



Irish Hospice Foundation Paper:
The International Experience of
Assisted Dying

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Contents

1. Introduction.....	1
2. Irish background and context	3
3. Terminology.....	4
4. Which jurisdictions permit assisted dying?	5
4.1 Europe	5
4.2 North and South America.....	6
4.3 Oceania.....	7
5. Trends in assisted dying.....	9
6. Eligibility for assisted dying	11
6.1 Age.....	11
6.2 Citizenship and residency	11
6.3 Illness and other circumstances	12
6.4 Decision-making capacity.....	14
7. Legislative safeguards.....	17
7.1 Requests for assisted dying.....	17
7.2 Reflection and waiting periods	18
7.3 Assessments and confirmations	18
7.4 Medication Management	19
7.5 Health professionals with a conscientious objection to assisted dying	19
7.6 Practitioner protections.....	19
7.7 Records, notification and review processes	20
7.8 Data collection and reporting.....	21
8. People who request and take up assisted dying	22
8.1 Characteristics of people who die by assisted dying	22
8.2 What reasons do people give for requesting assisted dying?	23
8.3 Where does assisted dying take place?	24
9. Palliative care and assisted dying	25
10. Summary	27
References	28

1. Introduction

Both voluntary euthanasia and assisted suicide are illegal under Irish law. As the Oireachtas Joint Committee on Justice and Equality (2018) pointed out, maintaining the current law as it stands is one course for the future in Ireland, and another possibility is the enactment of legislation to allow for some form of assisted dying. Events have moved on since the Oireachtas Joint Committee on Justice and Equality reported in 2018. Proposed legislation in the form of the Dignity with Dying Bill, 2020, is currently being considered by the Oireachtas Joint Committee on Justice, having been referred to it by the Dáil. This is the broad context in which this review was undertaken. Legislation is one of the most important instruments that governments use to organise society, and in addition to the question of which route should Ireland take – maintain the current status quo or enact legislation – two other questions are: (1) if legislation on assisted dying were to be enacted in Ireland, what should this legislation look like? and (2) what are the ethical, social, legal and policy implications of enacting such legislation?

This Irish Hospice Foundation (IHF) paper is a high-level rapid review on the international experience of assisted dying. It was undertaken to enable IHF to contribute to and help facilitate a measured, informed, balanced and compassionate debate about assisted dying. By presenting the experiences of and evidence available from a range of jurisdictions, this review seeks to gain insights into developments and experiences in other jurisdictions and identify important issues and questions that need to be carefully considered in the Irish context. In due course, it is intended that this paper will be read by a wide audience.

There is a limited but growing number of jurisdictions across the world where assisted dying is permitted. There is also a growing number of jurisdictions where legislative reform to permit assisted dying is either underway or under consideration. This review maps out and summarises the situation and key developments in selected jurisdictions that have legalised or are in the process of legalising assisted dying. A number of jurisdictions have considered assisted dying but have decided not to permit it (e.g. UK, US state of New York and some Australian states), and these jurisdictions will be referred to in this review, where relevant.

The paper draws on a range of sources including relevant legislation (Acts and Bills), official statistics, governmental and other official reports, and relevant governmental websites from a range of jurisdictions. Relevant journal articles, reviews and other publications have also been reviewed.

This report seeks to present the findings from the review in an objective manner, letting the evidence presented speak for itself. However, it is acknowledged that assisted dying is a highly complex issue and also highly controversial with powerful arguments put forward both in support of legalising assisted dying and in opposition to it (Campbell, 2018). In general, the notion of ‘evidence’ is problematic (Greenhalgh, 2018). As Holmes et al. (cited in Greenhalgh, 2018, p. 11), have stated:

‘The meaning of evidence is now the subject of lively debate. However, defined, the emerging consensus is that evidence is not a thing apart, generated in isolation and then passed on to those who will use it. It is clear that evidence alone does

not solve problems, and that myriad elements of context – including different professional, organisational and sectoral cultures and the role of power and politics – are critical considerations. ‘

In addition, evidence with respect to assisted dying is frequently informed by polarised opinion. Many ethical issues are raised by assisted dying, and ethical questions are rarely settled by empirical evidence (Campbell, 2018).

This paper has limitations. It is beyond the scope of this paper to provide an overview of the historical and social context to developments in the jurisdictions covered. Another shortcoming of this review is the limited extent to which the arguments and philosophical understandings behind the topics and issues identified have been considered and articulated.

The paper is structured around 10 sections. Section 2 briefly sets out the Irish background and context. Section 3 identifies and defines key terms, and outlines the terms that have been adopted for the purpose of this paper. Section 4 outlines which jurisdictions around the world have legalised assisted dying and what they have permitted. Section 5 presents an overview of the main trends and identifies key factors contributing to these trends. Section 6 covers eligibility criteria and how they vary between jurisdictions. Section 7 focuses on the range of safeguards put in place in various jurisdictions. Section 8 reports on who requests and takes up assisted dying, what reasons they give and where assisted dying takes place. The relationship between palliative care and assisted dying in different jurisdictions is examined in Section 9. Section 10 summarises the key findings from the review.

2. Irish background and context

In Ireland, in 1993, the Criminal Law (Suicide) Act 1993 decriminalised suicide. However, the act of “aiding, abetting, counselling or procuring” the suicide of another person remains a criminal offence and carries a maximum penalty of 14 years in prison (Campbell, 2018). Patients do have the right to refuse life-sustaining treatment. In Ireland, as in other jurisdictions, the law banning assisted dying has been subject to legal challenge and legal cases, and these form part of the legal context in Ireland relating to assisted dying. A case brought by Marie Fleming challenging the prohibition of assisted dying came before the courts in 2012. It was dismissed by the High Court in January 2013, and an appeal was dismissed by the Supreme Court later that year (Campbell, 2018). However, the Supreme Court made it clear that the Oireachtas is not precluded by the Constitution from legislating to decriminalise assisted dying in limited circumstances, and subject to appropriate safeguards. A legal case to come before the courts in 2014 related to the prosecution of Gail O’Rorke for allegedly assisting / attempting to assist her friend to die. She was found not guilty on three charges.

Politically, there have also been developments. A Private Members’ Bill, the Dying with Dignity Bill 2015, proposing to legislate for assisted dying, was introduced by John Halligan, TD, to the Dáil in November 2015, but did not advance through the legislative process at that time. As part of its Work Programme for 2017, the Joint Committee identified the Right to Die with Dignity as a priority issue for consideration and during November 2017, the Joint Committee examined the issue and reported in 2018 (Oireachtas Joint Committee on Justice and Equality, 2018). A second, Dying with Dignity Bill 2020, also a Private Members’ Bill, was tabled by Gino Kelly, TD, in September 2020. TDs voted to send the Bill to committee stage. Irish Hospice Foundation (IHF) has expressed concern that debate on the Dignity with Dying Bill, 2020, has been rushed and incomplete, and has called for a robust and balanced debate on the issue of assisted dying.

3. Terminology

When reviewing developments on assisted dying internationally, a key challenge is that many different terms are used. Two key terms are: euthanasia (voluntary and non-voluntary) and assisted suicide. *Euthanasia* is used when steps are deliberately taken with the intention of ending a person's life. A distinction can be made between voluntary and non-voluntary euthanasia. *Voluntary euthanasia* describes a situation where a lethal substance is directly administered to an individual at that person's request (Campbell et al., 2018; Dyer et al., 2015). *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' (Campbell, 2018). The main distinction that is usually made between euthanasia and assisted suicide is with regard to who performs the final, fatal act, the individual themselves or someone other than the individual. In euthanasia, the final act is undertaken by someone other than the individual, e.g. a doctor who administers a lethal substance intended to end the person's life. In assisted suicide, a lethal substance is prescribed to be voluntarily ingested by the person.

The terms *assisted dying* and *assisted death* are also commonly used. These terms are used to refer to both kinds of action, i.e. euthanasia (usually voluntary euthanasia), and assisted suicide. According to Campbell (2018), the use of terms such as assisted dying or assisted death is usually driven by a concern to avoid the negative connotations associated with terms such as euthanasia and suicide.

The terms physician-assisted suicide or medically-assisted suicide, and physician-assisted dying or medically assisted dying are also commonly used. More recently, the term 'medical aid in dying' and dying with dignity are sometimes used.

In addition to the wide range of terms used, the terms used often lack a common definition, and they can take on different meanings in different countries. For the purposes of this report and for the avoidance of any confusion, this report has opted to primarily use the term assisted dying as defined above. The terms voluntary euthanasia and assisted suicide are also used where relevant.

4. Which jurisdictions permit assisted dying?

There is a limited but growing number of jurisdictions across the world where assisted dying is permitted. In some, only assisted suicide is permitted, whereas in others both voluntary euthanasia and assisted suicide are permitted (Table 1).

Table 1: What is permitted in different jurisdictions and since when?

Assisted suicide only		Voluntary euthanasia and assisted suicide	
Jurisdiction	Year introduced	Jurisdiction	Year introduced
Europe		Europe	
Switzerland	1918	The Netherlands	2002
North America		Belgium	2009
US states of:		Luxembourg	2009
Oregon	1997	North America	
Washington	2008	Canada	2016
Vermont	2013	South America	
California	2016	Colombia	2015
Colorado	2016	Oceania	
District of Columbia	2016	Australia states of:	
Maine	2019	Victoria	2019
New Jersey	2019	Western Australia	From mid-2021
Hawaii	2019	New Zealand	From Nov 2021

Note: This may not be an exhaustive list of jurisdictions permitting assisted dying

4.1 Europe

There is a small number of countries in Europe where euthanasia and/or assisted suicide is permitted. In Switzerland, euthanasia is not permitted, but under Article 115 of the Swiss Penal Code, created in 1918, assistance with suicide is only considered a crime and open to prosecution if selfish interests are involved. In general, right-to-die organisations are involved in the process of assisted suicide in Switzerland. These organisations assist their members in dying (Steck et al., 2018).

Euthanasia is prohibited in the Netherlands under articles 293 and 294 of the Criminal Code (RTE, 2018). However, the Criminal Code makes an exception for physicians only. It is not a criminal offence if a physician performs euthanasia or assisted suicide in compliance with all the due care criteria set out in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, in force since 2002, and has notified the municipal pathologist (RTE, 2018). The law in the Netherlands ‘was a codification of a longstanding practice of condoning assisted dying’ (Widdershoven, 2005: 1). In contrast, Belgium, where both euthanasia and assisted suicide have been permitted by law since 2002, offers an example of a country where legalisation of assisted dying was enacted quite quickly in a country that had no longstanding tradition in this area

(Widdershoven, 2005). Both euthanasia and assisted suicide are permitted by law in Luxembourg since 2009.

In Germany, the provision of assisted suicide services was outlawed by a law —paragraph 217 of the German Criminal Code — introduced in 2015. The law did not allow a person either ‘the right to a self-determined death’ or ‘the freedom to take one’s life and seek help doing so’. However, following a campaign by doctors and terminally ill patients, this law was overturned by Germany’s Supreme Court in February 2020, which found it to be unconstitutional, and therefore void (Hyde, 2020). Legislation to reflect this decision needs to be drafted.

Both euthanasia and assisted suicide are illegal under law in other European countries. In Ireland, the Dying with Dignity Bill, 2020, currently before the Oireachtas, if enacted, will allow for voluntary euthanasia and assisted suicide. Alongside Ireland, debates on the legalisation of assisted dying have been or are currently underway in several other European countries including the UK, Finland, Spain and Portugal. The UK has maintained a firm stance against legislating for assisted dying, and assisted dying remains illegal under the Suicide Act, 1961. However, there are signs that the UK is moving towards a position where assisted dying is *de facto*, if not *de jure*, as cases of assisted suicide are not being prosecuted as an offence (Hurford, 2020).

In Finland, following the dismissal by Parliament of a Citizens’ Initiative on assisted dying, an Expert Working Group was established in 2018 to examine regulatory needs concerning end of life care and patients’ right to self-determination including terminal care and euthanasia. The work of Expert Working Group is ongoing and is expected to be continued until mid-2021. In its first phase, the working group is providing an overview of the health and social care system in Finland, and ongoing development with regard to the arrangement of palliative care and terminal care as well as the legislation governing end of life care. As part of this phase of work, the working group is also examining legislation and practices concerning euthanasia and assisted suicide in other countries. In its second phase, the Expert Working Group will conduct an initial assessment of the need for legislative changes concerning euthanasia. The Ministry of Social Affairs and Health has stated that palliative and terminal care services must be comprehensively put into practice, as it is only then that the actual need for legislative changes permitting euthanasia can be genuinely assessed. This view has the support of the Expert Working Group.

4.2 North and South America

In the US, criminal legislation is primarily drawn up by the individual states, and there are no nationwide compulsory regulations regarding euthanasia and assisted suicide. The federal courts must clarify whether the individual states’ legislation complies with the federal constitution. Euthanasia is prohibited in all states. In some states, initiatives have been taken to legalise assisted suicide including Oregon, Washington, Vermont, California, Colorado, the District of Columbia, Maine, New Jersey and Hawaii. Montana allows death with dignity by judicial ruling. A further

16 states are considering death with dignity, e.g. New York, and there are 25 states with no death with dignity legislative activity.¹

In Canada, assisted dying is referred to as medical assistance in dying (MAID). Quebec was the first province in Canada to set out the parameters for the provision of MAID to persons at the end of life when its government passed an Act Respecting End-of-Life Care in 2014. This provincial legislation came into effect in December 2015. Following a Supreme Court of Canada Judgement, federal legislation enacted Bill C-14 in Canada in June 2016, in the form of An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying). The MAID Act proposed amendments to the Criminal Code to allow physicians and nurse practitioners to provide a medically assisted death, in accordance with specified eligibility criteria and safeguards established under the legislation. The MAID Act came into force in June 2016 (Health Canada, 2020). Both voluntary euthanasia and assisted suicide are permitted in Canada.

The only country in South America where assisted dying is legalised is Colombia.

4.3 Oceania

In Australia, like the US, laws regarding assisted dying is the responsibility of individual states. It is commonly referred to as voluntary assisted dying (VAD). Laws (the Voluntary Assisted Dying Act, 2017, incorporating amendments as of 1 July 2019) permitting assisted dying came into force in the Australian state of Victoria in June 2019. It permits both voluntary euthanasia and assisted suicide. However, a doctor can administer the medication only if the patient is physically incapable of taking the medication themselves (McDougall and Pratt, 2020). Western Australia passed legislation in August 2019 which will allow voluntary assisted dying (both voluntary euthanasia and assisted suicide) to become a choice available to people. It is expected to come into force in mid-2021 (expected 1 July 2021), allowing for an 18-month implementation period.² While assisted dying is not currently lawful in other Australian States and Territories, this may change in the future as there have been many attempts to legalise assisted dying in Australian states and territories, and some are currently considering legislative reform in this area, e.g. Queensland.

In November 2019, New Zealand's Parliament enacted the End of Life Choice Act 2019 (NZ)³ to authorise the administration of a lethal dose of medication to competent adults suffering from a terminal illness likely to end his or her life within six months, should they directly and voluntarily request it. However, before this legislation could enter into force, it had to be approved by a majority of voters at a referendum on the Act, held at the general election on 17 October 2020. The results announced at the end of October 2020 revealed that a majority (65.2%) voted in favour of the referendum (Dyer, 2020); more than 50% of people had to vote 'Yes' in the referendum for the legislation to come into force. The results are binding and the Act will come into force in

¹ <https://www.deathwithdignity.org/in-your-state/>

² <https://ww2.health.wa.gov.au/voluntaryassisteddying>

³ <http://www.legislation.govt.nz/act/public/2019/0067/latest/DLM7285905.html>

November 2021, 12 months after the date of announcement of the final votes. The New Zealand Act permits voluntary euthanasia and assisted suicide.

5. Trends in assisted dying

This section examines the trends in assisted deaths in a range of jurisdictions, with a particular emphasis on those jurisdictions with longer-term experience of assisted dying.

Many countries that permit assisted dying report a steady increase in the number of cases of people receiving assistance with dying. In European countries, there have been steady increases in Switzerland, the Netherlands and Belgium, all countries with longer-term experience of assisted dying.

Switzerland: Steck et al. (2018) identified a total of 3,941 cases of assisted suicide of Swiss residents between 2003 and 2014. The number of cases of assisted deaths increased from 180 in 2003 to 688 in 2014, accounting for 0.32% and 1.3% of all deaths respectively.

The Netherlands: In the Netherlands, 6,361 cases of euthanasia were notified to the Regional Euthanasia Review Committees (RTE) in 2019, accounting for 4.2% of all deaths (RTE, 2020). This is up from 1,815 in 2003, the first full year of reporting by the RTE (RTE, 2004), more than a threefold increase.

Belgium: In Belgium, cases of assisted deaths are officially reported to the Federal Control and Evaluation Committee on Euthanasia. Between 2002 and 2018, over 12,000 people have been officially euthanised in Belgium. The number of reported cases of euthanasia increased year on year over this period, up from 235 (0.2% of all deaths) in 2003 to 1,807 (1.7% of all deaths) in 2013 (Dierickx et al., 2016). However, there appears to be significant under-reporting of deaths due to assisted dying in Belgium (Cohen et al., 2018).

The number of assisted suicides has also increased in Oregon and Washington, the US states with longest experience of assisted dying.

Oregon: In Oregon, the number of Dying with Dignity Act (DWDA) cases has risen from 16 in 1998 to 188 in 2019, accounting for 0.05% and 0.5% of all deaths, respectively (based on official annual reports).

In Canada, where assisted suicide has been legal since 2016, there has been a steady year on year increase in both the number of people requesting medical assistance to die and the number of people assisted to die by their doctor. In 2015, there were 1,012 cases of MAID reported in Canada. This rose to 5,631 reported cases of MAID in 2019, accounting for 2% of all deaths in Canada in that year (Health Canada, 2020).

In countries that permit both voluntary euthanasia and assisted suicide, the majority of people who avail of assisted dying opt for voluntary euthanasia. For example, of the 6,361 cases of assisted dying in the Netherlands in 2019, the vast majority (n=6,092; 95.8%) were cases of voluntary euthanasia;

the remainder were cases of either assisted suicide (n=245; 3.9%) or a combination of both (n=24; 0.4%) (RTE, 2020). The proportion of cases of assisted suicide (self-administered) in Canada is even smaller (n=<7; 0.12%); almost all of the 5,631 cases of assisted dying reported in Canada in 2019 were administered by a physician (Health Canada, 2020).

Assisted dying deaths as a proportion of all deaths (assisted dying death rates) tend to be higher in countries where both voluntary euthanasia and assisted suicide are permitted (e.g. 4.2% in the Netherlands) when compared with jurisdictions that permit assisted suicide only (e.g. 0.5% in Oregon). One of the concerns raised by opponents warning of a 'slippery slope' is that there will be steady year on year increases in both the number of people requesting assistance to die and the number of people assisted to die. While this has led to a focus on limiting the numbers of assisted deaths, there are differences of opinion with regard to what is an acceptable level of deaths from assisted dying. For some, assisted deaths at around 4% of all deaths is an indication that assisted dying is relatively rare (e.g., Campbell, 2018), whereas, for others (e.g., Keown, 2018), one in every 25 deaths due to assisted dying is considered to be significant. Borasio et al. (2019) have compared the frequency of assisted deaths in countries or states that allowed both euthanasia and assisted suicide (the Netherlands and Belgium) with the frequency of assisted deaths in countries or states that only allowed assisted suicide (Oregon and Switzerland). The authors concluded that legalising only assisted suicide with stringent procedural rules and safeguards that exclude patients who are not terminally ill seems to limit the number of assisted deaths and their increase with time (Borasio et al., 2019).

Factors other than procedural rules have been identified as contributing to increasing rates of assisted death. In Switzerland, the strong increase in the incidence of assisted suicide is linked to a broad acceptance in the Swiss population, as evidenced by surveys and confirmed by referenda (Steck et al., 2018). Similarly, in Belgium, it has been linked to a gradual increase in the acceptance of euthanasia in Belgian society (Dierickx et al., 2016). Using data from four waves of the European Values Surveys, Cohen et al. (2012) have shown that acceptance of euthanasia increased in Europe; it increased significantly in all western European countries including Ireland between 1981 and 2008, and increased less pronouncedly in most central and eastern European countries between 1990 and 2008. In Belgium, there have been increases in demand, as evidenced by the growth in the number of requests, and there has been a growing willingness among physicians to grant such requests (Dierickx et al., 2016; Chamberie et al., 2015). Population ageing may be a contributing factor. The vast majority of cases of assisted suicide in Switzerland are older people, and according to the FSO, the rise in the number of cases is a reflection of Switzerland's ageing population (FSO, 2016).

It is important to note that comparing trends between countries is fraught with difficulty because the legislation in different jurisdictions varies across a range of criteria. For example, countries that permit both voluntary euthanasia and assisted suicide often differ with regard to broad eligibility criteria. In addition, access to assisted dying is sometimes expanded over time, either through a relaxation of the interpretation of the safeguards or through court decisions that are handed down. The court decision handed down by the Quebec Superior Court on September 11, 2019, commonly known as the GladuTruchon decision, is one such example.

6. Eligibility for assisted dying

In countries where assisted dying is permitted, an individual must meet certain criteria to be eligible for assisted dying. The eligibility criteria for assisted dying, which can also be regarded as safeguards (Gunderson and Mayo, 2000), vary by jurisdiction. Key eligibility criteria include age, citizenship or residency, illness circumstances and decision-making capacity, and these are examined below. Some jurisdictions include ineligibility criteria in their legislation (e.g. New Zealand). A range of other safeguards are examined in Section 7.

6.1 Age

In most jurisdictions permitting assisted dying, eligibility is restricted to adults, i.e. people aged 18 years and older, including Luxembourg, Canada, the Australian states of Victoria and Western Australia, and New Zealand and the US states of Oregon (Table 2). Similarly, the proposed Irish Dignity with Dying Bill, 2020, specifies that an individual must be aged 18 years or over on the day that the declaration requesting assisted suicide is made.

In contrast, in Switzerland, any person capable of judgement can resort to assisted suicide regardless of age (FSO, 2014). In the Netherlands, anyone from 12 years of age can request assisted dying, but parental consent is sought if the child is under 16 years of age. In 2019, the RTEs in the Netherlands reviewed no notifications of cases of assisted dying involving a minor between the ages of 12 and 17 (RTE, 2020). The Dutch law permits physicians to terminate the lives of newborn infants with serious disorders once physicians fulfil specified due care criteria.

Table 2: Age eligibility in select jurisdictions

Restricted to 18+ years	Not restricted to 18+ years
Luxembourg	Switzerland
Canada	The Netherlands
Australian states of Victoria and Western Australia	Belgium
New Zealand	
US states of Oregon	

6.2 Citizenship and residency

Citizenship and / or residency are used as eligibility criteria in several jurisdictions. In **New Zealand**, an individual must be a citizen or a permanent resident of New Zealand. In **Oregon**, a person must be a current Oregon resident to be eligible for assisted suicide. The law does not require a person to have lived in Oregon for any minimum length of time. However, a patient must provide proof of residency to the attending physician. Forms of proof include, but are not

limited to: an Oregon Driver License, a lease agreement or property, ownership document showing that the patient rents or owns property in Oregon, an Oregon voter registration, or a recent Oregon tax return. It is up to the attending physician to determine if the patient has adequately established residency. In the Australian state of **Victoria**, in order to be eligible, a patient must be a resident of Victoria.

In **Ireland**, the proposed Irish Dignity with Dying Bill, 2020 states that a person must be resident on the island of Ireland and has been for not less than one year on the day that a declaration for assisted dying is made.

In **Canada**, MAID is delivered as part of a suite of publicly available health care services, and an individual must be eligible for publicly funded health care services to qualify (Health Canada, 2020).

Assisted suicide is allowed for Swiss citizens, foreigners resident in **Switzerland** and persons who travel to Switzerland from other countries. Because of the latter, Switzerland has become a destination for people internationally who wish to die by assisted suicide (Steck et al., 2018).

In **the Netherlands**, a request for assisted dying can be made by a person who does not reside in the Netherlands and has only recently arrived in the country. In such cases, it is up to the physician to decide if it is possible to comply with statutory due care criteria including having sufficient knowledge concerning the patient's medical history to be able to assess whether the patient's suffering is unbearable and without prospect of improvement and being convinced that the patient's request is voluntary and well-considered.⁴

6.3 Illness and other circumstances

Assisted dying can be made available to people who are terminally ill and to those who are not (Gunderson and Mayo, 2000). In some jurisdictions permitting assisted dying, a person must be terminally ill to qualify for assisted dying. However, the definition of what terminally ill means differs from one jurisdiction to another, there may be additional qualifying criteria, and some jurisdictions make it available only to those nearing death. For example, the terminal illness requirement is a prominent part of legislation in **US states** that permit assisted dying such as Oregon. Eligibility is limited to persons who have a terminal illness (usually defined as being within the last six months of life). In **New Zealand**, a person must suffer from a terminal illness that is likely to end their life in six months; have significant and ongoing decline in physical capability; and experience unbearable suffering that cannot be eased. To be eligible for VAD in the Australian State of **Victoria**, a patient must have an incurable condition expected to cause death within six months (12 months for neurodegenerative conditions), that is "causing suffering to the person that cannot be relieved in a manner that the person considers to be tolerable" (McDougall and Pratt, 2020). In **Ireland**, Section 7 of the proposed Dignity with Dying Bill, 2020 states that a

⁴ <https://www.government.nl/topics/euthanasia/is-euthanasia-allowed>

person is a qualifying person if the person is terminally ill. Under Section 8 of the Irish Dignity with Dying Bill, 2020, a person is terminally ill if that person –

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

In comparison to the US states and New Zealand, the definition of terminal illness seems to be broader in Ireland, as the person does not have to be nearing death, does not have to have significant and ongoing decline in physical capability and does not have to be experiencing unbearable or intolerable suffering. People with conditions such as motor neurone disease, multiple sclerosis and dementia that are not imminently terminal would potentially be eligible under the definition of terminal illness in the Irish Bill.

Excluding patients who are not terminally ill seems to limit the number of assisted deaths and their increase with time (Borasio et al., 2019). However, this restriction is not favoured by all. There are arguments for and against the terminal illness requirement. There are four main arguments against the terminal illness requirement. The first invokes compassion and the second invokes autonomy / self-determination. The third is that the concept of terminal illness is elusive and the distinction between patients that are terminally ill and those who are not is arbitrary and hence unfair. The fourth argument is that the concept of terminal illness is too vague and imprecise and therefore is not fit for the regulatory job asked of it (Gunderson and Mayo, 2000). A major concern, however, raised by opponents warning of a ‘slippery slope’ is that assisted dying may be initially restrictive, permitted only for competent, terminally ill patients who are suffering, but that it will only be a matter of time before the law becomes steadily more permissive with eligibility extended to other categories of people as a result of legal challenges. Opponents argue vigorously that extension of assisted dying to non-terminally ill people would expose vulnerable populations (Gunderson and Mayo, 2000). As well as people with chronic rather than terminal illnesses, vulnerable groups frequently referred to include older people, children, people with disabilities, people with dementia, people with illnesses that are stigmatised, e.g. AIDS, people who are disadvantaged and / or do not have access to good medical care, and people in minority groups who have experienced discrimination.

In some jurisdictions assisted dying is offered for anyone with a medical condition who experiences severe or intolerable physical or mental pain and suffering, whether or not they have a terminal illness (Gunderson and Mayo, 2000). In **Switzerland**, a person requesting assistance must suffer from a terminal illness, an unendurable incapacitating disability or unbearable and uncontrollable pain (Steck et al., 2018). The Benelux countries determine eligibility on this basis, among other criteria. In **the Netherlands**, the law does not distinguish between physical and psychological suffering: the suffering does not need to have a diagnosable origin.

In **Belgium**, the option of assisted is not restricted to people with a terminal condition. People with a chronic, non-terminal condition are also eligible, but such requests should adhere to the additional legal requirement of a 1-month waiting period between the assisted dying request and the performance of assisted dying. For people requesting assisted dying because of a terminal disorder, no waiting period is required.

The law in **Canada** is similar in some respects to that in the Benelux countries. In Canada, a person does not have to be diagnosed with a terminal illness, but the person must be diagnosed with a 'grievous and irremediable medical condition', and the person must meet all of the following criteria: serious and incurable illness, disease or disability; advanced state of irreversible decline in capacity; intolerable physical or psychological suffering. Unlike the Benelux countries, in Canada eligibility is limited to competent adults whose 'natural death was reasonably foreseeable'. Proximity to death is thus a requirement, but the requirement that natural death be reasonably foreseeable provides more flexibility than jurisdictions requiring a specific prognosis (e.g. six months) (Health Canada, 2020). The GladuTruchon decision may lead to the federal government removing the "reasonably foreseeable death" criteria from C-14 that limited access to MAiD to only those at the end of life.

The Netherlands has drawn up guidelines on assisted dying for semi-conscious patients.⁵

Some countries permit assisted dying for people living with dementia. In the Netherlands, a physician can perform euthanasia on a person with dementia only if an advance directive (living will) exists, if statutory care is taken and if, in his/her opinion, the patient is experiencing unbearable suffering with no prospect of improvement.

There is a strong lobby in the Netherlands for the legal right to assisted dying for a person who regards their life as completed and 'no longer worth living' (van Wijngaarden et al., 2018).

6.4 Decision-making capacity

Lewis and Black (2012) reported that of the jurisdictions internationally where assisted dying is legal, all include mental capacity as part of their safeguards. For example, in **Switzerland**, the person assisted with suicide must have capacity if their act is to be considered suicide. The physician must personally examine the person seeking assistance and assess their capacity according to the test set out in the Civil Code. Individual right to die associations have also developed their own tests (Lewis and Black, 2012). In **Oregon**, the attending physician and a consulting physician must determine whether the patient is capable of making and communicating health care decisions for him/herself. If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder (such as depression), the patient must be referred for a psychological examination. Capacity to make healthcare decisions is also an eligibility criterion for assisted dying in **Canada**. According to Lewis and Black (2012) only the Oregon and Washington statutes give an explicit definition of mental capacity.

⁵ <https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>

In **Ireland**, under the proposed Dignity with Dying Bill, 2020, a person must have the capacity to make the decision to end his or her own life. Under Section 10 of the Bill, the approach taken to the assessment of a person's capacity to make the decision is based on a functional test of capacity, which requires the person to demonstrate they can understand, retain, use and weigh information in order to make the decision, and can communicate the decision to others. The assessment of capacity for a person requesting assisted suicide is to be undertaken by two medical practitioners independently. Where a person is unable to complete one of these tasks in respect of the decision, she or he will be deemed to lack the capacity to make the decision, and as a consequence, his or her legal capacity to make the decision will be denied.

Lack of capacity appears to be a frequent reason reported for finding patients who have made a written request ineligible for assisted dying. For example, in Canada in 2019, lack of capacity was the most frequent primary reason reported for finding patients ineligible for MAID; in almost one-third (32.2%) of the 571 cases that were found to be ineligible, lack of capacity was given as the primary reason for ineligibility (Health Canada, 2020).

Capacity for decision-making as an eligibility criterion in legislation on assisted dying is not without its problems, as outlined by Price et al. (2014). The application of any definition of capacity in clinical practice is unclear and a number of difficulties arise including assessing and operationalising how a person uses and weighs information and how affective states impact on capacity. It has been argued that determining capacity is value-laden, and there may be a broad range of opinions about whether or not a person has capacity to make the decisions. Setting thresholds for capacity is not straightforward.

Price et al. (2014) found that experts contributing to the Commission on Assisted Dying in the UK, including those supportive of assisted dying, unanimously agreed that mental capacity should be included as a safeguard in any legislation on assisted dying. Nevertheless, from their review of submissions to the Commission, Price et al. (2014) found that, as capacity occurs along a spectrum, there are different conceptualisations of capacity. The boundaries between mental state and mental capacity can be blurred and it is not clear how depression might impact on decision-making capacity. The interface of capacity with other areas that might have a bearing upon its determination, particularly motivation, voluntariness, autonomy, rationality, was also blurred (Price et al., 2014). As Price et al. (2014) point out, such challenges are not unique to the assisted dying situation.

Some jurisdictions such as Oregon have developed guidelines for mental health professionals. Hotopf et al. (2011) suggest that there is an important role for psychiatrists to play in debates about assisted dying, and have identified three main areas where psychiatrists' expertise may be informative: (a) the complexities inherent in assessing mental capacity; (b) the extent to which safeguards to limit the availability of assisted dying to target groups can be applied safely and fairly, including to individuals with psychiatric disorders; and (c) the degree to which individuals adapt or change their desires, particularly in relation to suicidal behaviours.

Ireland is among a few countries internationally that has moved to provide support for the exercise of legal capacity based on the individual's 'rights, will and preferences' (Flynn, 2018). The Assisted

Decision-making (Capacity) Act was enacted in 2015, although this Act has not yet been fully commenced. If legislation permitting assisted dying were to be enacted in Ireland, the Province of British Columbia can offer useful lessons for Ireland for two reasons: (1) the Representation Agreement Act in British Columbia provides a well-known example of legislation that provides for supported decision-making (Flynn, 2018) and (2) assisted dying has been permitted there since 2016. In the Province of British Columbia, consent through an alternate or substitute decision maker or through a personal advance directive is not applicable.⁶

In addition to the safeguard that capacity should be present at the time the decision is being made, advance decision making for those likely to lose capacity in the future is not considered to be appropriate for assisted dying by many (Price et al., 2014), and is prohibited in many countries. However, in some countries, such as the Netherlands and Belgium, an individual may write an advanced directive outlining the circumstances in which they would want assisted dying to be performed, meaning that they need not have capacity to make the decision at the time of their death (Nicol and Tiedemann, 2015).

⁶ [Medical Assistance in Dying - Province of British Columbia \(gov.bc.ca\)](https://www2.gov.bc.ca/gov/content/health/care_services/assisted_dying/medical_assistance_in_dying)

7. Legislative safeguards

It has been acknowledged by supporters of assisted dying that there are dangers associated with assisted dying and a series of safeguards should be adopted. Different legislative frameworks have been adopted around the world, and this section outlines the range of safeguards adopted in jurisdictions permitting assisted dying. There are a high number of safeguards in legislation in Western Australia and Victoria (McDougall and Pratt, 2020). In Victoria, the Ministerial Advisory Panel on Voluntary Assisted Dying proposed a list of extensive safeguards for the legislative framework for Victoria (State of Victoria, Department of Health and Human Services, 2017). In appendices to its report, the Ministerial Advisory Panel considered how these safeguards compare with those operating in other jurisdictions in Europe and Northern America. These appendices are useful for comparing jurisdictions.

Safeguards are discussed here under the following headings: requests for assisted dying, reflection and waiting periods, assessments and confirmations, medication management, conscientious objection, practitioner protections, records, notification and review processes; and data collection and reporting. These headings are similar to those used by Victoria's Ministerial Advisory Panel (State of Victoria, 2017).

It is worth noting here that safeguards, like eligibility criteria, are subject to extensive debate and have proven to be controversial. On the one hand, it can be argued that if legislation to provide for assisted dying is enacted in Ireland, it will need to provide for a series of robust and carefully designed, carefully applied and monitored safeguards, in order to provide 'safety'. On the other hand, it can be argued that some provisions framed as 'safeguards' in legislation on assisted dying have substantial consequences for equal access, as has been argued by McDougall and Pratt (2020) using the Australian state of Victoria as a case example.

7.1 Requests for assisted dying

Common safeguards in relation to requests for assisted dying are:

- The request is a self-request only, that is, the request has to come directly from the eligible person
- The request is voluntary, well-considered and made without undue influence
- The request is a formal, written request
- In some jurisdictions, more than one request must be made. For example, in Victoria the legislated process for requesting voluntary assisted dying requires at least three formal requests (a minimum of two verbal and one written) to be made by the patient (McDougall and Pratt, 2020).
- The patient gives informed consent, e.g. patient has been made aware of all treatment options available
- The formal request must be witnessed and signed by independent witnesses and/or medical practitioners

In contrast to many other jurisdictions that permit assisted dying, the legislation in Victoria requires that any discussion of voluntary assisted dying must be initiated by the patient. It is prohibited for health professionals to raise voluntary assisted dying with their patients, and contravention of this prohibition is to be regarded as unprofessional conduct (McDougall and Pratt, 2020). The aim of this provision is to avoid coercion or undue influence by a health practitioner (Johnson and Cameron, 2018). However, it can, according to Wilmott et al. (2020), lead to less optimal patient outcomes.

7.2 Reflection and waiting periods

Legislation in some jurisdictions includes a waiting period or a reflection period, which can vary from one jurisdiction to the next. For example, in **Ireland**, the proposed Dignity with Dying Bill, 2020, provides that a period of not less than 14 days must have elapsed since the day on which the person's declaration took effect, but this can be reduced to six days in certain circumstances.

In **Canada**, MAID specifies there is a 10-day clear reflection period, but this can be waived in circumstances where death or loss of capacity is imminent. A retrospective cohort study of all MAID deaths in Ontario, Canada, between June 2017 and Oct 2018 found that the statutory 10-day reflection period was shortened for just over a quarter (26.6%) of people. The reflection period was significantly more likely to be shortened for patients who were followed or assessed by a palliative care provider and less likely to be shortened for neurodegenerative or respiratory disease compared with cancer. The reflection period was also less likely to be shortened for individuals living in an institutional setting, or when the estimated prognosis was 1–6 months or more than six months compared with a prognosis of less than one month (Downar et al., 2020).

In **Belgium**, there is a one-month waiting period requirement for people with a chronic, non-terminal illness requesting assisted dying, but not for those with a terminal illness.

7.3 Assessments and confirmations

Legislation can provide for confirmations that eligibility criteria are met. For example, in **Canada**, two independent practitioners must confirm eligibility criteria are met.

In **Ireland**, the proposed Dignity with Dying Bill, 2020, provides for two medical practitioners to be involved in confirming eligibility, the 'attending medical practitioner' and the 'independent medical practitioner'. In **Victoria**, two senior doctors are involved in assessing the patient's eligibility. The first is the lead doctor referred to as the "co-ordinating practitioner" who prescribes and administers the medication. The second is the "consulting practitioner" who conducts a second assessment of the patient's eligibility. In Victoria, in contrast to most other jurisdictions, both the coordinating and consulting practitioner must have received approved assessment training, before completing a first assessment.

Medical practitioners are also often involved in confirming that the request meets with legislative requirements, e.g. that the request has been made freely, without undue influence.

In Canada, the legislation provides for final confirmation and consent at time of administration or provision of medication or prescription of self-medication

7.4 Medication Management

Legislation in **Victoria** includes detailed provisions with regard to medication management including the role and responsibilities of pharmacists. This does not seem to be addressed by legislation in other jurisdictions, although in **Canada**, there is a requirement for pharmacists to inform the person.

7.5 Health professionals with a conscientious objection to assisted dying

In debates about assisted dying, there are differing opinions on whether to allow conscientious objection for assisted dying. At the extreme ends, one view is that conscientious objection should be prohibited altogether, and the other, that it should be allowed without any conditions, such as a requirement to refer a patient on to another health practitioner who does not conscientiously object, or to inform the patient of the existence of such practitioners. The concept of conscientious objection is commonly built into legislation as a safeguard for health professionals. Differences between countries tend to relate to the conditions attached,

For example, in **Ireland**, under the proposed Bill, there is no obligation for any medical practitioner or assisting healthcare professional to participate in anything authorised by the legislation on assisted dying to which he or she has a conscientious objection. However, there is a condition, that a person who has a conscientious objection ‘shall make such arrangements for the transfer of care of the qualifying person concerned as may be necessary to enable the qualifying person to avail of assistance in ending his or her life in accordance with this Act’.

In **Victoria**, there is strong protection in the legislation for health practitioners with a conscientious objection to voluntary assisted dying, and in contrast to Ireland, there is there is no requirement for health professionals with a conscientious objection to voluntary assisted dying to refer patients on to a willing practitioner (McDougall and Pratt, 2020). In **Western Australia**, the objector has an obligation to give patients some basic information about their options.

7.6 Practitioner protections

In the Netherlands, by law, physicians who perform euthanasia or assist in suicide are committing a criminal offence. However, they are not criminally liable if they comply with the statutory due care criteria and notify the municipal pathologist of their actions. A physician who performs either voluntary euthanasia or assisted suicide must fulfil the statutory due care criteria. Every instance of euthanasia and assisted suicide must be reported to one of the five regional euthanasia review committees. The committee will judge if the physician has taken due care. If a physician fails to do so, he may be prosecuted. Penalties vary but may be as much as 12 years in prison for euthanasia and up to 3 years for assisting suicide. The statutory due care criteria in the Netherlands are:

- Be satisfied that the request is voluntary and well-considered

- Be satisfied that the patient’s suffering is unbearable, with no prospect of improvement
- Have informed the patient about their situation and prognosis
- Have concluded, together with the patient, that there is no reasonable alternative in the patient’s situation
- Have consulted at least one other independent physician who must see the patient and give a written opinion on whether due care criteria have been fulfilled
- Have exercised due medical care and attention in terminating the patient’s life or assisting in the patient’s suicide.

In other jurisdictions, there are protections for health professionals who participate. In some jurisdictions they need to participate in good faith compliance, and in others there is no liability if the health professional complies with requirements.

Additional certification is required if a medical practitioner is to administer the lethal substance (i.e. perform voluntary euthanasia) in the Australian State of Victoria. Victoria is unusual in that it is mandatory for health professionals to notify authorities if another health professional acts outside the legislation. A member of the public can also notify authorities of a health professional acting outside the legislation, but this is voluntary, not mandatory (State of Victoria, 2018).

7.7 Records, notification and review processes

In Ireland, under the proposed Bill, there is an obligation to keep and provide records. However, there are no details on what information will be in the records and there doesn’t seem to be a provision for the establishment of a register.

Across different jurisdictions, it is most common for reporting to take place at after the final act has taken place, as proposed in the Irish Dignity with Dying Bill, 2020. However, in some jurisdictions, reporting must take place at various specified points, e.g. when a formal, written request is made; after the first/second assessment; when medication is dispensed.

For example, in **Canada**, under the Regulations for the Monitoring of MAID, physicians and nurse practitioners are required to report on all written requests for MAID, even if the request does not result in the administration of MAID. Pharmacists are required to report on the preparation and dispensing of substances in connection with the provision of MAID. Practitioners are required to provide other information such as basic sociodemographic information about the person requesting MAID; on the assessment of the request and whether eligibility requirements were met; information about procedural safeguards if MAID was provided; and information as to why a request may have gone unfulfilled (Health Canada, 2020).

In some jurisdictions the notification process is more detailed than others. For example, in some US states and Victoria, reporting forms are set out in the legislation.

Review committees have been established in many jurisdictions but other authorities are also often involved in the process. For example, in **the Netherlands**, as well as the medical practitioner who performs assisted dying, the review process involves the municipal pathologist and regional

euthanasia review committees. Where due care criteria are not complied with, the Board of Procurators General and the Health Care Inspectorate will become involved and the Regional Healthcare Disciplinary Boards or the Public Prosecutors and the Criminal Court may become involved.⁷ A Euthanasia Code outlining how the review process works in practice was first published in 2015 and was updated in 2018. It is primarily targeted at physicians who perform assisted dying and independent physicians (RTE, 2018).

In **Canada**, oversight varies by provinces, and includes review committees, the Chief Coroner's Office and professional regulatory bodies.

In **Victoria**, the Voluntary Assisted Dying Review Board has been established as the oversight committee. Its functions, powers, memberships, and procedures are set down in the legislation on VAD, as well as request by the Board for information, referrals of information.

In **Ireland**, the proposed Dignity with Dying Bill, 2020, provides for the establishment of an Assisted Dying Review Committee. However, there are no further details in the Bill about the Review Committee (e.g. its composition or functions) and there is no mention of other authorities that would be involved. Neither are there any details about the review process and what it entails.

7.8 Data collection and reporting

To support transparency and foster public trust in the application of the law on assisted dying, the consistent collection of information and public reporting on assisted dying is thought to be necessary. In some jurisdictions the requirements for collection and reporting of data are set down in legislation.

For example, in the **US**, Oregon's DWDA statute requires the Oregon Health Authority (OHA) to collect data on compliance and issue an annual report. The OHA states that it is committed to presenting data that are useful for informing the debate and public policy decisions, but takes a neutral position regarding the DWDA legislation.

In **Canada**, MAID legislation required the federal Minister of Health to make regulations to support data collection and reporting on both requests for, and the provision of, MAID. The Regulations for the Monitoring of Medical Assistance in Dying came into force in November 2018 (Health Canada, 2020).

Under VAD legislation in **Victoria**, the VAD Review Board must produce annual reports.

In **the Netherlands**, the regional euthanasia review committees publish an annual report in four languages in which they account for their work, both to government and to society.

⁷ <https://english.euthanasiecommissie.nl/review-procedure>

8. People who request and take up assisted dying

8.1 Characteristics of people who die by assisted dying

Gender

Deaths due to assisted dying are generally close to equal between men and women. In the Netherlands, of the 6,361 notifications of euthanasia received by the RTEs in 2019, 52% were men and 48% women (RTE, 2020). In Canada, the proportion of men and women receiving MAID was nearly equal with slightly more cases among men than women (Health Canada, 2020). This was also the case in Oregon; for the period 1998-2019 as a whole, 53% of men and 47% of women died from assisted suicide. However, during 2019, the pattern changed when 59% deaths from assisted suicide were men and 41% women.

Age

The majority of deaths due to assisted dying are of people aged 65 years and older. In the Netherlands in 2019, the highest number of notifications of euthanasia involved people aged 70 to 79 years (2,083 cases, 32.7%), followed by people aged 80 to 89 years (1,628 cases, 25.6%) and people aged 60-69 years (1,363 cases, 21.4%). There were 60 notifications concerning people aged between 18 and 40 years, including 38 people whose suffering was caused by incurable cancer and 10 people whose suffering was caused by a psychiatric disorder. In Oregon, of the 188 DWDA deaths during 2019, the majority (75%) were people aged 65 years or older, which is consistent with overall DWDA deaths between 1998 and 2019, 73.1% of which were people aged 65 years and older (Oregon Health Authority, 2020). In Canada, 80.5% of MAID deaths occur in people aged 65 years and older (Health Canada, 2020). There are relatively fewer MAID deaths in people in the 18 to 55 age group or people aged 91 years and over.

Underlying Illness conditions

In the Netherlands, in 2019, in the notifications of euthanasia, the most common underlying condition involved patients with incurable cancer, followed by neurological diseases (such as Parkinson's disease, multiple sclerosis, and motor neurone disease), cardiovascular disease, pulmonary disorders, or a combination of conditions (RTE, 2020). In Canada in 2019, cancer-related illness is the most frequently cited underlying medical condition associated with those receiving MAID. It is cited in 62.5% of cases (Health Canada, 2020). In Oregon, over the period 1998-2019, cancer was the underlying illness in 75.1%, neurological diseases in 11.3%, respiratory disease in 5.4% and heart/circulatory disease in 4.6% of DWDA deaths.

There were 106 cases notified involving people with early-stage dementia in the Netherlands in 2019. The RTE (2020) reported that these patients had insight into their condition and its symptoms, such as loss of bearings and personality changes, and were deemed to be competent to make decisions with regard to their request for euthanasia because they could still grasp the implications. Two notifications in 2019 involved patients at an advanced or very advanced stage of dementia who were no longer able to communicate regarding their request and in whose cases the advance directive was decisive in establishing whether the request was voluntary and well

considered. Among the notifications involving people with dementia, the majority (n=71) were in their 80s.

In the Netherlands, 2019, in 68 cases of notified euthanasia, the person's suffering was caused by one or more psychiatric disorders. The notifying physicians in these cases were psychiatrists, general practitioners, geriatricians, and other physicians. Most of the notifying physicians were affiliated to the Hague-based Euthanasia Expertise Center,⁸ which helps doctors carry out assisted dying (RTE, 2020). A Canadian study found that patients with psychiatric comorbidity comprise a substantial proportion of patients requesting MAID, highlighting the importance of recognising the psychiatric needs of patients requesting assisted dying and the involvement of psychiatrists in assessments (Isenberg-Grzeda et al., 2021).

8.2 What reasons do people give for requesting assisted dying?

People give a variety of reasons that prompt a request for assisted dying. The reasons are broadly similar across jurisdictions.

In Oregon, 'end of life concerns' most frequently reported by people who have died by assisted suicide in 2019 were 'less able to participate in activities making life enjoyable' (90.4%), 'losing autonomy' (86.7%) and 'loss of dignity' (72.3%). Other common concerns were 'burden on family, friends and caregivers' (59%), 'losing control of bodily functions' (39.4%), 'inadequate pain control or concern about it' (33%). Another concern given by 7.4% was 'financial implications of treatment'. The frequency with which these concerns are reported are broadly similar to previous years.

In Canada, practitioners are required to report on how the person requesting MAID described their suffering. Patients, when asked to describe the nature of their suffering prompting a request for assisted dying, gave a wide range of reasons. The most frequent reason given was 'loss of ability to engage in meaningful activities' (82.1% of cases) followed by 'loss of ability to perform activities of daily living' (78.1%). 'Inadequate control of symptoms other than pain (or concern about it)', 'Inadequate control of pain (or concern about it)' and 'loss of dignity' were given as reasons in 56.4%, 53.9% and 53.3% of cases respectively. In 34% of cases, the nature of suffering was described as 'perceived burden on family, friends and caregivers' and 'loss of control of bodily functions' in 31.9% of cases. 'Isolation or loneliness' was the reason given in 13.7% of cases (Canada Health, 2020).

⁸ This organisation was founded in 2012. It originated as a project from the NVVE, the Dutch Right to Die Society, and was originally called de Levensindekliniek (the End of Life Clinic). It was renamed Expertisecentrum Euthanasie in September 2019. The organisation counsels and supports physicians who are helping patients with a request for euthanasia and give care to patients who, for whatever reason, cannot be helped by their own physician. It has expanded to a professional health care organization, with a regional network of 140 physicians and nurses throughout the Netherlands. <https://expertisecentrum euthanasie.nl/en/>

A Canadian study based on a retrospective chart survey of 250 assessments for MAID carried out in the province of British Columbia in 2016 showed that reasons given tend to differ between people with different diagnoses (Wiebe et al., 2018),

8.3 Where does assisted dying take place?

Data from the Netherlands, Oregon and Canada show that the primary setting for assisted dying varies by jurisdiction, and sometimes within a jurisdiction.

In the Netherlands, in 2019, the vast majority of deaths as a result of assisted dying majority were at home (80.1%), followed by hospice (7.6%), care home (4.3%), nursing home (3.6%), a hospital (2.8%) or elsewhere (1.6%) (RTE, 2020).

In Oregon, where terminally ill patients must self-administer a lethal dose of medication, the vast majority (92.9%) of DWDA deaths were at home (i.e., in the patient's home or that of a family member or friend) over the period 1998-2019. Of the remainder, 4.7% were in an assisted living or foster care facility, 1.1% in a nursing home, 0.2% in a hospital, and 0.2% in a hospice facility (Oregon Health Authority, 2020).

A different picture emerges in Canada, where the primary setting for MAID deaths in 2019 were hospitals (36.3%) and a slightly smaller proportion (35.2%) were in patient's private residences. However, this varies by province. Some provinces report a higher proportion of MAID deaths at home, attributed in part to having strong care coordination services in place and sufficient distribution of practitioners in the community to support MAID deaths in the home. In other provinces, MAID is mainly provided in institutions and hospitals, which may be linked to procedural barriers limiting the ability of community pharmacists to prepare MAID medication as well of lack of infrastructure to provide MAID in the community, and to patient and provider preferences (Canada Health, 2020).

A variety of factors appear to influence where assisted dying takes place including form of assisted dying permitted, patient preferences, provider preferences, and the health and social care infrastructure.

9. Palliative care and assisted dying

Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems. Assisted dying, albeit performed for compassionate reasons, will hasten death. Accordingly, assisted dying, even if legalised, runs counter to the hospice philosophy and challenges the principles of palliative care in a fundamental way, particularly the principle that palliative care 'Intends neither to hasten nor postpone death'.

In both Belgium and Luxembourg, palliative care laws were passed establishing a right to palliative care simultaneously with their respective assisted dying laws (Shariff, 2012). The right to palliative care has not been established in Oregon (Shariff, 2012) or in Canada.

Most patients who die by assisted dying are enrolled with palliative care services.

Willingness to perform assisted dying is low among palliative care professionals. For example, a German study found that only 5.3% of palliative care professionals would be willing to perform euthanasia on a patient with terminal illness if asked to do so and reluctance grew with respect to patients with a non-terminal illness (Zenz et al., 2015). Low levels of willingness among health professionals to perform assisted dying highlight a key issue: if assisted dying is to be legalised, who will perform it and who should train doctors to perform it correctly? (Zenz et al., 2015)

Research from countries that permit assisted dying shows that palliative care and assisted dying intersect and are inextricably linked, but the relationship is complex (Shariff, 2012; Gerson et al., 2020a). The relationship between assisted dying and palliative care is variable ranging from supportive to conflicted, but little is known about how this plays out at a practice level (Gerson et al., 2020), how it impacts on service provision and how investment in assisted dying services impacts the investment in palliative and care at end of life. Assisted dying poses challenges for palliative care at the policy level, with regard to the development of guidelines and at a practice level. The limited evidence from other countries suggests that subtle dilemmas, uncertainties and variable practices are likely to emerge. Where legislation to permit assisted dying is enacted, these challenges are likely to be exacerbated if prior consideration is not given to the complex relationship between assisted dying and palliative care.

Gerson et al. (2020a) have identified the following questions: How does a person-centred multidisciplinary palliative care team work with patients who have voiced an interest in opting for assisted dying? What happens when a palliative care team want to support a patient in their decision to choose an assisted death and then come into conflict with an institutional policy or practice that objects to assisted dying as an option? What happens if evidence emerges suggesting that palliative care does work in conjunction with assisted dying once legislation has shifted the boundaries of what is permissible. What happens in a practical sense when a patient who is receiving palliative care and then opts for assisted dying, or alternatively, how might those choosing assisted dying then receive palliative care?

A follow-up qualitative study Gerson et al. (2020b) explored the relationship between palliative care and assisted dying in Quebec (Canada), Flanders (Belgium) and Oregon (USA) from the perspectives of clinicians and a range of other professionals involved in the practice in these jurisdictions. In Flanders, where an integrated approach has been adopted, assisted dying has become the special responsibility of palliative care. However, discontentment within palliative care was identified including in relation to internal conflict for clinicians, conflictual relationships between clinicians and patients requesting assisted dying because of poor knowledge about palliative care, insufficient time and effort given to psychosocial and spiritual aspects of suffering, failure to offer palliative as an alternative and the reification of the principle of autonomy. Concerns about the liberalisation of laws on assisted dying in Belgium and extension to people without terminal issues or psychiatric illnesses as well as a discourse that euthanasia is a preferable death were also raised. In Oregon, assisted dying and hospice have evolved together as part of a bigger picture with hospice care seen as complementary to assisted dying. However, institutional protocols are non-standardised and institutional policies vary. Access to medication and continuity of care are issues of concern in Oregon. In Quebec, the relationship between palliative care and assisted dying can be characterised as a contested one, with great opposition to assisted dying among the medical community and most palliative care professionals choose to conscientiously object. Most hospices in Quebec do not allow assisted dying and public knowledge about and access to palliative care is reported to be problematic.

Gerson et al. (2020b) concluded that there was no clear or uniform relationship between palliative care and assisted dying but that the relationship is influenced by a range of factors including legislation, variable institutional policies and support systems, the type of assisted dying introduced, and healthcare funding structures. However, across all three jurisdictions, a major concern is a lack of public knowledge, recognition and understanding of appropriate palliative care and access to it (Gerson et al., 2020b).

10. Summary

This draft paper is a preliminary high-level rapid review on developments on assisted dying internationally.

Switzerland and a growing number of US states allow assisted suicide. Assisted dying (i.e. both voluntary euthanasia and assisted suicide) are currently permitted in a small number of European countries, and in Canada, Colombia and the State of Victoria in Australia. It will be permitted in Western Australia and New Zealand by the end of 2021. The legislative framework for assisted dying varies considerably among these jurisdictions.

In jurisdictions that permit assisted suicide only as well as those that permit voluntary euthanasia and assisted suicide, there has been a steady increase in the number of people availing of the option. However, death rates due to assisted dying tend to be higher in those jurisdictions that permit both voluntary euthanasia and assisted suicide. Where patients have a choice between voluntary euthanasia and assisted dying, most opt for the former. Factors contributing to the growth in numbers include greater acceptability among the public, greater awareness, greater demand, less reluctance among physicians, and population ageing. There is no consensus on what is an acceptable death rate.

Key eligibility criteria include age, citizenship and residency, illness and other circumstances and decision-making capacity, and these vary by jurisdiction. Eligibility criteria can also be regarded as safeguards, and have proven to be controversial.

In all jurisdictions permitting some form of assisted dying, safeguards have been put in place, but again these vary from one jurisdiction to the next. Safeguards are wide-ranging. In jurisdictions with relatively high levels of safeguarding such as Victoria and Western Australia, a debate is emerging about the extent to which safeguarding is limiting equal access.

Men and women die by assisted suicide in close to equal numbers. However, assisted dying is age-related, as most are older people. Cancer is the most common underlying condition. Patients with psychiatric comorbidity are among those who opt for assisted dying and in some countries such as the Netherlands, people with dementia are permitted to opt for assisted dying.

People give a variety of reasons for their request for assisted dying, which are broadly similar across jurisdictions. A common reason is the loss of ability to participate in meaningful activities.

The relationship between palliative care and assisted dying is complex. While this relationship varies by jurisdiction, a common issue across all is the lack of public knowledge, recognition and understanding of appropriate palliative care.

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