To me, that puts a completely different emphasis on the issue, as it is then not about what the individual chooses and demands. That is part of the equation, but it has to be balanced with careful scrutiny of the implications for the rest of society and, in particular, the vast numbers of frail, vulnerable and frightened people whom we look after."**<sup>71</sup>

Addressing the House of Lords Select Committee on Medical Ethics, the Archbishop of York made the case that:

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<sup>70</sup> The United Universalist Church and Bishop Desmond Tutu, for example.

<sup>71</sup> Cited by Bob Dorris, MSP (Scottish National Party), in [first stage debate](#) of the *Assisted Suicide (Scotland) Bill* on 25 May 2015.

**"Autonomy cannot be absolute and, indeed, it would be morally self-destructive if it were. Freedom is always freedom within limits. To take moral responsibility for one's own life does not absolve one from a whole range of responsibilities towards other people. Even death is not a purely individual matter because others are affected by it, whether relatives, friends, medical staff or that abstraction, society as a whole, which in subtle ways, can be shaped by the manner of death of its members."**<sup>72</sup>

In the context of end-of-life care, the opening statement of Professor Desmond O'Neill of Trinity College Dublin **raised concerns regarding "an idealised version of unfettered autonomy"** that is not "embedded in a framework of care."

**Professor O'Neill's submission to the Committee also** argued that operating solely on the basis of personal choice and control ignores the interdependencies in care relations and the variable and partial character of actual human autonomy.<sup>73</sup> Similarly, a recent Irish paper raises concerns that:

"operating solely from a primacy of choice logic negates the interdependencies in care relations and assumes that all patients are independent and autonomous, even at moments of high vulnerability; there is a danger that those in end-of-life care are framed as abstracted rational choosers, ignoring that they are relational, emotional, and embodied human beings."<sup>74</sup>

### **De-valuation of the lives of people with disabilities, older people and other vulnerable groups**

It is argued that assisted dying has / would have a negative impact on the lives of those with disabilities. The rationale is that seeing (and the State endorsing) increased dependence or disability as a reason to die (for some) gives the message that the lives of people with a disability are less worthwhile than others, thereby exacerbating the social stigma surrounding disability.

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<sup>72</sup> [Archbishop of York \(UK\), as before.](#)

<sup>73</sup> O'Neill O. Paternalism and partial autonomy. *Journal of Medical Ethics*. 1984;10(4):173-178.

<sup>74</sup> Lolic L, Lynch K. No Choice without Care: Palliative Care as a Relational Matter, the Case of Ireland. *Soundings: An Interdisciplinary Journal*. 2017 Nov 1;100(4):353-74.

The US based campaign group 'Not Dead Yet' argues that:

**"Disability concerns are focused on the systemic implications of adding assisted suicide to the list of "medical treatment options" available to seriously ill and disabled people."**<sup>75</sup>

In the international literature, it is common for disability groups to campaign against laws or proposed laws allowing for assisted dying. However, such views are not universal amongst people with disabilities, with some disability activists in favour of allowing for assisted dying.<sup>76</sup>

The research for this paper has not identified disability organisations in Ireland campaigning on this issue. In Northern Ireland, Disability Action has taken a stance against a change in law to allow for assisted dying, stating:

**"Disability Action is opposed to the legalisation of assisted suicide. Whilst we believe that people should have a right to control in their lives, we believe that changing the law to benefit a small number of people would have much wider repercussions on how society values people with disabilities."**<sup>77</sup>

This position was affirmed when Disability Action (Northern Ireland) appeared before the Committee. The Irish Association for Palliative Care (IAPC) raised similar concerns.

This concern was also articulated by Professor Desmond O'Neill during his engagement with the Committee:

**"The worry here is not so much that we impact on the disabled and the vulnerable today but we set a matrix and a paradigm where their life is considered to be less worth living."**

### **Right to die may become a duty to die**

Allowing assisted dying may result in pressure on those in certain circumstances to choose death over continued care. It is argued that those who are eligible for assisted dying will feel a pressure to "choose" this to relieve the suffering of

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<sup>75</sup> See: <http://notdeadyet.org/assisted-suicide-talking-points>

<sup>76</sup> See, for instance, [Disabled Activists for Dignity in Dying](#), the UK-based advocacy group.

<sup>77</sup> See: <http://www.disabilityaction.org/fs/doc/publications/assisted-dying-position-paper.pdf>

others (e.g. family / friends) or to reduce healthcare costs, or for other external reasons. The IAPC has argued:

**"A cultural acceptance of euthanasia could lead to a dilution of the value of human life, resulting in people requesting euthanasia through being socialised into feeling that they are a burden on their families and on society."**<sup>78</sup>

The Methodist Church in Ireland has argued that changing the law is likely to result in major attitudinal shifts towards the terminally ill, and this would have negative consequences:

**"The effect on the feeling of worth in those where one of the options is PAS [physician assisted suicide] would be considerable. The fact that there is a right to die could easily be interpreted as a duty to die and...to allow choice is effectively to impose choice."**<sup>79</sup>

On 29 November 2017, Deputy Jim O'Callaghan questioned Professor Desmond O'Neill as to whether he felt the legalisation of assisted suicide would put pressure on older people, who may feel they have become a burden on their family, to choose to die. Professor O'Neill responded:

**"Yes, I think it would. It would be occult and very internalised. We must send a message to people with disability at any age that our impulse is to care – to cure sometimes, to relieve often and to comfort always."**

### **Doctors should not assist people to die**

This issue is focused on medical ethics and whether assisting people to die is outside the realm of health care, incompatible with a doctor's role and a distortion of the Hippocratic maxim of '*primum non nocere*' (first do no harm). The Committee heard that there are doctors who believe assisted suicide is ethically correct and those who do not.

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<sup>78</sup> Irish Association for Palliative Care (2011) Voluntary Euthanasia Discussion Paper.

<sup>79</sup> Methodist Church in Ireland (Undated) *Physician Assisted Suicide (PAS) paper with appendices*.

In his submission to the Committee, Professor Desmond O'Neill stated that doctors "killing patients short-circuits and undermines our impetus to care, comfort and support and damages our framework of care."

The World Medical Association (WMA) is opposed to assisted suicide and reiterated its opposition to assisted suicide in the wake of the recent legislative developments in the Australian state of Victoria.<sup>80</sup> The WMA believes the legislation is in:

**"direct conflict with physicians' ethical obligations to patients and will harm the 'ethical tone' of the profession."**

The position of the Scottish Council on Bioethics is that:

**"Crossing the boundary between acknowledging that death is inevitable and taking active steps to bring about death, with intent, fundamentally changes the role of the physician, changes the doctor-patient relationship and changes the role of medicine in society.**

Some physicians may become hardened to death and to causing death, particularly when patients are old, terminally ill, or disabled. Legalising assisted suicide would give persons, such as physicians, power that could be too easily abused, and a responsibility that they should not be permitted to have. It is not up to physicians to decide whether a life is happy or unhappy and worthwhile or not. If this happened they could become the most dangerous persons in a country. In very rare cases, physicians such as Harold Shipman<sup>81</sup> may actually feel empowered in being able to provoke death.

In the light of these cases, many vulnerable groups of people may begin to mistrust the real intentions of their doctors."<sup>82</sup>

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<sup>80</sup> See: <https://www.wma.net/news-post/world-medical-association-reiterates-strong-opposition-to-physician-assisted-suicide-and-to-australian-bill/>

<sup>81</sup> Dr Harold Shipman (b.1946-d.2004) was a British doctor and serial killer who murdered at least 215 of his patients. His crimes raised troubling questions about the powers and responsibilities of the medical community in Britain and about the adequacy of procedures for certifying sudden death. Source: [Encyclopaedia Britannica](#).

<sup>82</sup> Scottish Council on Bioethics (2017), [Position Statement of Assisted Suicide](#).

## The importance of intent

The issue of intent in relation to end-of-life care is an important element of this debate. Although the aim in both cases is to relieve suffering, it is argued that there is a very significant moral difference between issuing medicine intended to relieve symptoms (e.g. pain, distress) that has the result of hastening death and taking an action to deliberately end a life.

As above, proponents of assisted suicide argue that the practice is already in effect in palliative care whereby doctors administer painkillers in the knowledge that doing so **will lead to their patient's death. However,** the Irish Association for Palliative Care draws a clear distinction between this practice and administering **a drug with the express intention of ending a patient's life.**

The IAPC defines the Principle of Double Effect<sup>83</sup>. It states that where an action, intended to have a good effect, can achieve this effect only at the risk of producing a harmful effect, then the action is ethically permissible provided that:

- i. The action is good in itself;
- ii. The intention is solely to produce the good effect;
- iii. The good effect is not achieved through the harmful effect;
- iv. There is sufficient reason to permit the harmful effect.

As such, while the administration of painkillers may hasten death in certain circumstances, the intent is never to hasten death. The intent is solely to alleviate pain with the consent of the patient.

## The 'slippery slope' - allowing assisted dying, even in a very restricted way, will open the door to a more permissive regime in time

A common argument made in this area is that even a legal framework that permitted assisted dying in very limited circumstances would come under pressure to allow more and more people to become eligible by allowing for assisted death in more conditions / circumstances. Such pressures and resultant changes - broadening the circumstances in which assisted dying may be permitted - **is known as the 'slippery slope' argument.**

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<sup>83</sup> Available [here](#).

For instance, allowing competent adults to access assisted suicide could lead to changes in the law with respect to minors or those unable to make decisions for themselves for a variety of reasons, including mental illness or lack of consciousness. The slippery slope argument poses the question:

**"If we take a particular decision, even if it is a good decision, we need to ask: is it likely to lead to another decision which we would not desire or think is good?"<sup>84</sup>**

Deputy Jack Chambers referenced the expansion of the Netherlands and Belgium's regimes to minors. In certain circumstances, assisted suicide is also available to those with non-terminal psychological conditions.

### **May undermine palliative care**

Legislation to permit assisted dying could undermine the need to properly resource and recognise the importance of palliative care, as advocating assisted suicide or euthanasia would be **"quicker and easier"** than developing palliative care. It has been argued that:

**"If PAS [physician assisted suicide] were available, the motivation to provide good terminal care could be undermined."<sup>85</sup>**

Dr. Louise Campbell's submission to the Committee also acknowledged the concerns that **"legalisation of assisted dying has the potential to inhibit the development of palliative care provision and undermine the culture of palliative care."**<sup>86</sup>

Dr. Regina McQuillan raised similar concerns:

**"We do not currently have equitable access to palliative care, disability services, psychiatric or psychological support services and my concern and that of many working in health care is that to move in the direction of euthanasia would be to move away from investment in the appropriate services."**

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<sup>84</sup> McCarthy, J et al (2011) *End of life care – Ethics and Law*. Cork: Cork University Press. p. 216.

<sup>85</sup> Methodist Church in Ireland (Undated) *Physician Assisted Suicide (PAS) paper with appendices*.

<sup>86</sup> Madersvedt LJ et al (2003). "Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force". *Palliative Medicine* 17: 99.

The Committee heard that palliative care providers believe that timely, effective and accessible palliative care support can reduce or eliminate demand for assisted dying. **It has also been argued that a better response to people's fear of pain and hospitalisation is improved palliative care.**<sup>87</sup>

Multiple Sclerosis (MS) Ireland has sought better resources for palliative care, stating:

**"At present, regional discrepancies exist in the provision of palliative care services and this issue must be addressed by the HSE and the Department of Health."**<sup>88</sup>

There is, however, evidence to demonstrate the potential for increased support for palliative care when assisted dying is legalised. In Belgium, the law decriminalising euthanasia was accompanied by a law which made palliative care a basic right of all patients. Between 2003 and 2010, funding for palliative care services in Belgium increased by 108%, in contrast with an increase of only 2.34% in total health expenditure.<sup>89</sup>

Similarly, the Australian state of Victoria's recent assisted dying legislation will coincide with a \$62 million funding package<sup>90</sup>, which addresses a number of comparable gaps in care identified by The Irish Longitudinal Study on Ageing (TILDA) report – published in October 2017 - on *The end of life experience of older adults in Ireland*.<sup>91</sup>

Regardless of the legislative position regarding assisted dying, the need to ensure the provision of holistic palliative care was raised and acknowledged during the Committee debates.

### **Potential negative impact on broader suicide prevention**

This argument is based on the belief that regulating assisted suicide could undermine societal efforts to reduce suicide more generally. It is contended that

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<sup>87</sup> Baroness McFarlane of Landuff, in [House of Lords debate of the report of the Select Committee on Medical Ethics, 9 May 1994](#).

<sup>88</sup> MS Ireland (2017) [Treatment and Care Decisions in Advanced Multiple Sclerosis \(MS\) - Briefing Document and Position Paper](#). Dublin: MS Ireland.

<sup>89</sup> Chambaere K and Berhneim JL (2015). "Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience". *Journal of Medical Ethics* 41: 658.

<sup>90</sup> Source: Media release 16/11/2017; '[Palliative Care Boost To Support Terminally Ill Victorians](#)'

<sup>91</sup> Source: <http://tilda.tcd.ie/news-events/2017/1719-end-of-life-report/>



the message portrayed in legalising some forms of suicide (albeit in limited circumstances) would damage other efforts to prevent people taking their own lives. Essentially, legalising assisted suicide could be seen as State endorsement of suicide and make suicide more culturally acceptable.

"That there might be two forms of suicide – one which is clearly upsetting and worthy of strenuous societal efforts to prevent, and one which might be tolerated and given the support and protection of law – is a deeply challenging and contradictory premise."<sup>92</sup>

In his evidence to the Committee, Professor Desmond O'Neill felt that a differentiation cannot be made:

"One of the key issues in this debate is an artificial and inappropriate attempt to divide out two forms of suicide."

### **The availability of advance care planning**

An Advance Healthcare Directive, sometimes known as a 'living will', is a statement about the type and extent of medical or surgical treatment you want in the future, on the assumption that you will not be able to make that decision at the relevant time.<sup>93</sup> In Ireland, it is provided for in the Assisted Decision-Making (Capacity) Act 2015.<sup>94</sup>

Advance Healthcare Directives allow people to direct that treatment to prolong life is not given in certain circumstances. Advance care planning is an important element of end-of-life care that focuses on the values, beliefs and preferences of people, placing their voice at the centre of their care. It has been argued that advance care planning can help people avoid deaths that might be considered to be traumatic or lack dignity (such as attempting CPR in certain circumstances).<sup>95</sup>

Dr. Regina McQuillan of the Irish Association for Palliative Care (IAPC) informed the Committee that the IAPC is working to ensure its members have the appropriate education and training to assist patients in this respect.

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<sup>92</sup> O'Neill DJ. Matters arising from The BMJ's stance on assisted dying. BMJ 2015; 351: h4883.

<sup>93</sup> Source:

[http://www.citizensinformation.ie/en/health/legal\\_matters\\_and\\_health/advance\\_care\\_directives.html](http://www.citizensinformation.ie/en/health/legal_matters_and_health/advance_care_directives.html) .

<sup>94</sup> <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>

<sup>95</sup> National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 12

The Act also provides for the establishment of the Decision Support Service (DSS) within the Mental Health Commission. The DSS will facilitate the implementation of many of the provisions of the Act. It will support decision-making by and for adults with capacity difficulties and regulate individuals who are providing support to people with capacity difficulties. Work is underway to make the Service fully operational.<sup>96</sup>

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<sup>96</sup> <http://www.mhcirl.ie/DSS/>

## Recommendations

During the course of the hearings, the Committee did not achieve a clear consensus as to whether legislative change is justified. Therefore, the Committee is not in a position to recommend legislative change at this time.

However, based upon the hearings and broader consideration of related issues, the Committee believes serious consideration should be given to the following recommendations:

1. The Committee urges the Houses of the Oireachtas to consider referring the **issue** to the **Citizens' Assembly** for deliberation.<sup>97</sup> Assisted dying is an important and recurring topic that would benefit from a detailed consideration of the issues by a representative sample of citizens. The issue could then be referred to a Special Oireachtas Committee for further consideration. Given the gravity of the debate, it warrants as rigorous an examination as possible;
2. The Committee recommends that the Minister for Health publicise the importance of Advance Healthcare Directives (provided for in the Assisted Decision-Making (Capacity) Act 2015).<sup>98</sup> The Committee is of the opinion that those suffering from life-limiting illnesses should always be made aware of their right to make an advance care plan;
3. The Committee recommends that review of Government policy on palliative care - which will be undertaken as part of the *Palliative Care Services Three Year Development Framework (2017 to 2019)* - is cognisant of the findings of The Irish Longitudinal Study on Ageing (TILDA) report on *The end of life experience of older adults in Ireland*. Published in October 2017, the report is based on data from 375 completed end-of-life interviews;<sup>99</sup>

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<sup>97</sup> Dáil Éireann's Resolution approving establishment of the Citizens' Assembly includes a provision allowing for matters additional to those specified in the resolution to be referred to the Citizens' Assembly. Source: <https://www.citizensassembly.ie/en/About-the-Citizens-Assembly/Resolution.pdf>

<sup>98</sup> <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>

<sup>99</sup> Source: <http://tilda.tcd.ie/news-events/2017/1719-end-of-life-report/> .

4. The Committee is of the opinion that assisted dying should never be contemplated due to inadequate or insufficient supports or as a substitute for a holistic framework of care. The Committee supports the recommendations contained in the *Palliative Care Services Three Year Development Framework (2017 to 2019)* and urges the Minister for Health to ensure the recommendations are implemented in full;
5. Regional discrepancies in the provision of palliative care - as identified above by MS Ireland - should be addressed as soon as possible. The Committee welcomes the fact that the *Palliative Care Services Three Year Development Framework (2017 to 2019)* acknowledges the regional variations and states that “new development projects rectifying the infrastructural deficits are at an advanced stage, and will be delivered during the lifetime of this Framework”.<sup>100</sup>

The Committee recommends that the delivery of the new projects is prioritised to ensure regional discrepancies in the provision of palliative care are addressed as soon as possible;

6. As part of ensuring a holistic framework of care, the Committee emphasises the importance of ensuring care and support encompasses vulnerable groups including the disabled and those suffering from mental illness or chronic physical conditions. The need to widen palliative care provision to vulnerable groups is recognised in the *Palliative Care Services Three Year Development Framework (2017 to 2019)*.<sup>101</sup> Without appropriate care and the support to live as independently as possible, life for those living with such conditions can become particularly difficult;
7. Should the legislature consider the legalisation of some form of assisted dying in the future, it should be able to answer the following questions:

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<sup>100</sup> Source: [Palliative Care Services Three Year Development Framework \(2017 to 2019\)](#) p.34.  
<sup>101</sup> [Palliative Care Services Three Year Development Framework \(2017 to 2019\)](#) p.14.

- i. What criteria would render an individual eligible for such assistance?
- ii. What form would this assistance take and what would the role of the doctor be?
- iii. What due care criteria should be put in place (monitoring processes, mandatory reporting requirements, etc.)?
- iv. Could adequate safeguards be put in place to ensure that persons requesting such assistance are not doing so out of compulsion or because their decision-making capacity is compromised by illness, anxiety or depression?
- v. Could palliative care provision be enhanced to ensure that individuals making requests for assistance in dying have adequate access to such services?
- vi. Could supports for persons with disabilities be enhanced to reduce the likelihood that individuals will request assistance in dying because other supports are lacking?
- vii. Could trust in the medical profession be maintained in a healthcare context in which medicine facilitates the wish of certain patients to hasten death?

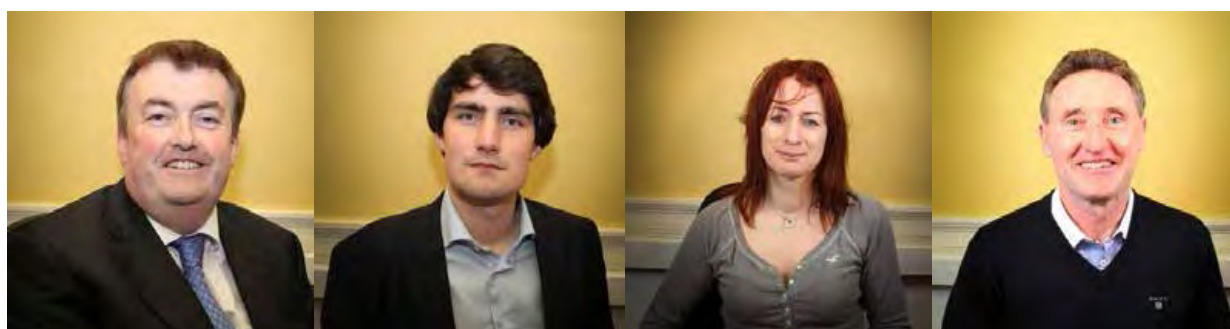
## Appendix 1 – Committee Membership

### Joint Committee on Justice and Equality

#### Deputies



Caoimhghín Ó Caoláin TD  
(SF) [Chair]

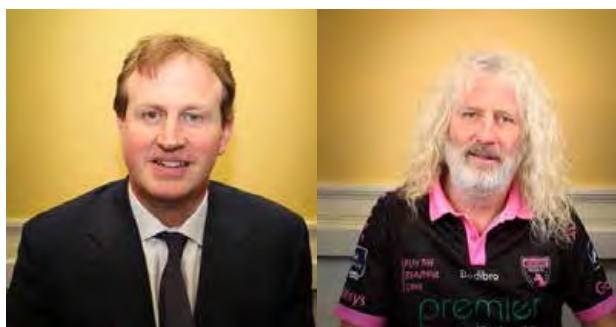


Colm Brophy TD  
(FG)

Jack Chambers TD  
(FF)

Clare Daly TD  
(I4C)

Peter Fitzpatrick  
TD  
(FG)



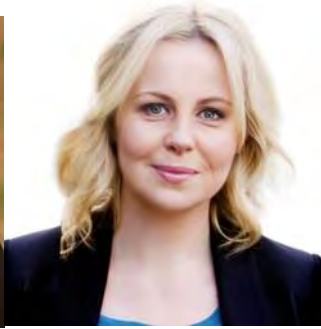
Jim  
TD  
(FF)

O'Callaghan Mick Wallace TD  
(I4C)

## Senators



Frances Black  
(CEG)



Lorraine Clifford-Lee  
(FF)



Martin Conway  
(FG)



Niall Ó Donnghaile  
(SF)

### Notes:

1. Deputies nominated by the Dáil Committee of Selection and appointed by Order of the Dáil on 16th June 2016.
2. Senators nominated by the Seanad Committee of Selection and appointed by Order of the Seanad on 20<sup>th</sup> July 2016.

## Appendix 2 – Terms of Reference of Committee

### JOINT COMMITTEE ON JUSTICE AND EQUALITY

#### TERMS OF REFERENCE

#### **a. Functions of the Committee – derived from Standing Orders [DSO 84A; SSO 70A]**

(1) The Select Committee shall consider and report to the Dáil on—

- (a) such aspects of the expenditure, administration and policy of a Government Department or Departments and associated public bodies as the Committee may select, and
- (b) European Union matters within the remit of the relevant Department or Departments.

(2) The Select Committee appointed pursuant to this Standing Order may be joined with a Select Committee appointed by Seanad Éireann for the purposes of the functions set out in this Standing Order, other than at paragraph (3), and to report thereon to both Houses of the Oireachtas.

(3) Without prejudice to the generality of paragraph (1), the Select Committee appointed pursuant to this Standing Order shall consider, in respect of the relevant Department or Departments, such—

- (a) Bills,
- (b) proposals contained in any motion, including any motion within the meaning of Standing Order 187,
- (c) Estimates for Public Services, and
- (d) other matters

as shall be referred to the Select Committee by the Dáil, and

- (e) Annual Output Statements including performance, efficiency and



effectiveness in the use of public monies, and

(f) such Value for Money and Policy Reviews as the Select Committee may select.

(4) The Joint Committee may consider the following matters in respect of the relevant Department or Departments and associated public bodies:

(a) matters of policy and governance for which the Minister is officially responsible,

(b) public affairs administered by the Department,

(c) policy issues arising from Value for Money and Policy Reviews conducted or commissioned by the Department,

(d) Government policy and governance in respect of bodies under the aegis of the Department,

(e) policy and governance issues concerning bodies which are partly or wholly funded by the State or which are established or appointed by a member of the Government or the Oireachtas,

(f) the general scheme or draft heads of any Bill,

(g) any post-enactment report laid before either House or both Houses by a member of the Government or Minister of State on any Bill enacted by the Houses of the Oireachtas,

(h) statutory instruments, including those laid or laid in draft before either House or both Houses and those made under the European Communities Acts 1972 to 2009,

(i) strategy statements laid before either or both Houses of the Oireachtas pursuant to the Public Service Management Act 1997,

(j) annual reports or annual reports and accounts, required by law, and laid before either or both Houses of the Oireachtas, of the Department or bodies referred to in subparagraphs (d) and (e) and the overall performance and operational results, statements of strategy and corporate plans of such bodies, and

(k) such other matters as may be referred to it by the Dáil from time to

time.

(5) Without prejudice to the generality of paragraph (1), the Joint Committee appointed pursuant to this Standing Order shall consider, in respect of the relevant Department or Departments—

(a) EU draft legislative acts standing referred to the Select Committee under Standing Order 114, including the compliance of such acts with the principle of subsidiarity,

(b) other proposals for EU legislation and related policy issues, including programmes and guidelines prepared by the European Commission as a basis of possible legislative action,

(c) non-legislative documents published by any EU institution in relation to EU policy matters, and

(d) matters listed for consideration on the agenda for meetings of the relevant EU Council of Ministers and the outcome of such meetings.

(6) Where a Select Committee appointed pursuant to this Standing Order has been joined with a Select Committee appointed by Seanad Éireann, the Chairman of the Dáil Select Committee shall also be the Chairman of the Joint Committee.

(7) The following may attend meetings of the Select or Joint Committee appointed pursuant to this Standing Order, for the purposes of the functions set out in paragraph (5) and may take part in proceedings without having a right to vote or to move motions and amendments:

(a) Members of the European Parliament elected from constituencies in Ireland, including Northern Ireland,

(b) Members of the Irish delegation to the Parliamentary Assembly of the Council of Europe, and

(c) at the invitation of the Committee, other Members of the European Parliament.

**b. Scope and Context of Activities of Committees (as derived from Standing Orders) [DSO 84; SSO 70]**

- (1) The Joint Committee may only consider such matters, engage in such activities, exercise such powers and discharge such functions as are specifically authorised under its orders of reference and under Standing Orders; and
- (2) Such matters, activities, powers and functions shall be relevant to, and shall arise only in the context of, the preparation of a report to the Dáil and/or Seanad.
- (3) The Joint Committee shall not consider any matter which is being considered, or of which notice has been given of a proposal to consider, by the Committee of Public Accounts pursuant to Standing Order 186 and/or the Comptroller and Auditor General (Amendment) Act 1993; and
- (4) any matter which is being considered, or of which notice has been given of a proposal to consider, by the Joint Committee on Public Petitions in the exercise of its functions under Standing Orders [DSO 111A and SSO 104A].
- (5) The Joint Committee shall refrain from inquiring into in public session or publishing confidential information regarding any matter if so requested, for stated reasons given in writing, by—
  - (a) a member of the Government or a Minister of State, or
  - (b) the principal office-holder of a body under the aegis of a Department or which is partly or wholly funded by the State or established or appointed by a member of the Government or by the Oireachtas:

Provided that the Chairman may appeal any such request made to the Ceann Comhairle / Cathaoirleach whose decision shall be final.
- (6) It shall be an instruction to all Select Committees to which Bills are referred that they shall ensure that not more than two Select Committees shall meet to consider a Bill on any given day, unless the Dáil, after due notice given by the Chairman of the Select Committee, waives this instruction on motion made by the Taoiseach pursuant to Dáil Standing Order 28. The Chairmen of Select Committees shall have responsibility for compliance with this instruction.

## Appendix 3 – Witnesses and Official Report

### 22 November 2017

- Irish Association for Palliative Care (IAPC)
  - Dr. Regina McQuillan
- Right to Die Ireland
  - Mr. Tom Curran
  - Mr. Michael Nugent
- King's College London
  - Professor Penney Lewis

[Official report](#)

### 29 November 2017

- Disability Action (Northern Ireland)
  - Ms Karen Hall
- Trinity College Dublin and Tallaght Hospital
  - **Professor Desmond O'Neill**
- National University of Ireland Galway and Clinical Ethics Ireland
  - Dr. Louise Campbell

[Official report](#)

## Appendix 4 - Opening Statements

Submission to Justice Committee by Tom Curran 22/11/2017

“Some people want to eke out every second of life, no matter how grim

And that is their right.

Some people don’t

And that should be their right”

This is a quote from an American Journalist called Betty Rolland from the 1990’s after she was diagnosed with incurable cancer. To me this sums up what the Right to Die is all about. It’s about choice. It’s about the ability to make decisions about your own end of life situation to possibly avoid a prolonged, painful and distressing death. It is commonly accepted that people have the right to live their life as they choose, providing they don’t do anyone else harm so why should a person not have the right to make decisions about the manner of their own death.

Most people that I know around the world who are involved in the Right to Die Movement are involved from some personal experience. They have either witnessed someone they love go through a bad death or they themselves or someone they love are facing the prospect of a bad death. I am no exception to this rule.

The person I loved, Marie, suffered from MS and, many years ago, when her MS moved from relapsing remitting to progressive and she saw the it was taking more and more control of her life and her ability to live she decided that the MS was not going to take control of her death. She knew that she faced to likelihood of a prolonged and possibly painful death and she, as the strong-willed person she was, she was not prepared to let that happen. Marie didn’t want to die. Far from it. Marie wanted to live, she was never suicidal, but she didn’t want a bad death. When she explained her wish to me it seemed a very natural this to want. It was only then we discovered that what she wanted was, by no means, easy to

achieve. As I had done voluntary work in suicide prevention for many years so I was aware that suicide had been decriminalised in the early 90's in Ireland. This meant that taking her own life was not an issue. The problem was how to provide a peaceful and painless death for yourself. Most of the irrational suicides that take place are performed in some horrific manner but that would completely defeat the purpose of what Marie wanted to achieve which brings up the question that if it is legal for rational person to take their own life why is assisting a person to do something that is legal a crime or why is assistance necessary. I can't answer the first question of why assisting someone to do something that is legal is itself a crime but the second of why assistance is required can be answered.

There are two basic reasons why assistance is necessary. The first is to do with the method of providing a peaceful, painless death for yourself. This is not as easy as it may seem. There is almost nothing sold anywhere today that will achieve that aim. Of course there are lots of substances that will kill but not peacefully and painlessly. Any substance that will provide that is almost exclusively in the hands of the medical profession but providing these substance would be classified as assisting a suicide and is therefore breaking the law. The second reason is that in most cases the reason for making the decision to die is because the person is suffering from some progressive and possible incurable disease which will eventually make it physical impossible for them to end their own life. To deny a person in these circumstances access to something that is legal and available to any able-bodied person has to amount to discrimination.

Let me at this point try to explain why the issue of the Right to Die has recently become an issue around the world. The first reason is the advancement of medical science. This advancement has brought with it the fact that, in most parts of the world, people are living to much greater ages that could have been imagined many years ago. But this brings with it it's own problems. With people living longer comes the likelihood that they will spend the final years of their life suffering for some disabling illness which will usually mean that the final years of their lives will be far from comfortable. This is coupled with the fact that in the early to mid twentieth century people started to think for themselves, the civil rights movement sprung up around the world and people were looking for personal freedom in lots of areas. The Right to Die is one of these, where people

decided that death, which used to be a very family affair, had now become a medical procedure. This is borne out here in Ireland where over 80% of people wish to die at home but less than 20% do. In fact over 50% of people in Ireland die in acute hospitals and in lots of cases in multiple bed wards. This has made the whole process of dying clinical and not the celebration of a life lived as it used be. This situation made people question why they themselves had very little say in the way they died and so the Right to Die movement started around the world. This has resulted in a slow but progressive acceptance that rational people should have the decision making powers on how they die. There are the usual arguments against allowing a person decide for themselves. They range from religion, to the danger to vulnerable people to the co-operation of the medical profession. These arguments are easily countered.

Getting back to the situation here in Ireland, you are probable aware that Marie and I took a constitutional challenge to the law on assisted suicide. Some very interesting points were made in the summing up in the High Court. Let me outline a few of them here.

Apart from stating that Marie was one on the most remarkable witnesses to ever come before the court they upheld the fact that Marie was being discriminated against by her MS preventing her having access to something that any rational able-bodied person has. To right this wrong the only option that the High Court has is to declare the law which allows this discrimination is un-constitutional and the law has to be struck out. It is not in their powers to amend a law. They stated that on a proportionality basis they were not prepared to do this as that without any law vulnerable people would be open the abuse. I agree completely with this decision but hey followed up by stating that there is nothing preventing the Oireachtas from enacting a law which would allow for assisted dying for people like Mare and at the same time protect the vulnerable. None of the parties have had the courage to tackle this and the closest we have got is the presentation of a private members Bill, which was drafted by myself with the help of four barristers, by John Halligan. This bill has since been withdrawn so we are no closer to providing this civil right to people that we were then.

The other interesting point of come out of the High Court was the statement in the summing up that if the court could provide a a law specifically for Marie they

would. To me this was an extraordinary statement to make. What they were saying is that they felt that Maire satisfied whatever criteria they would see as necessary to be allowed an assisted death. While to me Marie was an exceptional person, there was nothing exceptional is what she was asking for and certainly nothing that would suggest that other people would not satisfy the same criteria.

Why, therefore, have we still got the situation that if Marie can satisfy the highest court in Ireland that she should qualify for an assisted death that this right is still denied to others.



## **Opening Statement to Joint Oireachtas Committee on Justice and Equality from the Irish Association for Palliative Care**

**Good morning Chairman and members of the Committee.**

Thank you for inviting the Irish Association for Palliative Care to this meeting. The IAPC is an organisation of healthcare professionals involved in the delivery of palliative care across the country, and a collective and expert voice driving patient-centred, equitable and accessible palliative care for all who need it, and I am here to present the views of the IAPC on this issue.

Palliative Care is defined by the World Health Organisation (2002)<sup>1</sup> as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative Care seeks at all times to respect the integrity, individuality and unique worth of each person regardless of his/her ability or functional status. Palliative care affirms life and regards dying as a normal process and as a key principle intends neither to hasten nor postpone death.

Palliative care in Ireland is provided by healthcare professionals who care for people with life-limiting illnesses; this is provided by GPs, nursing home staff and hospital staff, for example oncologists and geriatricians, and by specialist palliative care staff, who care for people with complex problems related to life-limiting illness. The IAPC recognizes that palliative care should be provided on the basis of need, and not on the basis of diagnosis or prognosis.

The IAPC supports the work of the National Clinical Programme for Palliative Care. The IAPC welcomes the recent launch by Minister Simon Harris of the Palliative Care Three Year Development Framework<sup>2</sup>.

The IAPC works to support healthcare staff who want to help people with life-limiting illness live with and die with dignity. The IAPC rejects the idea that 'dying with dignity' is associated with the right to assisted suicide or euthanasia.

### **A Patient's Right to Choose Treatment**

One of the arguments advanced in favour of assisted suicide or euthanasia is a patient's concern that he/she will be subjected to treatments that are inappropriate, troublesome or futile. The IAPC recognizes that people have life-limiting illnesses, and regards dying as a natural process. Palliative care emphasises good communication between patients, those who matter to them and healthcare professionals. The IAPC endorses the right of a competent, informed patient to refuse medical treatment. We also recognize the right of a patient to make an

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<sup>1</sup> WHO definition of Palliative Care - <http://www.who.int/cancer/palliative/definition/en/>

<sup>2</sup> HSE Palliative Care Three Year Development Framework  
<http://hse.ie/eng/services/publications/Clinical-Strategy-and-Programmes/palliative-care-services-development-framework.pdf>

advance healthcare plan and for that plan to be respected in line with the HSE consent policy<sup>3</sup> and the Medical Council Guidelines<sup>4</sup>. In situations where no advance healthcare directive exists, the health care professionals are obliged to act in good faith, and on behalf of the patient, considering the patient's best interest. As all parts of the Assisted Decision-Making Act are commenced, the IAPC will work to ensure its members are well informed and able to support patients.

### **Treatment of Symptoms and other causes of distress**

Treatment of pain and other physical symptoms is a cornerstone of palliative care; symptoms can always be treated, and either reduced or eliminated. This requires input from all members of the multidisciplinary team, and specialists in other disciplines, for example radiotherapy. We recognise that for a variety of reasons, a patient in the final days and hours of life may experience restlessness and agitation, or may have other intractable symptoms. On occasion, it is necessary to use sedative medication in the final stages of life in order to achieve an acceptable level of patient comfort<sup>5</sup>. Treatment is appropriate when the intention of treatment is patient comfort, the harmful effects of treatment are foreseen but are not intended, and the benefits of treatment outweigh the burdens for the patient. Both the Medical Council of Ireland<sup>6</sup> and the Nursing and Midwifery Board of Ireland guidelines<sup>7</sup> state that when death is imminent it is the professionals' responsibility to ensure that the patient dies with dignity.

The IAPC is aware that there needs to be greater awareness among the public and healthcare staff about the value of palliative care, and greater education and training for healthcare staff to ensure that all staff meet the appropriate Palliative Care Competences developed by the National Clinical Programme for Palliative Care<sup>8</sup>.

There are areas within palliative care which need development, for example research into the best management of breathlessness and provision of advice and support outside regular working hours. These are among the top ten priorities for palliative care research identified by the All Ireland Institute for Hospice and Palliative Care<sup>9</sup>. The acceptance of assisted suicide and euthanasia could lead to an under investment in palliative care research and service delivery, as assisted suicide and euthanasia may be promoted as cheaper options than appropriate health care provision.

### **Personal Autonomy and Society**

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<sup>3</sup> HSE Consent Policy [http://www.hse.ie/eng/services/list/3/nas/news/National\\_Consent\\_Policy.pdf](http://www.hse.ie/eng/services/list/3/nas/news/National_Consent_Policy.pdf)

<sup>4</sup> Medical Council Guide to Professional Conduct and Ethics for Registered Medical Practitioners 7th Edition 2009.

<sup>5</sup> IAPC Position Paper: Palliative Sedation 2011.

<sup>6</sup> Medical Council Guide to Professional Conduct and Ethics for Registered Medical Practitioners 7th Edition 2009.

<sup>7</sup> The Code of Professional Conduct for each nurse and midwife. An Bord Altranais 2000

<sup>8</sup> HSE Palliative Care Competence Framework

<http://lenus.ie/hse/bitstream/10147/322310/1/CompetenceFrameworkFinalVersion.pdf>

<sup>9</sup> AIHPC Top 10 Palliative Care Research Priorities <http://aiihpc.org/research/launch-of-top-10-palliative-care-research-priorities/top-10-palliative-care-research-priorities-list/>

Healthcare professionals have a duty to provide care which respects the values and wishes of patients, and which aims to enhance the patient's personal autonomy and sense of self-worth. For some patients the availability of high quality palliative care will seem to have no relevance. For some, assisted suicide or euthanasia may be considered an expression of personal autonomy. However, individual autonomy is not absolute: it must be balanced with consideration of the needs of society as a whole. The legislation of assisted suicide or euthanasia may put pressure on vulnerable people, including, to quote from a recent High Court case 'the aged, the disabled, the poor, the unwanted, the rejected, the lonely, the impulsive, the financially compromised and the emotionally vulnerable' who may elect to hasten death so as to avoid a sense of being a burden on family and society.

Changing the law to allow assisted suicide and euthanasia will endanger the lives of many. Despite suggestions that abuse of this type of legislation can be prevented, there is evidence even with laws and regulations, many vulnerable people are at risk currently. Last year, the HSE received close to 8,000 reports of abuse of vulnerable people. The National Safeguarding Committee published research earlier this year, revealing that half of the population had witnessed abuse of an adult; 38% believed vulnerable people were badly treated<sup>10</sup>. Given the current problems in society in relation to protecting vulnerable people, it may not prudent to assume vulnerable people can be protected in the context of assisted suicide and euthanasia. Recent research published in the British Medical Journal has shown failures in the Dutch regulatory system. Concerns have been expressed by the Swiss Medical Association about offering euthanasia to those who are not terminally ill. In Belgium, there is conflict among medical professionals about the practice of a psychiatrist who is offering euthanasia to people with significant psychiatric problems, while undermining the second opinion system required in that country.

A recent study has highlighted gender issues in assisted suicide; women are more likely to live longer with greater disability; they are more likely to have less social support, more likely to die because of euthanasia or assisted suicide, and also are more likely to be a victim of 'mercy killing' by a male family member in cases which have come to the criminal courts in different countries.

An argument sometimes used in support of a change of legislation in relation to assisted suicide is the fact that suicide is not illegal. However, the decriminalization of suicide was a recognition that those who survive a suicide attempt need treatment, not prosecution. Suicide is rightly considered a blight on society and there are many efforts made to reduce it. That there are some people for whom suicide is considered appropriate may suggest that there are people whose lives are not deserving of the same level of protection.

## **Conclusion**

The IAPC represents healthcare professionals who have day to day experience caring for people with life-limiting illness, including many who are vulnerable either as a result of serious illness or because of other factors.

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<sup>10</sup> Vulnerable Adults in Irish Society Nationwide Public Opinion Survey <http://safeguardingcommittee.ie/wp-content/uploads/2017/04/Red-C-Survey-Vulnerable-Adults-in-Irish-Society-060417.pdf>

The IAPC believes that there should be no change in the law to allow assisted suicide or euthanasia because:

1. A change in the law would put vulnerable people at risk
2. It is not possible to put adequate safe-guards in place.
3. The drive to improve the care of people with life-limiting illnesses by education, service development and research may be compromised
4. Personal autonomy is not absolute and we are part of a society
5. Allowing assisted suicide or euthanasia for some populations for example the terminally ill or the disabled, devalues the lives of those compared to those targeted in suicide prevention campaigns.

Regina Mc Quillan, Palliative Medicine Consultant  
MCRN 09943

# Assisted dying regimes

## Briefing note

Oireachtas Committee on Justice, 22 November 2017

### Introduction

A small but growing number of jurisdictions now permit euthanasia and/or assisted suicide. This briefing note discusses how the law was changed in those jurisdictions, outlines the regulatory regimes, and summarises the empirical evidence of the practice of euthanasia and assisted suicide (defined in box 1).

### How the law was changed to permit assisted dying

#### The Netherlands

In the Netherlands, euthanasia and assisted suicide were effectively legalised through the use of the defence of necessity in prosecutions of (primarily) doctors. The defence is available when the doctor faced a conflict between his or her duties to preserve life and relieve suffering. The courts held that only doctors can face such a conflict of duties because only doctors have a professional duty to relieve suffering: laypersons (who include relatives) and nurses do not. Over some thirty years, the courts developed this duty-based defence of necessity in euthanasia cases, placing conditions on the defence, including: an express and earnest request; unbearable and hopeless suffering; consultation; careful termination of life; record-keeping; and reporting. These conditions became known as *requirements of due care* or *careful practice*. The Dutch legislature eventually codified the parameters of the defence in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, which lists six *due care criteria* which must be met in cases of euthanasia and assisted suicide (see box 2). The judicially-developed necessity defence is still applied to cases involving incompetent persons, particularly neonates.

#### Belgium

Unlike in the Netherlands, there had been few criminal prosecutions in euthanasia cases prior to its legalisation in Belgium, so legal change had to come from outside the judiciary. The 1980s and 1990s witnessed a series of unsuccessful legislative moves to allow euthanasia. After a change of government and intense legislative debate, the Law on Euthanasia was passed in 2002. It allows only doctors to perform euthanasia. Assisted suicide is not explicitly covered, although Belgium's oversight body, the Federal Euthanasia Control and Evaluation Commission (CFCEE) has accepted cases of assisted suicide as falling under the law.<sup>1</sup>

#### Luxembourg

The Law on Euthanasia and Assisted Suicide came into force in Luxembourg in 2009 after a heated political and public debate. The law is closely based on the Belgian law, although it does specifically permit assisted suicide as well as euthanasia.

#### Box 1. Definitions

- *Euthanasia*: an intervention undertaken with the intention of ending a life to relieve suffering. In the Dutch and Belgian contexts, the term *euthanasia* refers only to the termination of life upon request.  
Some common (and often confusing) modifiers of *euthanasia* are:  
active: a deliberate intervention to end life  
passive: withdrawal/withholding of life-sustaining treatment  
voluntary: at the request of the person killed  
involuntary: in the absence of a request by the person killed, although that person is competent  
non-voluntary: in the absence of a request by the person killed, when that person is not competent and has not made an advance request for euthanasia
- *Assisted suicide*: any act which intentionally helps another person to commit suicide, for example by providing him or her with the means to do so. In the Netherlands, *assisted suicide* is often included in the term *euthanasia*. Legal regimes often permit only *physician-assisted suicide* which is commonly referred to as PAS.
- *Assisted dying*: (voluntary active) euthanasia and assisted suicide. (Though sometimes used as a synonym only for *assisted suicide*.)

#### Switzerland

In Switzerland, it is a criminal offence to assist a suicide only where the assister has a selfish motive. This provision in the Penal Code has not changed since 1942. When it was originally drafted in 1918, "the attitudes of the Swiss public were shaped by suicides motivated by honour and romance, which were considered to be valid motives. Motives related to health were not an important concern, and the involvement of a physician was not needed."<sup>2</sup> Euthanasia is not permitted in Switzerland, although as in many other European jurisdictions, the separate offence of murder at the victim's request carries a lower minimum sentence than murder.

#### Oregon, Washington, Colorado, California, Vermont, District of Columbia, USA ("Oregon-model states")

Many US states allow legislation to be enacted if a majority votes for an initiative placed on the ballot following a petition signed by a minimum number of voters. Following two narrowly unsuccessful attempts to permit physician-assisted suicide by ballot initiative in Washington and California, Oregon voters passed the first Death with Dignity Act in 1994 by a majority of 52%. The Act permits the provision of a prescription for lethal medication to be self-administered by the patient. The Act was controversial from the moment the ballot measure was passed, and there were a number of ultimately unsuccessful legal challenges to it. Washington state voters passed an almost identical Act in 2008, as did Colorado voters in 2016. In 2013,

2015 and 2016 respectively, Vermont and California state legislators and District of Columbia council members passed statutes very similar to the Oregon Act, all of which are now in force. The Vermont Act was amended in 2015 to remove certain sunset clauses which would have changed the regulatory framework after three years from a regime modelled on Oregon to a professional practice standard. This would have permitted PAS on the basis of a valid request from a terminally ill patient, without requirements for consultation with a second physician, psychiatric evaluation, or waiting periods. The Oregon-model regime will now continue.

## Colombia

In 1997, the Colombian Constitutional Court ruled that a physician should not be prosecuted for ending life at the repeated request of a terminally ill patient who is suffering unbearably because the physician's action "is justified". The Court called on Congress to establish a regulatory regime to vindicate the fundamental right to die with dignity. Although a number of Bills were introduced, no progress was made in Congress on this issue. In 2014, the Constitutional Court reviewed the case of a terminally ill patient who had repeatedly and unsuccessfully sought euthanasia. The Court ordered the Ministry of Health immediately to issue a directive to health care providers requiring them to set up local expert committees to respond to requests for euthanasia. A national expert committee collaborated in the writing of the resulting Resolution which came into force in 2015.

## Canada & Québec

In 2014, the provincial legislature of Québec passed *An Act Respecting End of Life Care* which came into force on 10 December 2015 and legalised euthanasia ("medical aid in dying") for patients at the end of life. In February 2015 in *Carter*, the Supreme Court of Canada struck down the criminal prohibition on assisted suicide found in the federal *Criminal Code* on the grounds that it infringes the rights of competent adult patients with a grievous and irremediable medical condition causing enduring and intolerable suffering who consent to an assisted death.<sup>3</sup> The Court granted a one year suspension of the declaration of invalidity to give the Parliament of Canada the opportunity to craft a regulatory regime. The suspension was subsequently extended by four months; during the extension individuals were permitted to access assisted dying by making a court application.<sup>4</sup> Just after the expiry of the extension in June 2016, the Parliament of Canada enacted a statute amending the *Criminal Code* to permit medical assistance in dying, which is defined as "(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death."

## Features of assisted dying regimes

This section outlines and compares the main legal regimes permitting assisted dying: those in the Netherlands, Belgium, Luxembourg, Oregon (the model for Washington, Colorado, California, Vermont and the District of Columbia), Colombia, Québec and Canada.

The requesting person's condition and experience of suffering  
The legal requirements relating to the requesting person's condition and experience of suffering vary widely across these jurisdictions. It is notable that despite this variation, over 70% of all reported cases of euthanasia or physician-assisted suicide involve cancer patients.<sup>5</sup>

In the Netherlands, the "attending physician . . . must have been satisfied that the patient's suffering was unbearable, and that there

was no prospect of improvement". The patient's suffering need not be related to a terminal illness and is not limited to physical suffering such as pain. It can include, for example, the prospect of loss of personal dignity or increasing personal deterioration, or the fear of suffocation.<sup>6</sup> A related due care criterion (see box 2) is that there must be "no reasonable alternative in light of the patient's situation". In cases where the source of the suffering is a physiological disorder, the patient's reasonable decision to refuse a realistic treatment possibility (whether curative or palliative) which might ease his or her suffering does not stand in the way of a request for euthanasia based on that suffering.

In Belgium, the "patient [must be] in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident". As in the Netherlands, there is no requirement that the patient be suffering from a terminal illness, although additional procedural requirements are imposed if the patient is "clearly not expected to die in the near future". Again there must be "no reasonable alternative" to euthanasia. However, euthanasia is permissible only if the disorder is incurable, so a patient's reasonable refusal of potentially curative treatment will generally prevent access to euthanasia;<sup>7</sup> the reasonable refusal of a palliative treatment possibility will not have this effect.<sup>8</sup> In recent years, the CFCEE has accepted the possibility that refusal of a potentially curative treatment with particularly serious side-effects could be reasonable and would not, therefore, prevent access to euthanasia.<sup>9</sup>

The Netherlands permits assisted suicide in cases where the source of the patient's suffering is a psychiatric rather than a physiological disorder. In such cases, the patient may not reject "a realistic alternative to relieve the suffering",<sup>10</sup> although "patients are not obliged to undergo every conceivable form of treatment."<sup>11</sup> In Belgium, the permissibility of euthanasia in psychiatric cases was initially unclear, but such cases are now accepted by the CFCEE.<sup>12</sup>

The Oregon-model states, Colombia and Québec all require a terminal diagnosis; the Canadian requirement is less clear. In Oregon, the patient must be suffering from a terminal disease, defined as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months". In Colombia, the patient must be in the terminal phase of an illness or serious pathology, which is progressive, incurable and irreversible, with death predicted in the relatively short term. Similarly in Québec, the patient must be at the "end of life". The Act requires that the patient "suffer from a serious and incurable illness; be in an advanced state of irreversible decline in capability; and experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable." The Canadian Act requires that the patient have a "grievous and irremediable medical condition" for which there are four criteria: (1) a serious and incurable illness, disease or disability; (2) an advanced state of irreversible decline in capability; (3) that illness, disease or disability or that state of decline must cause the patient enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and (4) their natural death must have become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

## The request

In the Netherlands, the patient's request must be "voluntary and carefully considered". The patient must be competent to make such a request. The request must also be well-considered.

In Belgium, the patient must be "legally competent". The request must be both "completely voluntary" and "not the result of any external pressure". The doctor must inform the patient about "his health condition and life expectancy" and "the possible therapeutic and palliative courses of action and their consequences".

In Oregon, the competence, voluntariness and information requirements are set out in some detail. The patient must have "the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available." Two witnesses must attest that the patient is acting voluntarily and is not being coerced to sign the request. The patient must make an "informed decision ... that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of: (a) his or her medical diagnosis; (b) his or her prognosis; (c) the potential risks associated with taking the medication to be prescribed; (d) the probable result of taking the medication to be prescribed; (e) the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control."

In Colombia, the request must be free, informed and unequivocal. In Québec, the patient must have capacity, be informed and be acting freely. In Canada, the person must be a capacitous adult who has made a voluntary and informed request for assistance in dying.

## The requesting person's age

The Dutch law applies both to adults and to patients under the age of majority (18). A patient between the ages of 16 and 18 who is "capable of making a reasonable appraisal of his own interests" may request euthanasia or assisted suicide. The parent(s) or guardian does not have a veto, but must be consulted. Patients aged between 12 and 16 must pass the same test of capacity. In addition, the consent of the parent(s) or guardian is required.

In Belgium, euthanasia was originally legal only for patients over the age of 18 and for minors over the age of 15 who have been legally emancipated by a judicial decision. In 2014, the Belgian Act was amended to include minors with the capacity of discernment, although this group of minors must be suffering from a terminal illness in order to access euthanasia. An additional consultation with a child psychiatrist or psychologist is required to verify capacity. The consent of the minor's legal representatives (usually the parents) is also needed.

The Oregon, Luxembourg, Québécois and Canadian laws apply only to patients over the age of 18.

## Consultation and referral

All of the regimes require another physician (or nurse practitioner in Canada) to confirm the fulfilment of the legal requirements. A number of additional functions may be served by a consultation requirement, including quality control; avoidance of idiosyncratic judgments; provision of information to the attending physician; and enabling effective retrospective scrutiny of actions and decisions.<sup>13</sup>

### Box 2. The Dutch due care criteria

The due care criteria are set out in section 2(1) of the 2001 Act.

"The attending physician must:

- a. be satisfied that the patient has made a voluntary and carefully considered request;
- b. be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
- c. have informed the patient about his situation and his prospects;
- d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
- e. have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in a. to d. above; and
- f. have terminated the patient's life or provided assistance with suicide with due medical care and attention."

In the Netherlands, the independent physician must see the patient and give a written opinion on the extent to which the due care criteria are met (see box 2). The consultation requirements are more stringent if the patient's suffering is due to a psychiatric disorder.<sup>14</sup> The state-funded programme Support and Consultation on Euthanasia in the Netherlands (SCEN) trains physicians to be consultants and to provide support and advice for doctors treating patients at the end of life. The "vast majority" of reported euthanasia cases involve a SCEN consultant.<sup>15</sup>

In Belgium, the consulting physician must examine the patient and the medical record and ensure that the suffering requirement has been met. Moreover, if the patient "is clearly not expected to die in the near future", there is a mandatory additional consultation with either a psychiatrist or relevant specialist (and a waiting period of at least one month). Although a consultation with a palliative care expert is not legally required, many Catholic hospitals in Flanders impose such a *palliative filter* in addition to the statutory criteria.<sup>16</sup>

In Oregon, the attending physician must refer the patient to "a consulting physician for medical confirmation of the diagnosis, and for determination that the patient is capable and acting voluntarily." Further, a counselling referral must be made if either the attending or consulting physician suspects that the patient "may be suffering from a psychiatric or psychological disorder, or depression causing impaired judgment". PAS is allowed only if the counsellor determines that the patient is not suffering from such a condition.

In Québec, the consulting physician was originally required to be independent of both the attending physician and the patient. This was interpreted as meaning that the consulting physician could not be involved in the patient's care. This requirement has now been re-interpreted by the Commission on End of Life Care, so that the consulting physician may have a treating (but not a personal) relationship with the patient.<sup>17</sup>

The person providing assistance

In the Netherlands, the courts originally required that the person who providing euthanasia was the patient's *treating* physician.<sup>18</sup> The current requirement focuses more closely on its purpose: the doctor must know the patient sufficiently well to be able to assess whether the due care criteria are met (see box 2).<sup>19</sup>

The Belgian Act requires that the physician have "several conversations with the patient spread out over a reasonable period of time" in order to be certain of the persistence of the patient's suffering and the enduring character of the request. The Dutch purpose-focused argument (that in order to assess whether the due care criteria are met, the doctor must have some familiarity with the patient) might also be applied in Belgian euthanasia cases. However, the legislative history makes clear that the patient should be able to bypass his or her attending physician if so desired – from which one might infer that there is no requirement for a pre-existing physician-patient relationship.<sup>20</sup>

In Oregon, the attending physician is defined as "the physician who has primary responsibility for the care of the patient and treatment of the patient's terminal disease". The evidence suggests that many patients who sought assisted suicide had to ask more than one physician before finding one who was willing to provide a prescription. Over the first three years of operation of the Oregon law, only 41% of patients received their prescription from the first physician asked.<sup>21</sup> This suggests that in many cases there was no longstanding or pre-existing physician-patient relationship.<sup>22</sup> The median duration of that relationship in Oregon over the first ten years was 11 weeks. The range was between 0 and 1440 weeks.<sup>23</sup> Commentators opposed to the Oregon law have raised the possibility that a patient refused PAS by one physician on the grounds of failing to meet one of the statutory criteria may obtain the prescription from a more accommodating physician.<sup>24</sup>

The laws in Belgium, the Oregon-model states, Québec and Canada contain conscientious objection provisions. Although there is no such provision in the Dutch law, it is nonetheless clear that "no doctor has any obligation to accede to a request [for euthanasia], however well-founded."<sup>25</sup> The Royal Dutch Medical Association (KNMG) has reiterated this position, stating that "physicians are not under any obligation to assist in euthanasia. Physicians who have fundamental objections to euthanasia and assisted suicide must be respected in their views."<sup>26</sup>

### Reporting and scrutiny

Termination of life on request and assisted suicide remain criminal offences in the Netherlands. The defences inserted into the Penal Code by the Act require the doctor to report the case as euthanasia or assisted suicide to the municipal pathologist, who then passes the file to the relevant Regional Euthanasia Review Committee (RERC). If the RERC finds that the doctor did not act in accordance with the due care criteria (see box 2), the case is referred to the Public Prosecution Service. Ninety three cases were referred between 1999 and 2016 (0.17% of reported cases).<sup>27</sup> No prosecutions have been brought following these referrals. Lack of, or inadequate, consultation is the most significant reason for referral. Consultation may be considered inadequate if the doctor consulted is insufficiently independent from the attending doctor, or the consultation takes place too early or too late. Problems with the way in which euthanasia is carried out are the second-most significant reason for referral. In recent years, most of these cases involve concerns about the dosage of the coma-inducing sedative administered prior to the muscle relaxant which causes death

and the need to ascertain the depth of the patient's coma before administering the muscle relaxant.<sup>28</sup>

Compliance with the Belgian law is monitored by the CFCEE, to which all cases of euthanasia must be reported. Only one case has been reported to the prosecutorial authorities by the CFCEE (in late 2015; 0.008% of reported cases). It is not yet known on what grounds the referral was made. The biannual report covering this period does not describe this case in any detail.<sup>29</sup> Concerns have been raised in the media about the patient's underlying medical condition, the consultation requirement for cases where the patient is not expected to die in the near future, and the waiting period for such cases.<sup>30</sup>

Compliance with the Luxembourgish law is monitored by the National Commission of Control and Evaluation of the Law of 16 March 2009 on Euthanasia and Assisted Suicide (CNCE). From 2009 to 2016 there were 52 reported cases. No cases have been referred to the prosecutorial or medical authorities by the CNCE.

In Oregon, the physician must report each prescription written under the Act to the Oregon Department of Human Services (ODHS), and report each death resulting from the ingestion of the prescribed medication. A total of 22 physicians were referred by the ODHS to the Board of Medical Examiners between 1998 and 2016 for non-compliance with the provisions of the Oregon Act (1.96% of all reported deaths under the Act). Non-compliance with the Oregon Act identified by the ODHS has been almost exclusively of a clerical nature, the most common items being incomplete or late physician reporting forms or incomplete witness forms.<sup>31</sup> In relation to the other Oregon-model states, there is no evidence to suggest that non-compliance with the Washington or California Acts is reported to the state medical authorities. There was originally no requirement for physicians to report prescriptions written under the Vermont Act or deaths resulting from the ingestion of prescribed medication. A reporting requirement was added by amending the Vermont Act in 2015. The first biennial statistical report of the data collected must be published in 2018.

In Colombia, the Resolution requires requests for euthanasia to be approved by a special three-person multi-disciplinary hospital-based committee comprising a specialist in the patient's condition (not the treating physician), a lawyer, and a psychiatrist or clinical psychologist. The committee also bears responsibility for ensuring that the assistance in dying is provided within strict time-limits, and for accompanying the patient and their family members. A retrospective reporting requirement is also imposed.

Between 10 December 2015 and 30 June 2017, the Québec Commission on End of Life Care received 786 reports of medical aid in dying. At the time of publication of the second annual report, the Commission had examined 703 of these and reached decisions on 648. In 43 cases (6.6%) the Commission found that one of the legal requirements had not been met. In 29 of these 43 cases, the consultant physician was not professionally independent of the patient (ie was treating the patient). As previously noted, this interpretation of the independent consultation requirement has since been abandoned. Leaving out these cases, the referral rate would be 2.2%. All of these cases were referred to the professional regulatory body.<sup>32</sup> In Canada, a monitoring system will be implemented by regulations in 2018. Interim official data indicate that at least 2149 cases were reported across Canada between June 2016 (after the federal legislation came into force) and June 2017.<sup>33</sup>



## Empirical evidence

### What is known about the effectiveness of safeguards?

An extensive body of empirical evidence exists relating to the safeguards and criteria outlined above, and how they operate in permissive regimes, with the most detail available in the Netherlands, Belgium, Oregon and Switzerland.<sup>34</sup> The evidence from these jurisdictions suggests that the legal criteria that apply to an individual's request for assisted dying are well respected: individuals who receive assisted dying do so on the basis of valid requests; third parties who assist individuals to die do not act unlawfully.<sup>35</sup>

### What is known about reporting?

Evidence of the effectiveness of the reporting requirement and the scrutiny of reported cases in the Netherlands, Belgium, Oregon and Switzerland is less consistent. There is no data on the reporting rate in Oregon. The reporting rate within the right to die organisations in Switzerland may be 100%. The reporting rate in the Netherlands rose when the RERCs were inserted as a buffer between physicians and the authorities, although the Swiss experience suggests that a buffer may not be needed to encourage reporting if the process leading up to the assistance involves several layers of administration involving a number of different actors coupled with few legal requirements.<sup>36</sup> The reporting rate is significantly higher (81% in 2015) in the Netherlands than in Belgium (53% in 2007) where legalisation occurred more recently.<sup>37</sup> The reporting rate has risen over time in the Netherlands; it is not yet known whether this is the case in post-legalisation Belgium. "The major reason for failure to report [a case as euthanasia] is that the physician does not regard the course of action as a life-terminating act".<sup>38</sup> These unreported cases frequently involve the use of non-typical drugs to cause death (morphine rather than barbiturates and/or muscle relaxants which are typically used in euthanasia cases) and/or a very short life expectancy.<sup>39</sup> The number of *estimated* deaths from euthanasia includes such cases, as it does not rely on doctors' labelling of their own practice. Since almost all cases involving typical euthanasia drugs are reported,<sup>40</sup> this inconsistent labelling now likely accounts for almost all unreported cases. This thesis is supported by anonymous data collected from physicians which indicates that consistently close to 100% of the acts termed *by physicians* as euthanasia and assisted suicide were reported.<sup>41</sup>

### What is known about vulnerable groups?

In 2007, researchers examined data from the Netherlands and Oregon in order to see if members of vulnerable groups were more likely to receive assistance in dying (either euthanasia or PAS). They examined the frequency of such assistance in ten groups of potentially vulnerable patients, defined by gender, age, ethnicity, educational and socio-economic status, illness and disability. They found "no evidence of heightened risk ... with the sole exception of people with AIDS." It should be noted though that the lack of Oregon data on pre-existing disabilities weakens the force of this conclusion with respect to disability.<sup>42</sup> The researchers concluded that "the available data ... shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges."<sup>43</sup>

### What is known about the frequency of end of life decisions?

Many of the empirical claims made about the practice of euthanasia and PAS under existing legal regimes misrepresent the data, take it out of context or neglect important comparisons with jurisdictions where these practices are prohibited.<sup>44</sup> Chart 1 shows the percentage of all deaths in specific years that were cases of euthanasia (EUT), PAS or termination of life without request (TLWR). It combines data from a number of different anonymous prevalence surveys of doctors.<sup>45</sup> All surveys were based on one originally designed by Dutch researchers.<sup>46</sup> The relatively broad and overlapping confidence intervals suggest that fine comparisons should not be made between countries with the lowest percentages. As indicated, some comparisons are from different years. Although similar, the surveys are not identical. The percentage of deaths in which an end of life decision (ELD) is made varies across jurisdictions.

This evidence does not support the argument that there is a slippery slope between the legalisation of euthanasia (termination of life on request) and termination of life without request (TLWR).<sup>47</sup> The rates of TLWR vary. The evidence suggests that TLWR takes place in both permissive and non-permissive jurisdictions, with some of the highest rates in non-permissive jurisdictions (eg Australia in 1997), although rates of TLWR in some permissive jurisdictions are higher than in some non-permissive jurisdictions. TLWR occurs more frequently than euthanasia in all countries that have been surveyed except the Netherlands and Belgium.<sup>48</sup> Rates of TLWR have decreased since legalisation in the permissive jurisdictions of the Netherlands and Belgium.<sup>49</sup>

Chart 1. Rates of euthanasia, PAS and termination of life without request

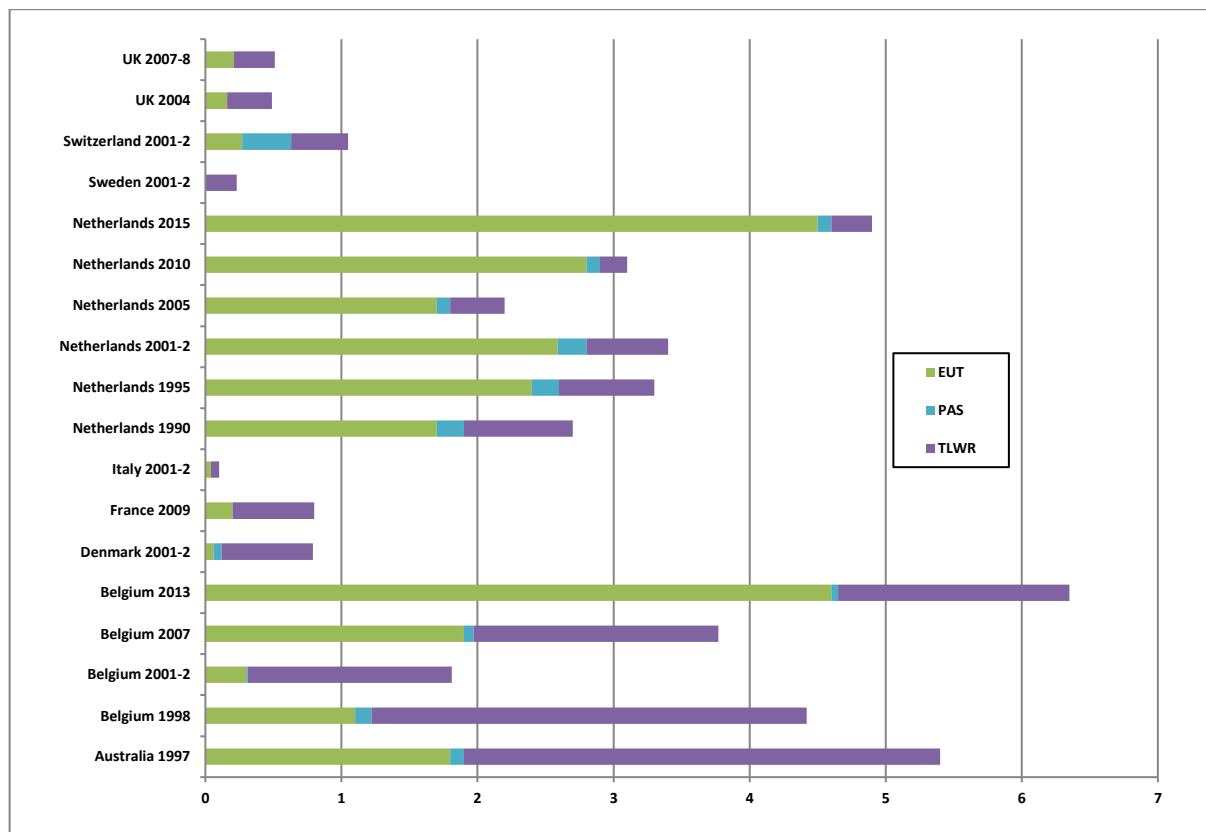
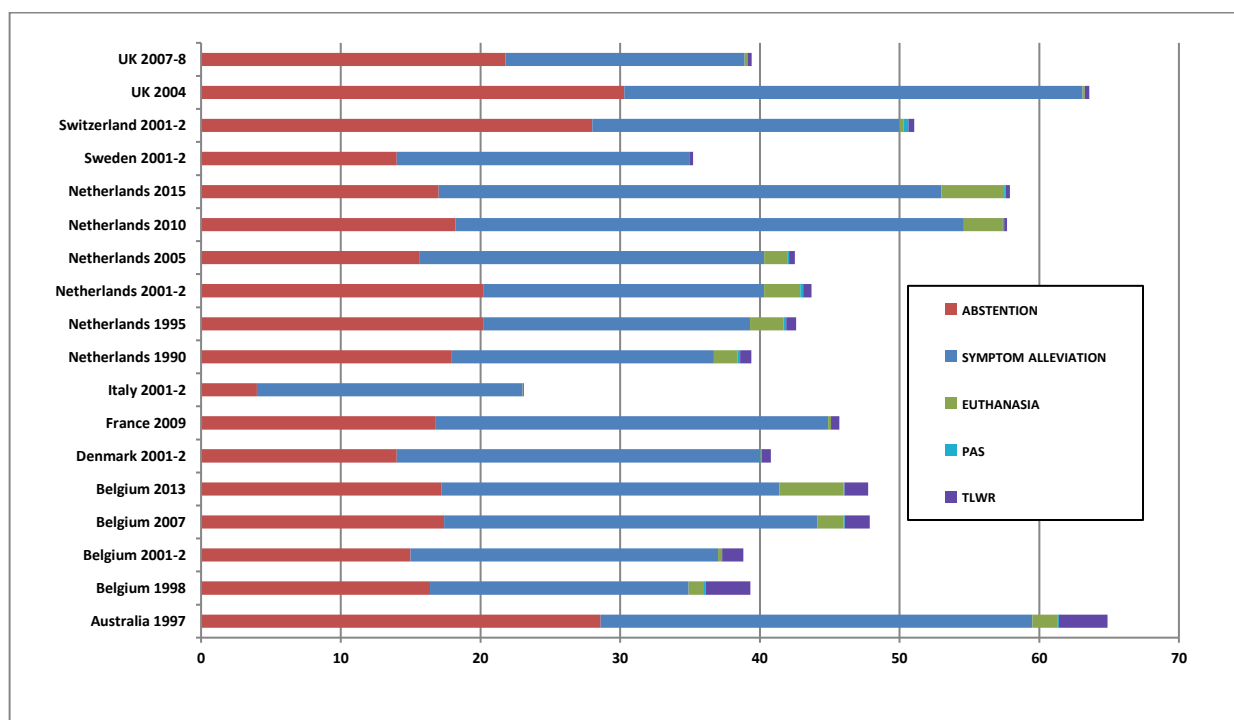


Chart 2: Rates of end of life decisions (percentage of all deaths)

Chart 2 compares the types of ELDs in the jurisdictions in which the original Dutch survey has been carried out. In addition to euthanasia (EUT), PAS and termination of life without request (TLWR), two much larger categories are included: *abstention* (withdrawing or withholding life-sustaining treatment) and *alleviation of symptoms* taking into account possible or probable hastening of death. In all countries, EUT, PAS and TLWR are relatively rare.



#### Endnotes

<sup>1</sup> CFCEE (2004) [First report to the legislature (2002-2003)] 13-14.

<sup>2</sup> Hurst & Mauron. Assisted suicide and euthanasia in Switzerland: allowing a role for non-physicians. *BMJ* 2003;**326**:271-3, 271.

<sup>3</sup> *Carter v Canada (Attorney General)* 2015 SCC 5.

<sup>4</sup> *Carter v Canada (Attorney General)* 2016 SCC 4.

<sup>5</sup> Emanuel et al. [Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe](#). *JAMA* 2016;**316**:79-90.

- <sup>6</sup> [Regional Euthanasia Review Committees] (RERCs) (2015) [Code of Practice](#) §3.3.
- <sup>7</sup> Massion. [The euthanasia exception in Belgian law]. *Louvain Médical* 2005;**124**:238-45, 238, 243.
- <sup>8</sup> Lewis & Black (2012) [The effectiveness of legal safeguards in jurisdictions that allow assisted dying](#). Commission on Assisted Dying 18-19, n 23.
- <sup>9</sup> CFCEE (2014) [Sixth Report to the Legislative Chambers (2012-2013)] 15.
- <sup>10</sup> Chabot [Supreme Court], *Nederlandse Jurisprudentie* 1994, no. 656.
- <sup>11</sup> RERCs (2015) [Code of Practice](#) §4.3.
- <sup>12</sup> Lewis & Black (2012) [The effectiveness of legal safeguards in jurisdictions that allow assisted dying](#). Commission on Assisted Dying 19; Thienpont et al. [Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders](#). *BMJ Open* 2015;**5**:e007454.
- <sup>13</sup> Griffiths, Weyers & Adams (2008) *Euthanasia and Law in Europe* 93-95.
- <sup>14</sup> RERCs (2015) [Code of Practice](#) §4.3.
- <sup>15</sup> RERCs (2015) [Code of Practice](#) §3.6.
- <sup>16</sup> Gastmans et al. [Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium \(Flanders\)](#). *Health Policy* 2006;**76**:169-78, 176.
- <sup>17</sup> [Commission on end of life care] (2017) [Annual Report of Activities 1 July 2016-30 June 2017] 15.
- <sup>18</sup> Griffiths, Weyers & Adams (2008) *Euthanasia and Law in Europe* 79, 93-94.
- <sup>19</sup> RERCs (2015) [Code of Practice](#) §3.1.
- <sup>20</sup> Adams & Nys. Comparative Reflections on the Belgian Euthanasia Act 2002. *Med Law Rev* 2003;**11**:353-76, 359.
- <sup>21</sup> ODHS (2001) *Oregon's Death with Dignity Act: Three Years of Legalized Physician-Assisted Suicide* Table 3 (no further data has been reported).
- <sup>22</sup> Ganzini et al. [Physicians' Experiences with the Oregon Death with Dignity Act](#). *New Eng J Med* 2000;**342**:557-63, 559-61.
- <sup>23</sup> Oregon Dept. of Human Services (2008) *Tenth Annual Report* Table 1 (no further data has been reported).
- <sup>24</sup> Martyn et al. [Now is the Moment to Reflect: Two Years of Experience with Oregon's Physician-Assisted Suicide Law](#). *Elder Law J* 2000;**8**:1-56, 13.
- <sup>25</sup> Griffiths, Weyers & Adams (2008) *Euthanasia and Law in Europe* 107.
- <sup>26</sup> KNMG (2011) [The Role of the Physician in the Voluntary Termination of Life](#) 6, [4.1].
- <sup>27</sup> Lewis & Black. [Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful: a review of the evidence in the Netherlands, Belgium, Oregon and Switzerland](#). *Med Law Int'l* 2013;**13**:221-239, 225; RERCs (2014) *Annual Report 2013*; RERCs (2015) *Annual Report 2014*; RERCs (2016) *Annual Report 2015*; RERCs (2017) [Annual Report] 2016.
- <sup>28</sup> Lewis & Black. [Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful: a review of the evidence in the Netherlands, Belgium, Oregon and Switzerland](#). *Med Law Int'l* 2013;**13**:221-239, 226-227.
- <sup>29</sup> CFCEE (2016) [Seventh report to the legislature (2014-2015)] 10, 13.
- <sup>30</sup> Hovine. [\[Simone was euthanised because she was 'tired of living': The federal Commission for the control of euthanasia has referred its first case to prosecutors\]](#) *La libre Belgique* 28 October 2015; SBS [Belgian euthanasia doctor could face criminal charges](#) 2015.
- <sup>31</sup> Lewis & Black. [Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful: a review of the evidence in the Netherlands, Belgium, Oregon and Switzerland](#). *Med Law Int'l* 2013;**13**:221-239, 229; ODHS (2014) *Oregon Death with Dignity Act 2013* 3; ODHS (2015) *Oregon Death with Dignity Act 2014* 3; ODHS (2016) *Oregon Death with Dignity Act 2015* 4; ODHS (2017) *Oregon Death with Dignity Act 2016* 7.
- <sup>32</sup> [Commission on end of life care] (2016) [Annual Report of Activities 10 December 2015 – 30 June 2016] [4.1]; [Commission on end of life care] (2017) [Annual Report of Activities 1 July 2016-30 June 2017] 9, [4.1].
- <sup>33</sup> Health Canada (2017) *Interim update on medical assistance in dying in Canada June 17 to December 31 2016* (2017); Health Canada (2017) *Second Interim Report on medical assistance in dying in Canada January 1 2017 to June 30 2017*.
- <sup>34</sup> Lewis & Black. (2012) [The effectiveness of legal safeguards in jurisdictions that allow assisted dying](#). Commission on Assisted Dying.
- <sup>35</sup> Lewis & Black. [Adherence to the Request Criterion in Jurisdictions Where Assisted Dying Is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon, and Switzerland](#). *J Law Med Ethics* 2013;**41**(4):885-898.
- <sup>36</sup> Lewis & Black. [Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful: a review of the evidence in the Netherlands, Belgium, Oregon and Switzerland](#). *Med Law Int'l* 2013;**13**:221-239.
- <sup>37</sup> Onwuteaka-Philipsen et al. (2017) [Third Evaluation of the Termination of Life on Request and Assisted Suicide Act] 181-182; Smets et al. [Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases](#). *BMJ (Clinical research ed)* 2010;**341**:c5174, 3; Bilsen et al. [Medical End-of-Life Practices under the Euthanasia Law in Belgium](#). *New Eng J Med* 2009;**361**:1119-1121, 1120.
- <sup>38</sup> Onwuteaka-Philipsen et al. (2007) [Evaluation of the Termination of Life on Request and Assisted Suicide Act] 15.
- <sup>39</sup> Buiting et al. [Law, ethics and medicine: Physicians' labelling of end-of-life practices: a hypothetical case study](#). *J Med Ethics* 2010;**36**:24-29; Onwuteaka-Philipsen et al. (2017) [Third Evaluation of the Termination of Life on Request and Assisted Suicide Act] 22.
- <sup>40</sup> Onwuteaka-Philipsen et al. (2017) [Third Evaluation of the Termination of Life on Request and Assisted Suicide Act] 107, 186 (97% in 2015; 100% in 2010); Onwuteaka-Philipsen et al. (2007) [Evaluation of the Termination of Life on Request and Assisted Suicide Act] 15; Rurup et al. [The reporting rate of euthanasia and physician-assisted suicide: a study of the trends](#). *Med Care* 2008;**46**(12):1198-1202, 1201; Onwuteaka-Philipsen et al. [Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey](#). *Lancet* 2012;**380**(9845):908-915, 912-913.
- <sup>41</sup> Onwuteaka-Philipsen et al. (2007) [Evaluation of the Termination of Life on Request and Assisted Suicide Act] 176 (97%); Onwuteaka-Philipsen et al. (2017) [Third Evaluation of the Termination of Life on Request and Assisted Suicide Act] 186 (99% in 2015; 100% in 2010).
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- <sup>43</sup> Battin et al. [Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups](#). *J Med Ethics* 2007;**33**:591-7.
- <sup>44</sup> Lewis. [The Empirical Slippery Slope from Voluntary to Non-voluntary Euthanasia](#). *J Law Med Ethics* 2007;**35**:197-210.
- <sup>45</sup> Bilsen et al. [Medical End-of-Life Practices under the Euthanasia Law in Belgium](#). *New Eng J Med* 2009;**361**:1119-21, Table 1; Chambaere et al. [Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium](#). *New Eng J Med* 2015;**372**:1179-1181; Deliens et al. [End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey](#). *Lancet* 2000;**356**:1806-11, Table 1; Kuhse et al. *End-of-Life Decisions in Australian Medical Practice*. *Med J Aust* 1997;**166**:191-196; Onwuteaka-Philipsen et al. (2017) [Third Evaluation of the Termination of Life on Request and Assisted Suicide Act]; Onwuteaka-Philipsen et al. [Trends in end-of-life practices before & after the enactment of the euthanasia law in the Netherlands from 1990 to 2010](#). *Lancet* 2012;**380**:908-15, Table 1; Pennec et al. [End-of-life medical decisions in France: a death certificate follow-up survey 5 years after the 2005 act of parliament on patients' rights and end of life](#). *BMC Palliat Care* 2012;**11**:25, Table 1; Seale. [End-of-life decisions in the UK involving medical practitioners](#). *Palliat Med* 2009;**23**:198-204, Table 1; Seale. [National survey of end-of-life decisions made by UK medical practitioners](#). *Palliat Med* 2006;**20**:3-10, Tables 2&3; Van der Heide et al. [End-of-life decision-making in six European countries: descriptive study](#). *Lancet* 2003;**362**:345-50, Table 2; Van der Heide et al. [End-of-Life Practices in the Netherlands under the Euthanasia Act](#). *New Eng J Med* 2007;**356**:1957-65, Table 1; Van der Maas et al. [Euthanasia and other medical decisions concerning the end of life](#). *Lancet* 1991;**338**:669-74.
- <sup>46</sup> Van der Maas et al. [Euthanasia and other medical decisions concerning the end of life](#). *Lancet* 1991;**338**:669-74.
- <sup>47</sup> Lewis (2007) *Assisted Dying & Legal Change* 169-187; Lewis. [The Empirical Slippery Slope from Voluntary to Non-voluntary Euthanasia](#). *J Law Med Ethics* 2007;**35**:197-210.
- <sup>48</sup> Chambaere & Cohen (2017) [Euthanasia and Public Health](#) in Quah, ed. *International Encyclopedia of Public Health* (2<sup>nd</sup> ed) 46-56, 47.
- <sup>49</sup> Lewis (2007) *Assisted Dying & Legal Change* 175-187.



## Responding to the proposal to legalise assisted suicide

To cure sometimes, to relieve often, and to comfort always

*Hippocrates*

...And so each venture is a new beginning, a raid on the inarticulate

*TS Eliot*

Healthcare ethics has been an evolving and dynamic part of medicine since ancient times. As well as covering basic principles such as the Hippocratic maxim of *primum non nocere* (first do no harm), it is increasingly clear that an important aspect of modern medical ethics is *primum non tacere* (first do not be silent)<sup>i</sup>. This has been particularly the case in terms of the silence or collusion of the medical profession at times of harmful practices engendered by contemporary widespread social pressure or enthusiasms, such as that of the German medical profession at the time of the T4 euthanasia programme in National Socialist Germany<sup>ii</sup>, or the Swedish medical profession during the long period of forcible sterilisation of people with disability<sup>iii</sup>.

Among the important roles of teaching healthcare ethics are those of developing an articulacy to tease out the complexities of the care of life with disability, challenging simplistic tropes, outlining the substantial body of work in clinical ethics, illuminating the challenge of recognising prejudices (such as those based on age, gender, race or disability) in public healthcare discourse, and reflecting on the challenges of contextualising concepts such as autonomy in terms of the aspects of existence such as that of our relational nature as human beings.

Formal teaching of healthcare ethics is relatively new in Ireland: I was involved in establishing the first interdisciplinary undergraduate course as recently as 2004<sup>iv</sup>. Since this time there has been an increase in teaching at postgraduate and trainee levels, and the successive iterations of the ethical guidelines of the Medical Council represent a degree of sophistication and constant renewal unparalleled in other professional guidelines in Ireland.

Medical ethics represent a fusion between elements of philosophy and other aspects of the humanities allied to a vibrant sense of both the traditions but also the rapid evolution of the clinical sciences, best described in terms of care, communication and competence<sup>v</sup>.

The proposal by Minister Halligan and others to join the minority of jurisdictions which have legalised assisted-suicide represents a point where it is important that we pause and reflect on what this means, what impulses draw some people to this concept, and what positive responses we can make to concerns and needs.

### **Two forms of suicide?**

There have been major advances in promoting high-quality care at the end of life across the spectrum of healthcare provision in Ireland, and in particular through the provision of both palliative care services and increased training in palliative care across the professions. In addition, the professions have encouraged the development of advance care planning and provided assistance in ensuring that treatment at the end of life is proportionate to the goals of such advance healthcare plans.

One area of major concern in Ireland at end of life is that of suicide: suicide kills more people each year than road crashes, and is a source of grievous hurt to family, friends and those affected by the death. Much effort has been directed towards suicide prevention, and it is encouraging that the incidence of suicide has fallen from 13.5 to 9.7 per 100,000 between 2001 and 2015, albeit with persistently high rates among certain groups<sup>vi</sup>.

That there might be two forms of suicide – one which is clearly upsetting and worthy of strenuous societal efforts to prevent, and one which might be tolerated and given the support and protection of law – is a deeply challenging and contradictory premise<sup>vii</sup>. Simplistic tropes also haunt the discussion, with assumptions about psychiatric illness and irrationality.

The decriminalisation of suicide was a humane initiative, aimed at avoiding stigma and further hurt in terms of both completed suicide and attempted suicide, and emphasising the need for help and support for people in this situation, an impulse that holds true for those seeking assisted suicide as well. It was certainly never seen to be an expression of a societal desire to extend access to suicide as a human right, or to position suicide as an act that equality legislation might facilitate.

### **An idealised vision of unlimited autonomy**

One of the striking aspects of the arguments advanced by the proponents of assisted suicide is an emphasis of choice and control, reflecting an emphasis on autonomy disconnected from the relational nature of our nature reminiscent of the central concepts of the market place, neoliberalism and the writings of Ayn Rand.

As described in a recent Irish paper on end-of life care<sup>viii</sup> operating solely from a primacy of choice logic negates the interdependencies in care relations and assumes that all patients are independent and autonomous, even at moments of high vulnerability; there is a danger that those in end-of-life care are framed as abstracted rational choosers, ignoring that they are relational, emotional, and embodied human beings.

Choice logic may also lead to the prioritization of performance and control over compassion and care<sup>ix</sup>, failing in the process to fully acknowledge the reality of bodily decline and the needs of caregivers.

This has evoked concerns in healthcare ethics of how autonomy is defined in relationship to other aspects of ethics and how it has emerged as a dominant trope in ethics: the leading philosopher (and Chair of the UK Equality and Human Rights Commission until 2016) Onora O'Neill has proposed that ideally practice has to be developed within an ethical theory that does not impose an idealised picture of unlimited autonomy but allows for the variable and partial character of actual human autonomy<sup>x</sup>. This has been further developed by ethicists Pellegrino and Thomasma as the concept of the physician as moderate autonomist and moderate welfarist<sup>xi</sup>.

In this healthcare has moved far from a previous stance of paternalism towards one which situates autonomy within a matrix most often expressed as a dynamic between the four pillars of beneficence, non-maleficence, autonomy and justice. Attaining this balance requires insight into the factors and practices that underpin these attributes, including a sensitivity to the potency of prejudice against ageing and disability.

### **Prejudice against ageing and disability**

In terms of ageing, a recent paper described how younger older people harbour prejudices against their own future ageing: asked about their opinion on living to the age of 100, this in their 90's were broadly welcoming, while those in their 70's showed marked ambivalence<sup>xii</sup>.

Prejudice against disability is equally prevalent, and it is not surprising that all major UK advocacy groups for disability have rejected assisted suicide<sup>xiii</sup>.

Where there is legislation for assisted suicide it is often claimed that there is no evidence that the existence of legislation has led to significant harms for those with disability, but such studies have rarely looked at perceptions of illness, nihilism or ageism, all of which can be affected and influence care policies. For example, in societies where a negative public discourse related to living with dementia is tolerated, despite evidence of maintained quality of life for those so affected, assisted suicide may undermine the collective will to improve services and supports for those living with dementia<sup>xiv</sup>.

This was described with considerable impact by Susan Sontag in her *Illness as Metaphor* when she wrote "Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. ...It is impossible to take up residence unprejudiced by the lurid metaphors with this it is landscaped".

It is also a matter of concern that there are deep misperceptions about current medical practice: for example, a documentary on the matter broadcast on RTE Radio 1 in October 2017 proposed a rationale for assisted suicide in part on the basis that tube feeding would be used in a condition with a progressive dementia<sup>xv</sup>, a course of action rarely if ever followed in clinical practice.

These concerns are mirrored in recent paper showing that for psychiatric patients who seek assisted suicide, symptoms of unbearable suffering may start at an early age and may further progress because of insufficient and/or poor patient-physician communication and inefficient treatment practices. Moreover, financial issues are also relevant – for example, low income necessitating careful consideration to determine whether alternative stays and treatments are feasible<sup>xvi</sup>.

### **More sophisticated conceptualisation of dignity**

Some of the advocates of assisted suicide use the phrase of ‘death with dignity’: its proponents perceive dignity as being undermined by disability and suffering. Because the concept of human dignity carries strong rhetorical and moral force, we are obliged to examine any claims that our society is failing to act in accordance with it. Human dignity is not a thing that can be lost through disability, disease, dependency, or suffering, although insensitive treatment or attitudes to those so affected can constitute undignified care. It is important that the healthcare professions promote a critical debate on the complexities of discourse relating to dignity, and maintain care philosophies and routines that promote dignified care. Practical research on the topic points to elements including listening, communication, information, symptom control, facilitating daily living and including patients in decision-making: additionally, nurses’ perceptiveness towards the patients is a core approach<sup>xvii</sup>.

### **Responding to concerns for future care**

It would appear that much of the impetus for seeking assisted suicide relates to a complex web of issues, including existential concerns over the future, fears that one’s voice will not be heard, misperceptions of care paradigms, occult (and sometimes overt) prejudice against disability and age, denial of the resilience of the human spirit in the face of adversity, and a failure to contextualise autonomy as one component of our relational framework of care and support through life. Public and private discussion with regard to assisted suicide should be seen to represent concerns over adequacy of treatment and support as well as existential concerns relating to the future: these need to be proactively addressed.

To ask doctors to run counter to this by killing patients short-circuits and undermines our impetus to care, comfort and support and damages our framework of care. Current and future patients need to be reassured that the response of the healthcare professions to distress and pain is one of compassion and care, addressing the needs at a range of levels - biological, psychological, social and spiritual - while respecting wishes to the greatest extent possible.

They should be reassured by not only the evidence that death is widely experienced as occurring with dignity within current paradigms<sup>xviii</sup>, but also by the existing and ongoing development of care paradigms, training and research to continually enlarge the framework within which the final period of our lives is spent.

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## Statement for the Oireachtas Joint Committee on Equality and Justice on the permissibility of legalising medical assistance in dying

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### Brief background

Voluntary euthanasia is a deliberate act undertaken with the intention of ending the life of another person at his or her request. Assisted suicide is the act of intentionally providing another person with the knowledge or means to end his or her life, at his or her request. Whereas euthanasia involves the administration by a doctor of a lethal substance intended to end the patient's life, assisted suicide involves the prescription of a lethal substance to be voluntarily ingested by the patient. The terms 'assisted death', 'assisted dying', or, more recently, 'medical aid in dying', avoid the negative connotations associated with suicide and are used to refer to both kinds of action.

In response to voter initiatives or legal challenges, a number of jurisdictions have legalised assisted death during the past decade. In the US, assisted death is now legal in Oregon (1997), Washington state (2008), Vermont (2013), California (2015), Colorado (2016), Washington DC (2016) and decriminalised in Montana (2009), while both euthanasia and physician-assisted suicide are legal in Canada (2016). In Europe, physician-assisted suicide has been legal for a number of years in the Netherlands, Luxembourg and Switzerland, while euthanasia is legal in Belgium and the Netherlands. Outside of these jurisdictions, the only other country in which assisted dying is legal is Colombia. In all jurisdictions in which the practice is legal, there has been a slow but consistent increase in the number of patients receiving assistance in dying, ranging from 0.4% of all deaths in Oregon and Washington state to 4.6% of all deaths in Flanders<sup>1</sup>. Despite an increasing trend towards legalisation, however, assisted dying remains relatively rare<sup>2</sup>.

Legislative reform to permit assisted dying in these jurisdictions is indicative of an increased emphasis on personal autonomy in healthcare decision-making and a societal shift in the perception of the role of medicine. In all countries in which it has been legalised, the practice of assisted dying is subject to regulation: criteria for eligibility are specified, including the presence of a terminal illness or 'unbearable' suffering, stability over time of the patient's decision to end his or her life, the voluntary nature of the decision, and the capacity to make the decision. Due care criteria for physicians are set down which absolve participating physicians of liability, provided that certain steps are followed, including consultation with an independent physician and notification of all deaths involving physician assistance.

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<sup>1</sup> Emanuel EJ et al (2016). "Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe". *JAMA* 316 (1): 83-4. See also Dierickx et al (2016). "Euthanasia in Belgium: trends in reported cases between 2003 and 2013". *Canadian Medical Association Journal* 188 (16), E412. See also Onwuteaka-Philipsen et al (2012). "Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey". *Lancet* 380

<sup>2</sup> Emanuel et al, (2015), 88.

Those in favour of legalising assisted dying rely primarily on two arguments: first, the argument that autonomous, capable individuals who are suffering unbearably should have the right to determine the manner and timing of their death, and, second, the argument that healthcare professionals have an obligation to provide patients experiencing this kind of suffering with relief. Arguments against legalisation of assisted dying focus on the threat to the vulnerable in society, the alleged impossibility of designing sufficiently robust safeguards and the potential threat to the public's trust in the healthcare profession. All of these arguments are persuasive and I will consider them in turn below.

### Autonomy

The capacity for autonomy or self-determination is a core value within the liberal political tradition, and it is regarded as one of the unenumerated constitutional rights of citizens in many jurisdictions, including Ireland. Contemporary clinical practice places increasing emphasis on a patient's right to make and execute decisions based on his or her values and beliefs. Currently, patients have the right to refuse life-prolonging medical treatment and to request the withdrawal of clinically-assisted nutrition and hydration, even though such requests may lead to death. Proponents of assisted dying argue that the practice should be seen as merely a logical extension of this right; opponents claim that there are limits on individual autonomy in a society which must respect a plurality of competing rights: one person's choice must always be balanced against its implications for the rights of other members of society.

At the heart of the argument from autonomy is not a defence of 'mere, sheer choice' for its own sake, but the view that every competent person "has a right to make momentous personal decisions which involve fundamental religious or philosophical beliefs about life's value for him-[or her-] self".<sup>3</sup> In *Purdy v DPP*, Baroness Hale argued that, "[i]f we are serious about protecting autonomy, we have to accept that autonomous individuals have different views about what makes their life worth living"<sup>4</sup>. According to this view, the ultimate arbiter of the quality or value of a person's life is that person him- or herself. In the context of assisted dying, recognising a person's autonomy means understanding the importance she places on dying in a manner which "keeps faith with the way (...) [she] want[s] to have lived".<sup>5</sup>

### Relief of suffering

Requests for assistance in dying are made by patients who experience suffering which is grievous or extreme and which cannot be relieved by any therapeutic or non-therapeutic means. Relief of suffering has long been perceived as a component of the role of healthcare professionals, but it has received increasing attention in recent decades, particularly as palliative care gains acceptance as a specialty within medical and nursing practice. Among other things, palliative care aims to improve the quality of life of patients with a life-limiting diagnosis or approaching the end of their lives, many of whom experience intense suffering. Although palliative care as a discipline addresses the physical, emotional, psychological and spiritual needs of these patients, suffering is a complex and

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<sup>3</sup> Dworkin et al (1997). *The Philosophers' Brief*. *New York Review of Books* March 27, 1997. Available at: <http://www.nybooks.com/articles/1997/03/27/assisted-suicide-the-philosophers-brief/>

<sup>4</sup> R (On the application of Purdy) v Director of Public Prosecutions [2009] UKHL 45, para. 6

<sup>5</sup> Dworkin R (1993). *Life's Dominion*, 199.

inherently subjective phenomenon<sup>6</sup>, and some patients' suffering cannot be relieved even by the most expertly administered palliative measures. Despite the ongoing integration of palliative care into the care continuum, there is great variability within any given jurisdiction in the provision and range of palliative care services. Many patients who cannot access such services receive suboptimal end-of-life care: patient preferences are misunderstood, treatment choices are not respected, pain relief is inadequate and doctor-patient communication is ineffective<sup>7</sup>.

Even where high-quality services are accessible to patients, not all physical suffering can be alleviated by pain medication, and not all suffering can be reduced to physical pain. 'Existential' suffering is distinct from physical pain and may incorporate elements of anxiety, hopelessness and depression, as well as fear of what the future holds. Empirical research suggests that what many patients requesting assistance in dying want most to avoid is not physical pain, but loss of dignity, loss of control and ultimately, of their 'sense of self'<sup>8</sup>. "What is called existential distress arises from the impact of sickness on a person's existence: the helplessness, isolation, and loss of control that characterize severe illness, and which is brought on by symptoms as varied as pain or profound weakness"<sup>9</sup>.

While euthanasia is not, and never should be, a substitute for striving to relieve the suffering of patients at the end of their lives, the central question here, given that individuals tolerate suffering in very different ways, is whether an individual who is suffering irremediably should have the right to determine that the value and quality of her life are compromised to an unacceptable degree by the suffering she experiences. For opponents of this view, compassion is not a sufficient justification for relieving pain and suffering 'at any cost'.

### The interface between palliative care and euthanasia

Palliative care is a highly-specialised multidisciplinary approach to caring for patients for whom curative treatment is no longer deemed appropriate or beneficial. It continues to gain recognition for its success in reducing suffering and promoting autonomy and dignity for patients in the final months, weeks and days of life. Palliative care and assisted dying are traditionally regarded as irreconcilably-opposed approaches to the problem of refractory suffering at the end of life. Good palliative management of symptoms at the end of life is put forward as an alternative to assisted death and the WHO definition of palliative care states explicitly that palliative care aims "neither to hasten nor to postpone death"<sup>10</sup>. The European Association for Palliative Care has categorically stated that the provision of euthanasia and physician-assisted suicide should not be included within the remit of palliative care<sup>11</sup>. There is a genuine concern among palliative care providers and organisations that legalisation of assisted dying has the potential to inhibit the development of

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<sup>6</sup> Rich BA (2011) "A Death of One's Own: The Perils and Pitfalls of Continuous Sedation as the Ethical Alternative to Lethal Prescription". *American Journal of Bioethics* 11: 6, 53.

<sup>7</sup> Bok, S. "Euthanasia", in (eds) Dworkin et al (1998). *Euthanasia and Physician-Assisted Suicide: For and Against*. Cambridge: Cambridge University Press.

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<sup>9</sup> Cassell EJ and Rich BA (2010). "Intractable End-of-Life Suffering and the Ethics of Palliative Sedation". *Pain Medicine* 11: 437.

<sup>10</sup> <http://www.who.int/cancer/palliative/definition/en/>

<sup>11</sup> Radbruch L et al (2016). "Euthanasia and physician-assisted suicide: a white paper from the European Association of Palliative Care". *Palliative Medicine* 30 (2): 105.

palliative care provision and undermine the culture of palliative care<sup>12</sup>. The worry is that patients who are eligible for palliative care may choose assisted dying, thereby lowering the demand for palliative care. Advocates of assistance in dying argue that this claim is not borne out by existing data from countries in which the practice is legal. In Belgium, for example, the law decriminalising euthanasia was accompanied by a law which made palliative care a basic right of all patients. Between 2003 and 2010, governmental funding for palliative care services in Belgium increased by 108%, in contrast with an increase of only 2.34% in total health expenditure.<sup>13</sup> Despite antagonism in other contexts, the symbiotic relationship between palliative care provision and assisted dying in Belgium points to several values which are shared by both palliative care providers and advocates of legal assisted dying: the central imperative of reducing suffering, the importance of enhancing choice, the need to avoid dependence on aggressive medical intervention at the end of life, and the shared concept of a 'good death'<sup>14</sup>.

### Disproportionate impact

The most prominent civil rights critique of assisted dying refers to its potential to have a disproportionate impact on vulnerable populations, such as people from socio-economically disadvantaged groups, elderly people, people living with disabilities and ethnic minorities<sup>15</sup>. Risk is greatest for these groups because their autonomy and well-being are already compromised by poverty, advanced age, marginalisation and lack of access to good medical care<sup>16</sup>. Vulnerability is a multifaceted concept which refers to a person's inability to advocate for herself or assert her rights. People are vulnerable for many different reasons: they may be unable to assert their wishes or advocate for their rights because their capacity to be involved in any treatment decisions is compromised or because of external factors, such as lack of social or psychosocial supports, socio-economic disadvantage, inadequate pain management or poor palliative care provision. Often in combination, these factors may render some people living with disability or with chronic, incurable or life-limiting illness more inclined to evaluate positively the prospect of an end to their suffering than to rationally consider alternatives<sup>17</sup>, or they may simply be more susceptible to coercion or manipulation in their decision-making. If this discussion is to progress beyond the level of conjecture, evidence must be put forward to demonstrate the failure of safeguards to protect vulnerable members of society from the putative risk of abuse. Existing data, however, do not currently support this conclusion.

### Depression

Requests for assisted death made by patients with mental illness present a particular challenge for advocates of assisted dying. In the US, but not in Canada, access to assisted suicide is restricted to people suffering from incurable physical illnesses. Some proponents of legalised assisted dying argue that this restriction should be lifted because "[i]ncurable disease conditions that are not

<sup>12</sup> Madersvedt LJ et al (2003). "Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force". *Palliative Medicine* 17: 99.

<sup>13</sup> Chambaere K and Berhneim JL (2015). "Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience". *Journal of Medical Ethics* 41: 658.

<sup>14</sup> Hurst SA and Mauron A (2006). "The ethics of palliative care and euthanasia: exploring common values." *Palliative Medicine* 20: 107.

<sup>15</sup> Heyer (2011): 75

<sup>16</sup> King and Wolf (1998):1016

<sup>17</sup> Cohen-Almagor R (2017). "Euthanizing People Who Are 'Tired of Life' in Belgium". In (eds.) Jones DA, Gastmans C and MacKellar C, *Euthanasia and Assisted Suicide: Lessons from Belgium*. Cambridge: Cambridge University Press pp. 188-201.

terminal by most definitions can also render competent people's lives not worth living in their own well-considered judgement"<sup>18</sup>. If someone is suffering as a result of a mental illness which will not end his or her life in a matter of weeks or months, there is no 'natural way' to bring an end to [her] continuing suffering<sup>19</sup>. If it is the suffering of people living with incurable illness which justifies their competent requests for assistance in dying, then it could be argued that the law permitting assisted dying in the US discriminates against people living with mental illness by not acknowledging the devastating impact of illnesses such as depression on people for whom available therapies fail<sup>ii</sup>.

In Europe, the law does not distinguish between physical and mental illnesses as grounds for requesting assisted dying; nor does it require a specific prognosis. Patients do not have to suffer from a terminal or physical illness to be eligible to request assistance in dying; it is sufficient that a competent patient experiences unbearable suffering which has no prospect of improvement. Between 2005 and 2013, the percentage of people with a diagnosis of mental illness or dementia (but not physical illness) who were assisted to die in Belgium increased from .8% to 3.9% of all cases of euthanasia (197 cases in total)<sup>20</sup>. Of notified cases in the Netherlands in 2016, 60 individuals with mental illness and 141 individuals with dementia (primarily early-stage dementia) received assistance in dying. Although these numbers are small and although all except one were judged to meet the Dutch due care criteria, these cases are increasing year on year<sup>21</sup>, and the data raise concerns about a potential broadening of the eligibility criteria for assisted death. While the presence of a depressive disorder does not automatically entail that a patient lacks decision-making capacity, depression can compromise a person's capacity to adjudicate his or her own experienced quality of life. A misdiagnosed patient may receive assistance in dying "when competent psychiatric, psychotherapeutic or other treatment might have permitted her to improve her quality of life to such an extent that she would not have wanted to see her life prematurely terminated"<sup>22</sup>. For this reason, expertise and caution are required in reviewing requests by patients with mental illness, particularly depression and mood disorders, for assistance in ending their lives.

Worryingly, a study of Dutch data published earlier this year found that the requirement that an independent psychiatrist be consulted by the referring physician in situations where patients with mental illness request assistance in dying was not met in all cases<sup>23</sup>. However, a proposal to change the review procedure to include a mandatory psychiatric assessment of all cases concerning patients with mental illness has recently been accepted by the Dutch regional review committees<sup>24</sup>. A robust approach to capacity assessment and the involvement of a psychiatrist in all such cases would potentially act as safeguards to ensure that the decision made "is the outcome of an adequate weighing process and is stably enduring through time"<sup>25</sup>. Finally, given the ambiguity of some of the Belgian and Oregonian data, further research is needed to determine the effect of treatment for depression on patients' requests for assisted dying<sup>26</sup>.

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<sup>18</sup> Schuklenk U, Van de Vathorst S (2015). "Treatment-resistant major depressive disorder and assisted dying". *Journal of Medical Ethics* 41: 578.

<sup>19</sup> Schuklenk and de Vathorst (2015), 578.

<sup>20</sup> Dierickx et al (2016): 3

<sup>21</sup> Regional Euthanasia Committee (RTE) Annual Report 2016: 13.

<sup>22</sup> Schuklenk and de Vathorst (2015): 578

<sup>23</sup> Kim, (2017). "Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands, 2011 to 2014". *JAMA Psychiatry* 73 (4): 367.

<sup>24</sup> Den Hartogh G (2015). "Why extra caution is needed in the case of depressed patients". *Journal of Medical Ethics* 41 (8): 589.

<sup>25</sup> Den Hartogh G (2015): 588.

<sup>26</sup> Ganzini et al (2008).

## Perceptions of disability and the value of life

Disability rights organisations and advocacy groups are strenuously opposed to the legalisation of assistance in dying on the grounds that it would have a disproportionate impact on persons with disabilities and because it would reinforce “pervasive (...) assumptions that life with a severe disability is unbearable and not worth living”<sup>27</sup>. Proponents of assisted dying and disability rights organisations have ‘profoundly different understandings’ of how illness and disability affect the quality and meaning of a person’s life<sup>28</sup>. Much of the discourse around the right to assistance in dying is focused on the perspective of people who are in great physical pain, have lost control of their bodily functions, and are wholly or partially dependent on others for everything they need. The rejection of this kind of life is used by some terminally-ill patients as a rationale for requests for assisted death. Yet, for many persons with disabilities, restricted mobility, functional impairment and dependence on others are realities of daily life and they claim that the implication that this way of living is undignified, humiliating or intolerable reinforces existing prejudices about people with disabilities and diminishes the value of their own lives.

Disability rights scholars argue that social privilege may limit our appreciation of the consequences of a policy change “whose greatest impact could be felt by socially marginalised groups”<sup>29</sup>. This is a compelling reminder that persons with disabilities require resources and support to enable them to become integrated into society and to navigate the discrimination they experience in the healthcare setting as well as in the community. However, taking disability rights seriously does not necessarily entail curtailing the autonomy of those who request assistance in dying. These are two distinct kinds of situation: a person who has lost the ability to function is permitted to find that loss of function intolerable on her terms, without prejudice to a person who has lived all her life with disability and has the resilience to cope with it. These are simply different ways of enacting one’s autonomy. No two individuals have the same personal experience of disability<sup>30</sup> and adjudicating the value of one’s own life is a complex and deeply personal judgement which does not imply a judgement about the value or quality of the life of another person. Supporting people with disabilities should not mean denying others who experience intolerable suffering the right to request assistance in dying. But the disability perspective must be heeded in the debate on assistance in dying because there is a real danger that the stigma surrounding the experience of disability may influence some terminally ill people to request assistance in dying<sup>31</sup>. Assisted dying should never become a substitute for “effective psychosocial intervention and support in cases in which individuals requesting physician-assisted suicide cite isolation and loneliness as reasons for their requests”<sup>32</sup>.

## What the data shows

Powerful arguments have been put forward both in support of legalised assistance in dying and in opposition to it. Advocates for both sides cite evidence to substantiate their respective positions. Available data from official sources in Oregon, Washington, Belgium and the Netherlands seem to support the view that the practice of assisted dying in those jurisdictions operates within its intended limits. Reviewing evidence from Oregon and the Netherlands, Smith J in *Carter v Canada*

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<sup>27</sup> Heyer K (2011). “Rejecting Rights: The Disability Critique of Physician-Assisted Suicide”. *Studies in Law, Politics and Society* 54: 97.

<sup>28</sup> Asch, A (2005). “Recognizing Death while Affirming Life: Can End of Life Reform Uphold a Disabled Person’s Interest in Continued Life?” *Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report Special Report* 35 (6): S31-S36.

<sup>29</sup> Gill, Carol J (2010). “No, we don’t think our doctors are out to get us: responding to the straw man distortions of disability rights arguments against assisted suicide”. *Disability and Health Journal* 3: 32.

<sup>30</sup> Gill (2010), 36.

<sup>31</sup> Gill (2010), 37.

<sup>32</sup> Applebaum P (2016). “Physician-Assisted Death for Patients with Mental Disorders - Reasons for Concern”. *JAMA Psychiatry* 73 (4), 325.

(2012) found that there was no evidence to support the claim that assisted dying posed greater risk to socially vulnerable populations and concluded that “it is possible for a state to design a system that both permits some individuals to access physician-assisted death and socially protects vulnerable individuals and groups”.<sup>33</sup> In a recent study of legal assistance in dying in the US, Europe and Canada, Emanuel and colleagues found that the evidence consistently demonstrated that “those who avail of the practice are more likely to be white, educated and living with a diagnosis of terminal cancer”<sup>34</sup>, while Rietjens and colleagues found that euthanasia was “performed less often among the elderly, women, less-educated individuals and unmarried patients and [that] there was no clear evidence for a slippery slope”<sup>35</sup>. In 2016, 80% of reported cases of life-ending practices in the Netherlands were classified as ‘straightforward’, whereas 20% raised complex issues which were investigated by the relevant regional euthanasia committee<sup>36</sup>.

Although statutory due care criteria are in place to promote transparency and accountability in jurisdictions in which assisted dying is legal, however, critics of the process query whether these safeguards are adequate to protect vulnerable patients from abuse. Authors of a recently-published analysis of 32 Dutch cases in the period 2012-6 in which the due care criteria were not met point to violations of the eligibility criteria for assisted dying, difficulties experienced by physicians in interpreting some of the due care criteria (especially the unbearable suffering criterion), and situations in which physicians “knowingly pushed the boundaries of the [euthanasia/ assisted suicide] law”<sup>37</sup>. These failures raise a legitimate concern about “whether a trust-based retrospective review system [such as that in existence in the Netherlands] provides adequate oversight for particularly vulnerable patients”<sup>38</sup>. Although verification of cases of abuse would not serve as proof that the legislation is flawed, because abuses will occur under any legislative regime<sup>39</sup>, these data highlight the need for ongoing scrutiny of the robustness of the existing safeguards, especially given the increase in Belgium and the Netherlands in the number of patients with neuropsychiatric illnesses who are requesting assistance in dying<sup>40</sup>.

However, basing arguments for or against legalisation entirely on available data is problematic, because “partisanship on the issue of physician-assisted suicide makes it extremely difficult to assess the data objectively”<sup>41</sup>. While it may seem straightforward to argue that the need for assistance in dying must be assessed and weighed against the risks of misuse, abuse and error<sup>42</sup>, determining what weight to ascribe to the relative benefits and risks associated with the practice is far from

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<sup>33</sup> Carter v Canada (Attorney General) [2012] BCSC 886 at 666-7. See also Battin M et al (2007). “Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in “vulnerable” groups “. *Journal of Medical Ethics* 33:591–597.

<sup>34</sup> Emanuel et al (2016): 80.

<sup>35</sup> Rietjens J et al (2012). “Medical end-of-life decisions: does its use differ in vulnerable patient groups? A systematic review and meta-analysis”. *Social Science and Medicine* 74 (8): 1286. See also Dierickx et al (2016). “Euthanasia in Belgium: trends in reported cases between 2003 and 2013”. *Canadian Medical Association Journal* 188 (16), E412.

<sup>36</sup> Dutch Regional Euthanasia Committees (RTE) Annual Report (2016): 19.

<sup>37</sup> Miller DG and Kim SYH (2017). “Euthanasia and physician-assisted suicide not meeting due care criteria in the Netherlands: a qualitative review of review committee judgements”. *BMJ Open* 7 (10): 2ff.

<sup>38</sup> Miller and Kim (2015): 11.

<sup>39</sup> Dahl and Levy (2005), “The case for physician-assisted suicide: how can it possibly be proven?” *Journal of Medical Ethics* 32: 336.

<sup>40</sup> Dierickx et al (2016): E410.

<sup>41</sup> Dahl E and Levy N (2005): 336.

<sup>42</sup> Steinbok B (2004). “The case for physician-assisted suicide: not yet proven”. *Journal of Medical Ethics* 31, 235.



straightforward<sup>43</sup> because it is inevitably underlain by values and assumptions about what constitutes harms and benefits<sup>44</sup>.

### Palliative or continuous deep sedation

Data from Europe indicate an increase in the administration of medication to alleviate distressing symptoms at the end of life<sup>iii</sup>. Palliative sedation is defined by the European Association for Palliative Care as “the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and healthcare providers<sup>45</sup>. Sedation “is potentially indicated for patients with intolerable distress due to physical symptoms, when there is a lack of other methods for palliation within an acceptable time frame and without unacceptable adverse effects”<sup>46</sup>. Palliative care providers argue that, although the use of sedation at the end of life may have the effect of shortening a patient’s life, this practice is distinct from assisted dying because the intention of the physician is not to hasten death, but only to relieve refractory symptoms, and the medications used for this purpose are not the same as the agents which are used to assist death<sup>47</sup>. Advocates of assisted dying, however, point to the difficulty of drawing a clear line between palliative sedation and assistance in dying. Great care is needed to manage palliative sedation appropriately in order to be able “to distinguish end-stage palliative sedation from euthanasia without having to refer to intentions that are difficult to verify”<sup>48</sup>. A recent study found that “in some cases continuous sedation was resorted to as an alternative option at the end of life when euthanasia was not an option”<sup>49</sup>. For reasons of space, this issue cannot be discussed here in detail, but there is a need for close monitoring of the practice of palliative sedation in countries in which assisted dying is legal.

### Erosion of trust

Those opposed to assisted dying argue that the legalisation of this practice distorts the values of medicine, jeopardises the relationship between physician and patient<sup>50</sup> and will ultimately undermine trust in the medical profession. Conversely, advocates of assisted dying argue that trust can be maintained, and may even be increased, by clarification of “the parameters of legal [euthanasia/ assisted suicide] and strict and explicit respect of patient choices at the end of life”<sup>51</sup>. The Dutch notification process is seen to promote transparency<sup>52</sup> and a majority of Dutch physicians believe that the legislation has provided them with greater legal clarity and enhances the care with which they approach requests for ‘life-terminating acts’<sup>53</sup>. That medicine is an evolving discipline based on dynamic values is evident from the fact that some professional associations in Belgium, the

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<sup>43</sup> Dahl and Levy (2005): 336

<sup>44</sup> Coggon J (2005) “Arguing about physician-assisted suicide: a response to Steinbock”. *Journal of Medical Ethics* 32: 339.

<sup>45</sup> Czerny et al EAPC, 2009, 581.

<sup>46</sup> Radbruch et al., 2016: 111

<sup>47</sup> Chambaere K, Cohen J, Robijn, L, Baily, SK, Deliens L (2015). “End-of-life Decisions in Individuals Dying with Dementia in Belgium”. *Journal of the American Geriatric Society* 63: 290.

<sup>48</sup> Reutzel et al (2008). “Inappropriateness of using opioids for end-stage palliative sedation: a Dutch study

<sup>49</sup> Robijn et al (2017). “Reasons for continuous sedation until death in cancer patients: a qualitative interview study”. *European Journal of Cancer Care* 26: e12405ff.

<sup>50</sup> Radbruch et al (2016): 109.

<sup>51</sup> Hurst S and Mauron A (2006). “The ethics of palliative care and euthanasia: exploring common values” *Palliative Medicine* 20: 107- 112: 108

<sup>52</sup> Onwuteaka-Philipsen et al (2012): 908

<sup>53</sup> Rietjens et al (2009): 282. See also the Dutch Regional Euthanasia Committees (RTE) Annual Report (2016)



Netherlands and the US have formally changed their position in relation to the practice of assisted dying, while others have maintained a neutral stance. In 2008, for example, the American Public Health Association stated its support for physician aid in dying practised along the lines of the Oregon model. It remains to be seen whether other medical organisations will follow suit as the discussion of assisted dying unfolds.

What is absolutely vital in this debate is the attention it focuses on the need to improve care for people with disabilities, mental health issues and individuals with dementia, in order to ensure that they do not request assistance in dying “as a result of a lack of proper community and other supports”<sup>54</sup>. It is clear that improvements in the overall quality of end-of-life care “would benefit a much larger number of patients than those who request euthanasia”.<sup>55</sup>

## Conclusion

As an ethicist, my role is to identify and evaluate the harms and benefits associated with a given practice. I have attempted above to provide a balanced assessment of the principal harms and benefits associated in the literature with the legalisation of assisted dying. However, as mentioned above, empirical evidence “rarely settles ethical questions conclusively” because how facts are interpreted depends in large part on the viewpoint of the interpreter<sup>56</sup> and the ‘objectivity’ of the data generated by any study is coloured by human decisions about which questions to ask, and how. The debate concerning the permissibility of legalising assisted dying is highly polarised and stakeholders on both sides of the divide will interpret the available evidence in the light of their own value-systems. As an academic analyst (as opposed to someone who has a personal or a professional interest in the outcome of this debate), I concur with Lynn Smith J that the benefits of establishing a properly-regulated system of assisted dying with genuine oversight and robust safeguards outweigh the risk of harm to vulnerable persons. However, not until vast improvements are made in the provision and organisation of services to support those living with disability, mental illness or chronic physical conditions and in the provision of accessible, effective palliative care services should any legal changes be implemented.

In summary, legislatures considering legalising medical assistance in dying should be able to answer the following questions:

1. What criteria would render an individual eligible for such assistance?
2. What form would this assistance take and what would the role of the doctor be?
3. What due care criteria should be put in place (monitoring processes, mandatory reporting requirements, etc)?
4. Could adequate safeguards be put in place to ensure that persons requesting such assistance are not doing so out of compulsion or because their decision-making capacity is compromised by illness, anxiety or depression?
5. Could palliative care provision be enhanced to ensure that individuals making requests for assistance in dying have adequate access to such services?
6. Could supports for persons with disabilities be enhanced to reduce the likelihood that

<sup>54</sup> “Medical Assistance in Dying: A Patient-Centred Approach”. *Report of the Special Joint Committee on Physician-Assisted Dying*. Canadian Parliament (February 2016): 3

<sup>55</sup> Lo, Bernard (2012). “Euthanasia in the Netherlands: what lessons for elsewhere?” *The Lancet* 380: 870.

<sup>56</sup> Holm S (2015). “The debate about physician assistance in dying: 40 years of unrivalled progress in medical ethics?” *Journal of Medical Ethics* 41: 42.

- individuals will request assistance in dying because other supports are lacking?
7. Could trust in the medical profession be maintained in a healthcare context in which medicine facilitates the wish of certain patients to hasten death?

## Notes

<sup>i</sup>Between 2003 and 2010, Belgian spending on palliative care in home and home-replacement settings increased by 34%, accounting for 70% of the total increase in palliative care expenditure during this period. In 2010, 47% of all non-accidental deaths in Belgium involved multidisciplinary palliative care intervention. Almost all palliative care received in the home setting is reimbursed. Supporters of legalisation acknowledge that this increased funding is offset by the growing demand for palliative care involvement in situations in which euthanasia is requested. See Chambaere et al, 2015: 658.

<sup>ii</sup> “For these and other reasons, a Canadian expert panel in their report on end-of-life decision-making in that country recommended that terminal illness not be made a necessary condition for access to assisted dying”. See Schunklenk and de Vathorst (2015): 577.

<sup>iii</sup> Onwuteaka-Philipsen et al (2012) note an increase in continuous sedation until death (CDS) from 8.2% of all deaths in the Netherlands in 2005 to 12.3% in 2010. Onwuteaka-Philipsen et al (2012): 908.

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I would like to thank the Committee for inviting us to speak to day on what is a highly sensitive topic. I understand that the Committee is looking at what is happening in other jurisdictions in relation to 'the right to die with dignity'. Firstly I will tell you a little about our organisation.

Disability Action is an organisation working with people with disabilities in Northern Ireland for over 30years. We are a human rights based organisation and our work is underpinned by our own Charter of Rights and the UN Convention on the Rights of Persons with Disabilities.

As a campaigning body we work to bring about change and influence policy to ensure that people with disabilities are not disadvantaged in society and can make a valuable and valued contribution. I am not a lawyer or academic, I worked with disabled people and our members to produce a position paper on the issue. This only relates to Northern Ireland and we have not consulted or engaged disabled people outside of the jurisdiction on the issue.

In the UK there has been significant debate on the area of assisted dying. This is the terminology I will use as this is the terminology we use in relation to this issue. In 2010 we published a Position Paper which set out our position on Assisted Dying. In the years running up to this subject of assisted dying and the right to die were increasingly debated in the media, legislation had been proposed and individuals had sought clarification on the workings of the current law through appeals to the House of Lords. A consultation was undertaken by the Public Prosecution Service in relation to new guidance for prosecutors. There were key issues that we felt needed to be considered. I will go through some of them briefly and I am happy to take questions later.

## **Push for Legislative Change**

Lord Joffe attempted to bring legislation through the House of Lords in 2004 which was specifically regarding assisted dying for the terminally ill. However the definition of terminal illness that as used terms like 'is inevitably progressive' and 'cannot be reversed through treatment'. Disabled people felt that this 'could be them' and that it was a medical model that did not take any account of the social model of disability. The Bill was defeated in the House of Lords in 2006.

In July 2009 a free vote in the House of Lords on an amendment to the

Coroners and Justice Bill was defeated. The amendment would have removed the threat of prosecution from those who go abroad to help an assisted suicide.

The House of Lords Judgement (Purdy v Director of Prosecutions) in 2009 led to the Director of Prosecutions in Northern Ireland preparing an interim policy which was subject to public consultation. The Code for Prosecutors provides guidance in Northern Ireland as to how decisions as to prosecution should or are likely to be taken in the public interest.

## **Implications of the Debate for People with Disabilities**

While it is unlawful for someone to assist someone to die, there are few if any prosecutions. Whatever the reason, any law that is meant to protect some of the most vulnerable in our society is weakened by its lack of application.

We must also question the terminology of the 'right to die'. In UK and International Human Rights Law there is no 'right to die', there is the right to life, one of the most fundamental rights that we have.

Talking about a 'right to die' erodes the fundamental right of life that can be applied to ensure that we all are able to live with dignity and respect for our choices.

There must be a clear distinction between someone wanting to end their life because they are terminally ill and wanting control over the implementation of that decision and a person who wants to end their life because of the effects of their disability.

Fundamentally as a society we must ask ourselves if someone taking their own life because they have a disability is any different that someone taking their own life if they are not disabled. Do we as a society accept it more because it a person with a disability who has ended their own life rather than someone without a disability.

In the increasing complex debate on this issue, disabled people argue that society's acceptance of disabled people's deaths is as a result of their negative and stereotypical attitudes which see disabled people as passive and non-contributing. If we give this message out in society we are truly saying that a disabled person has less right to life than a non-disabled person.

## **Does Legislation Need to Change?**

People with certain medical conditions have firmly indicated that they want to make the choice about how they end their lives. These are often individuals with progressive conditions who fear that they may have to end their lives sooner than they would otherwise choose to ensure that they are fully in control of the decision and how and when it is implemented. They want some protection for their loved ones who may want to assist them at a later stage and who would be open to prosecution for assisting suicide.

Disabled people are concerned that the medical profession makes decisions on treatment based on how they perceive the individual's quality of life. The overwhelming response from disabled people is how anyone can, other than the individual, make that decision.

## **Conclusion**

Disability Action took a clear policy position on the issue in 2010 and this has not changed since.

Disability Action is opposed to the legalisation of assisted suicide. Whilst we believe that people should have a right to control in their lives, we believe that changing the law to benefit a small number of people would have much wider repercussion on how society values people with disabilities.

The stringent controls that would need to be put in place for the legalisation of assisted suicide would ultimately force the individual to forego his or her choice.

It is not a position we have been challenged on and it is as applicable today as it was then. The debate will continue, but until society values disabled people as fully contributing members of our society then it is unlikely our position will change – the risks are just too high.

Thank you for your time and I am happy to take any questions.

## Appendix 5 - Correspondence



COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH  
Ollscoil Átha Cliath

TRINITY COLLEGE DUBLIN  
The University of Dublin

Caoimhghín Ó Caoláin TD  
Chair, Justice and Equality Committee  
Dáil Eireann  
Dublin 2

1 Dec 2017

Dear Chairman

I am writing to the Committee on foot of reviewing the video of Dr Louise Campbell's presentation, and in particular in relation to her answer to your final question to her on her perception of a societal shift in the perception of medicine.

I think that her answer with respect to the 're a Ward' case was (almost certainly unintentionally) is a misrepresentation of the elements of this case and existing practice. Indeed, possibly in the heat of the moment, she mistakenly and repeatedly referred to removal of ventilatory support in this case, where in fact it was to the removal of feeding and hydration through a tube.

I was an expert witness for the family in this case, and the key issue was not one of preserving life at all costs but rather:

- a. concerns over what were the likely wishes of the Ward, and to what extent the perceived distress or burden was that experienced by the family or by the Ward - clinicians are deeply aware of how common it is that there are divergent assessments of quality of life between those with this significant disability and their families, with families more usually than not assessing this quality as lower than the assessment of the person directly affected.
- b. serious concerns over the diagnostic formulation of the Ward: the family were convinced that she had persistent vegetative state, and had enlisted the originator of the concept, the late Prof Jennett, to back this up. Disturbingly, it was clear to the expert witnesses that this was not the case: for example, she tracked with her eyes and the nurses felt that they had developed a relationship with her (although their witness was not accepted at the case). Prof Jennett had to recant from his original assessment that she had persistent vegetative state, and she was diagnosed as minimally conscious state. This is of relevance as there had been increasing attention at this time in rehabilitation circles about misdiagnosis of persistent vegetative state and missed opportunities for communication with those so labelled\*.

This case did not provoke a dichotomous temporal divide in clinical practice - as long ago as my time as a medical student in the late 1970's, it was clear in medical practice that there was no imperative to provide burdensome or futile treatment, and was clearly so stated consistently in the literature. Removal of treatment in the context of a serious acute illness which is not resolving has long been a part of the practice of medicine, as has that of providing comfort and relief of suffering.



What was different in this case was the removal of feeding from someone who had been largely clinically stable over several decades, a much more challenging decision, particularly in the light of points a) and b) above, and the Supreme Court recognised the challenges and complexities inherent in this case to the point that they stated that it did not represent a precedent for future practice, and that future requests to remove food and hydration from patients who were clinically stable would need to be considered afresh by the courts.

I hope that this is helpful and I have shared this reflection also with Dr Campbell.

\*Andrews K, Murphy L, Munday R, Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. BMJ. 1996 Jul 6;313(7048):13-6.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Desmond O'Neill', with a stylized, cursive script.

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## Addendum to Joint Committee submission

Louise Campbell

February 2018.

In what follows I would like to revise and correct my response to Mr. O’Caolain’s question during the Joint Committee meeting on November 29, 2017. I also wish to address the points raised by Professor O’Neill in his correspondence of December 1, 2017.

Towards the close of the discussion, Mr. O’Caolain asked me to substantiate the ‘blunt and bald’ statement that there has been a societal shift in the perception of the role of medicine. In what follows I provide a more complete response to this complex question.

(i) *Partnership between doctors and patients*

It is widely accepted in the literature on medical ethics and law that there has been a significant shift over the course of the past five decades from a paternalistic model of care provision to a conception of healthcare decision-making rooted firmly in patient rights, particularly their autonomy rights<sup>1</sup>. The right of patients to participate as equal partners in medical decision-making is now given expression in codes of practice for health professionals (particularly doctors)<sup>2</sup>, in guidance issued by professional associations, in healthcare policy and in recent case law<sup>3</sup>. That medicine is an evolving discipline, influenced by changes in social morality<sup>4</sup> - such as greater acceptance of diversity (including disability) and increased liberalisation - is evident from the evolution of medical codes of practice themselves<sup>5</sup>. It is of note that, to date, ten chapters of the American Medical Association have publicly stated their neutrality on the issue of assisted dying and that the American Public Health Association has publicly endorsed the practice<sup>6</sup>.

Shared decision-making between patients and doctors is now regarded as central to patient-centred care, encompassing the right of patients to have their values

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<sup>1</sup> Beauchamp T and Childress J (2001), *Principles of Biomedical Ethics*: 77. Faden R and Beauchamp T (1986). A

<sup>2</sup> Irish Medical Council (2009, 2016). *Guide to Professional Conduct and Ethics for Registered Medical Practitioners*.

<sup>3</sup> Montgomery v Lanarkshire Health Board. SC 11 [2015] 1 AC 1430.

<sup>4</sup> Creuss and Creuss (2008), 582.

<sup>5</sup> For example, informed consent to treatment is dealt with in a single brief paragraph in the 1981 *Guide to Ethical Conduct and Behaviour*, a full page in the 2004 *Guide* and five densely-packed pages in the 2016 *Guide to Professional Conduct and Ethics for Registered Medical Professionals*.

<sup>6</sup> APHA (2008). “Patients’ Rights to Self-Determination at the End of Life”.

and preferences elicited and heard in healthcare decision-making<sup>7</sup>. This realignment of the therapeutic relationship has been accompanied by a diminution in the authority of doctors; many patients now exercise their right to research their own health conditions and to obtain alternate opinions. The Bristol Royal Infirmary and Alder Hey Hospital scandals in the UK and the Michael Neary case in Ireland drew public attention to the need for increased accountability and transparency in the practise of medicine<sup>8</sup> and this has been reflected in legislation and in more stringent regulation<sup>9</sup>. Doctors now have to earn the trust of members of the public<sup>10</sup>, who expect them to account for their practice and conduct and are increasingly likely to complain if expected standards are not met<sup>11</sup>. Although this shift has been gradual, it marks a profound change from the paternalistic practices which were the norm prior to the 1970s and 1980s.

(ii) *The increasing importance of patient values and patient expertise*

The relatively recent emphasis on patient values in healthcare decision-making follows directly from the increasing importance placed on patient autonomy in many jurisdictions around the world during the last quarter of the twentieth century. Autonomy refers, not to unfettered choice, but to a person's capacity to determine what is important to her and her right to make decisions on the basis of those values. It is this capacity which entitles people to be partners in healthcare decisions which may have a great impact on their lives for years to come. The rise of autonomy in healthcare was initially fuelled, not by rampant individualism, but primarily by reports of exploitation of vulnerable participants in research, restricted access to healthcare provision for the poor and marginalised and decades of paternalism in the context of clinical decision-making<sup>12</sup>.

Since the turn of the millennium, the primacy of doctors' clinical expertise in the context of decision-making has been challenged by the idea that patients are themselves experts in the lived experience and day-to-day management of their

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<sup>7</sup> Institute of Medicine (2001). *Crossing the Quality Chasm*: 40. Chan et al (2017) "Montgomery and informed consent: where are we now?" *British Medical Journal* 357.

<sup>8</sup> Harding Clark Report (2006), S26.1

<sup>9</sup> Medical Practitioners Act (2007),

<sup>10</sup> Creuss R and Creuss S (2008). "Expectations and obligations: professionalism and medicine's social contract with society". *Perspectives in Biology and Medicine* 51: 4, 589.

<sup>11</sup> Complaints against doctors increased by 46% between 2008 and 2012. Irish Medical Council (2016). *Listening to Complaints, Learning for Good Professional Practice*. Available at: <https://www.medicalcouncil.ie/News-and-Publications/Reports/Listening-to-Complaints-Executive-Summary.pdf>

<sup>12</sup> Donnelly M (2010). *Healthcare decision-making and the law*: 12-16. Faden and Beauchamp (1986).

health conditions<sup>13</sup>. This emphasis on patient autonomy, expertise and values has made it impossible for doctors to continue to define the best interests of patients in purely clinical or medical terms, without seeking the views of the patient him- or herself. This is reflected in increased emphasis on advance care planning and in the introduction of a statutory provision for advance healthcare directives. In fact, the notion of best interests itself is so loaded with paternalistic overtones that it has been omitted altogether from recent Irish capacity legislation, and replaced with a recurring emphasis on the ‘will and preferences’ of the person making the decision<sup>14</sup>. This legislative nuance is ample evidence of a dramatic shift from doctor-centred to patient-centred medical practice.

In my response to Mr. O’Caolain’s question, I referred to *In re a Ward of Court*, a case which came before the Irish courts in 1995, in which the family of a woman who had been in a near-vegetative state for 23 years sought direction from the court in respect of the withdrawal of the artificial nutrition and hydration which were keeping her alive. In my effort to answer the question in the time remaining, I inadvertently mentioned mechanical ventilation instead of artificial nutrition and hydration. Professor O’Neill is correct to point out this mistake.

In brief, the point I was trying to make was this:

As society grows more accustomed to the widespread use of advanced technologies to sustain life, health professionals and members of the public are becoming increasingly aware of the limitations of such technologies in restoring function to many seriously-ill people, particularly elderly people with multiple health issues. A newer understanding of the concept of ‘best interests’ departs from the earlier emphasis on the preservation of life at any cost and the expertise of clinicians and incorporates in addition a weighing of balance of burdens and benefits which directly incorporates references to the person’s values and preferences<sup>15</sup>. Current codes of conduct state clearly that doctors are not obligated to start or continue treatment which is deemed futile or disproportionately burdensome, even if it prolongs the patient’s life<sup>16</sup>. A similar evolution in practice has taken place in relation to the

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<sup>13</sup> UK Department of Health (2001). *The expert patient: a new approach to chronic disease management for the 21<sup>st</sup> century*.

<sup>14</sup> Assisted Decision-Making (Capacity) Act (2015).

<sup>15</sup> UK Mental Capacity Act (2005)

<sup>16</sup> Irish Medical Council (2016). *Guide to Professional Conduct and Ethics for Registered Medical Professionals*, s45; Irish Medical Council (2009) *Guide to Professional Conduct and Ethics for Registered Medical Professionals*, s22. General Medical Council (2010). *Treatment and Care Towards the End of Life*.

withdrawal or withholding of clinically-assisted (or ‘artificial’) nutrition and hydration, which is now viewed explicitly as a medical treatment and no longer as ‘basic care’. Subsequent to the Supreme Court ruling in *In Re a Ward of Court* in 1995 that the removal of artificial nutrition and hydration from the Ward was lawful, both the Irish Medical Council and *An Bord Altranais* issued statements responding to the judgement<sup>17</sup>. The Irish Medical Council asserted that artificial nutrition and hydration constituted basic care (as opposed to treatment) and *An Bord Altranais* reaffirmed its commitment to the preservation of human life. The 2004 version of the Irish Medical Council’s *Guide to Ethical Conduct and Behaviour* reiterated the statement that ‘all reasonable and practical efforts should be made to maintain [artificial nutrition and hydration]’, described as ‘one of the basic needs of human beings’. But by 2009, the Irish Medical Council, in accordance with international evidence and practice, had redefined clinically-assisted nutrition and hydration as a medical treatment which doctors are not obligated to start or continue<sup>18</sup>. It is this shift in perspective – away from an emphasis on the preservation of human existence at any cost and towards a greater recognition of the complex interrelationship between autonomy and best interests – which I was trying to illustrate by referring to the *Ward* case. I see this as a gradual evolution in thinking and practice - informed both by international developments and by a greater maturity in Irish public discourse in the late 20<sup>th</sup> century - rather than in terms of a ‘dichotomous temporal divide’, to use Professor O’Neill’s phrase.

Finally, Professor O’Neill is correct to point out that the Ward’s diagnosis was revised in 1995, but it is not correct to say that she was diagnosed as being in a minimally-conscious state, since that diagnosis only originated in the work of Giacino and colleagues in 2002<sup>19</sup>. Presumably Professor O’Neill meant that the Ward was diagnosed as being in a ‘near persistent’ vegetative state as opposed to a ‘full’ persistent vegetative state. Whereas the vegetative state is characterised by “complete absence of behavioural evidence for self- or environmental awareness”, the person in the minimally-conscious state – a diagnosis which encompasses a very broad range of levels of responsiveness - may display some behaviours which indicate a minimal degree of interaction with their surroundings<sup>20</sup>. While patients may on rare occasions emerge from a vegetative state into a minimally-conscious state, predicting recovery from a continuing minimally-conscious state is extremely difficult. For both disorders of consciousness, recovery is extremely rare, the likelihood of significant functional improvement diminishes over time and, for most patients, any level of recovery is still associated with severe long-term disability<sup>21</sup>. The recent case *W v M*, which came before the UK Court of Protection in 2011<sup>22</sup>, illustrates the complexity of making decisions in

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<sup>17</sup> *Medico-Legal Journal of Ireland* 1:2.

<sup>18</sup> This shift reinforces the point made in footnote 5 above.

<sup>19</sup> Giacino JT et al (2002) “The minimally conscious state: definition and diagnostic criteria”. *Neurology* 58: 349-53.

<sup>20</sup> Royal College of Physicians (2013). *Prolonged disorders of consciousness: national clinical guidelines*: 3.

<sup>21</sup> Royal College of Physicians (2013), 9.

<sup>22</sup> *W v M and S and A NHS Primary Care Trust* 2011 EWHC 2443.

the best interests of someone in a minimally-conscious state<sup>23</sup>, but the controversy generated by the ruling in this case had as much to do with the statutory responsibility of the Court of Protection to consistently promote the best interests of people lacking decision-making capacity as with the perceived prioritising of life over the autonomy interests of the woman at the centre of the case.

Withdrawal of non-beneficial treatment from a critically-ill person (who may or may not lack capacity) is distinct from providing a patient who is capable of decision-making and suffering intolerably with medical assistance to end his or her life. Although these two kinds of situation should never be conflated, they have one important theme in common. That is the interest an autonomous person has in determining (in advance or contemporaneously) the value and quality of her own life and what is tolerable to her in terms of treatment, impairment, pain and disability. Patients' values, beliefs and past and present wishes are now a central component in the determination of their best interests, in situations in which they may be unable to voice their preferences<sup>24</sup>. The landscape of medical practice has changed dramatically in the past thirty years, and with this change has come a growing recognition by members of the public, by the courts and by medical professionals of the importance of the patient's voice in the context of treatment and decision-making. The increased engagement and participation of patients and members of the public in healthcare provision and policy development has far-reaching implications for the practice of medicine.

Thank you for your attention. I hope I have answered Mr. O'Caolain's question.

Yours sincerely,

Louise Campbell.

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<sup>23</sup> Damanta J and Samanta A (December 2017). "Awake and (only just) aware: a typology, taxonomy and holistic framework for withdrawing clinically-assisted nutrition and hydration in the minimally conscious state". *Medical Law Review* (published ahead of print).

<sup>24</sup> UK Mental Capacity Act (2015), S4.