

#### **POSTbrief 47**

By Devyani Gajjar, Abbi Hobbs

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# **Assisted dying**



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## Summary

The Government and Supreme Court's position is that any change to the law in this area is a matter for Parliament.

# Warning: This briefing discusses issues around end of life and suicide which some readers may find distressing.

There is no consensus on which terminology to use when debating the issue of whether people should be legally permitted to seek assistance with ending their lives. A range of terms are used internationally, and the choice of term often reflects underlying views on the debate. The terms used in this briefing are not intended to endorse or reflect any particular stance on the debate about changing the law.

'Assisted dying' refers here to the involvement of healthcare professionals in the provision of lethal drugs intended to end a patient's life at their voluntary request, subject to eligibility criteria and safeguards. It includes healthcare professionals prescribing lethal drugs for the patient to self-administer ('physician-assisted suicide') and healthcare professionals administering lethal drugs ('euthanasia').

It is an offence (in England and Wales) to assist or encourage another person's suicide under section 2(1) of the Suicide Act 1961. Euthanasia is illegal across the UK under the Homicide Act 1957 and could be prosecuted as murder or manslaughter.

This POSTbrief provides a brief overview of assisted dying, including ethical debate and stakeholder opinion. It examines how assisted dying functions within health services in countries where it is a legal option, focusing on jurisdictions where most data are available on outcomes: Belgium, Canada, the Netherlands, Oregon (United States), Switzerland and Victoria (Australia). It also covers evidence and expert opinion on key practical considerations that are raised in the context of assisted dying.

Further information on the criminal law on assisted suicide (a subset of assisted dying), human rights challenges and previous parliamentary activity is provided in the Commons Library briefing on <u>The law on assisted suicide</u>.

#### **Key points**

Key ethical debate centres on autonomy and the protection of vulnerable groups. Robust data on UK public perspectives on assisted dying and variations between different groups are limited. Public understanding of the term 'assisted dying' is low in the UK, but some recent UK polls and surveys suggest that a majority of the UK public support some form of assisted dying.

No medical Royal College has expressed support for changing the law on assisted dying in the UK. Several medical bodies are opposed, while others have moved from opposing assisted dying to a position of neutrality, meaning that they neither support nor oppose a change in UK law. At the time of writing, some form of assisted dying is legal in at least 27 jurisdictions worldwide. Legislation on eligibility and governance of assisted dying varies:

- In almost all jurisdictions, it is restricted to adults (including Canada, Oregon, Switzerland and Victoria), while in a few it can also include children with parental consent (including Belgium and the Netherlands).
- In some jurisdictions, assisted dying is restricted to people with terminal illness (including Oregon and Victoria). In others, it can also be accessed by those experiencing "constant and unbearable" suffering that cannot be relieved, but who are not terminally ill. This can be restricted to suffering arising from serious physical illness only (including Canada until 2023), or also include those whose suffering arises from psychiatric illness (including Belgium, Canada from 2023 and the Netherlands).
- In many jurisdictions where it is a legal option, assisted dying is provided as part of the healthcare system; in Switzerland it is not part of the healthcare system.
- Recent official data show that use in different jurisdictions varies. For example, recorded deaths from assisted dying were 0.59% of the total deaths in Oregon in 2021 and 4.2% of the total deaths in the Netherlands in 2019. Research suggests that there is underreporting of assisted dying in some jurisdictions where it is a legal option. Official figures show increasing use over time.

Research and stakeholders highlight a range of key practical considerations in the context of assisted dying. Many of these issues are interrelated and are raised in ethical debates:

- There are different perspectives on whether it is difficult to prevent incremental extension of legislation and eligibility criteria once assisted dying is legalised, and whether this is perceived as a concern or as removing barriers to access.
- Determining prognosis of terminal illness can be difficult and there is debate on how to evaluate whether suffering is "constant and unbearable". For patients with mental disorders, debate also focuses on how to assess whether suffering is irremediable or whether it could be relieved over time.
- Assessing patients' mental capacity for assisted dying requests is complex and can be particularly challenging where the person has psychiatric disorders, such as severe depression, which can impair decision-making capacity. There is also debate on who is best placed to assess capacity and identify potential coercion. The practice of relying on advance directives to authorise euthanasia and the use of assisted dying in those aged under 18 years is controversial.
- There are limited empirical data on the impact of assisted dying on vulnerable groups, including older people and people with disabilities, in jurisdictions where it is legal. Available studies do not report evidence that assisted dying has a disproportionate impact on vulnerable groups. However, concerns about potential abuses in some jurisdictions have

been reported in academic literature and several studies have called for detailed monitoring of assisted dying practice and further research.

- There is debate on whether assisting dying is compatible with the role of healthcare professionals. Research on the effects of their involvement in assisted dying on healthcare professionals in jurisdictions where it is a legal part of healthcare suggests that healthcare professionals have a range of experiences, both positive and negative.
- None of the drugs used for assisted dying are approved by a regulatory authority for medicines for a lethal purpose. There is not consensus on the most effective drug or drug combination for ending a human life and specific drugs, doses and monitoring vary.
- There is very limited research on the social and cultural impact of legalising assisted dying.
- There is debate on whether legalising assisted dying has an adverse or beneficial impact on palliative and end of life care (P&EOLC) resources and services. Evidence is mixed and suggests that the relationship between P&EOLC and assisted dying is varied and that impacts in any jurisdiction may not be the same as in other jurisdictions, even within the same country.

#### **Getting help**

If you are affected by the themes of this briefing, you can call Samaritans on 116 123 (UK and ROI) or visit the <u>Samaritans website</u> to find details of the nearest branch.

If you are covering a suicide-related issue, please consider following the <u>Samaritans' media guidelines on the reporting of suicide</u>, due to the potentially damaging consequences of irresponsible reporting.

# 1 Background

Many different terms are used in the assisted dying debate internationally and people do not agree on the terminology. Many different terms are used in the assisted dying debate internationally.<sup>1,2</sup> The following key definitions have been adapted from those used by the British Medical Association (BMA):<sup>3</sup>

- **'Physician-assisted suicide':** where healthcare professionals **prescribe** lethal drugs at the voluntary request of an adult patient with capacity, who meets defined eligibility criteria, to enable that patient to self-administer those drugs to end their own life. Sometimes referred to as **'physician-assisted dying'.**<sup>4,5</sup> In this briefing, the term physician-assisted suicide is used.
- **Euthanasia:** where healthcare professionals **administer** lethal drugs at the voluntary request of an adult patient with capacity, who meets defined eligibility criteria, with the intention of ending their life. Sometimes referred to as voluntary euthanasia or active euthanasia.<sup>6,7</sup>

People do not agree on the terminology. The term 'assisted dying' is sometimes used only where eligibility criteria are restricted to people who are terminally ill and are "reasonably expected" to die within 6 months.<sup>8</sup> The term 'assisted suicide' is sometimes used where eligibility criteria are not restricted to only those who are terminally ill.<sup>9</sup> Some proponents argue that prescribing patients lethal drugs is conceptually, medically and legally different to suicide and therefore should be called 'physician-assisted dying' not 'physician-assisted suicide.'<sup>10,11</sup> Some opponents do not consider the concepts distinct and contend that the term 'assisted dying' is ambiguous.<sup>1,4</sup>

This POSTbrief uses the term 'assisted dying' as an umbrella term to include physician-assisted suicide and euthanasia, unless specified otherwise.

# 2 Current law on assisted dying

Further information on the criminal law on assisted suicide (a subset of assisted dying), human rights challenges and parliamentary activity is provided in the Commons Library briefing on <u>The law on assisted suicide</u>.

The term 'assisted dying' does not currently exist in UK law. In England and Wales, suicide or attempted suicide are not in themselves criminal offences. However, under section 2(1) of the Suicide Act 1961 it is an offence for a person to carry out an act capable of encouraging or assisting the suicide (or attempted suicide) of another, with the intention of encouraging or assisting suicide or attempted suicide.<sup>12</sup> Euthanasia is illegal across the UK under the Homicide Act 1957 and could be prosecuted as murder or manslaughter.<sup>13</sup>

To date, the UK Government and Supreme Court have taken the view that any change to the law in this area is a matter for Parliament to determine as an issue of individual conscience. In a debate in the House of Commons in July 2022 on an e-petition to legalise assisted dying for terminally ill, mentally competent adults, the Parliamentary Under-Secretary of State for Justice responded on behalf of the Government that: "our neutral stance means that such a change would have to be made via private Members' legislation."<sup>14</sup> The Government response to the e-petition stated that: "If the will of Parliament is that the law on assisting suicide should change, the Government would not stand in the way of such change, but would seek to ensure that the law could be enforced in the way that Parliament intended."<sup>15</sup>

The 2010 Code for Crown Prosecutors sets out a list of public interest factors to consider when deciding whether to prosecute assisted suicide cases and the consent of the Director of Public Prosecutions (DPP) is required before an individual may be prosecuted.<sup>16,17</sup> In practice, prosecutions under section 2(1) of the Suicide Act occur rarely, with 4 convictions from 174 cases between April 2009 and March 2022.<sup>18</sup>

In early 2022 the Crown Prosecution Service (CPS) consulted on proposed changes to its legal guidance on homicide offences, which covers prosecution decision-making in murder and manslaughter cases. The consultation sought views on introducing new guidance on the public interest factors that prosecutors should consider when dealing with homicide cases involving failed suicide pacts or so-called 'mercy killings', defined by the CPS as "any killing in which the suspect believes they are acting wholly out of compassion for the deceased".<sup>19</sup> At the time of writing, there have been no further updates.

In Northern Ireland, assisted suicide is illegal under section 13 of the Criminal Justice Act 1966.<sup>20</sup> In Scotland, there is no specific statutory offence of assisting suicide. However, persons involved in assisting a suicide could be liable to prosecution under other offences, such as murder or culpable homicide.<sup>21</sup>

Several attempts have been made recently to change the law on assisted dying across the UK and in the Republic of Ireland and the British Crown Dependencies, by way of Private Members' Bills (see Box 1).<sup>22,23</sup> In November 2021, Jersey's States Assembly decided "in principle" that assisted dying should be allowed (Box 1).<sup>24</sup>

### Box 1. Recent examples of attempts to change the law on assisted dying across the UK, British Crown Dependencies and in the Republic of Ireland

- **UK Parliament**: The most recent Bill was the Assisted Dying Bill [HL] 2021-2022, a Private Member's Bill (PMB) introduced by Baroness Meacher (Crossbench), which aimed to legalise physician-assisted suicide for terminally ill, mentally competent adults.<sup>25</sup> The bill fell at the end of the 2021-22 Session. See the Commons Library briefing on <u>The law on assisted suicide</u> for a history of parliamentary activity.
- **Scottish Parliament**: In September 2021 a draft proposal for a Member's Bill to introduce "the right to an assisted death [physicianassisted suicide ] for terminally ill, mentally competent adults" was lodged by Liam McArthur MSP, accompanied by a public consultation.<sup>26</sup> At the time of writing, there has been no announcement on further stages.<sup>27,28</sup>
- **Tynwald (Isle of Man)**: In May 2022, the Tynwald agreed to allow Alex Allison MHK to introduce a PMB to "to enable adults who are terminally ill to be, at their request, provided with specified assistance to end their own life."<sup>32</sup> Before the bill is drafted, a consultation is set to be held on various principles, including the definitions of an adult and a terminal illness, as well as the legal protections needed. A public consultation is expected to be held later this year.<sup>33</sup>
- **States Assembly (Jersey)**: In November 2021 the States Assembly agreed, in principle, that physician-assisted suicide and euthanasia should be permitted in Jersey for terminally ill people and those with "an incurable physical condition that causes enduring and unbearable suffering".<sup>24,34</sup> This followed the recommendations of the Jersey 2021 Assisted Dying Citizens' Jury, which was established by the Government after a 2018 e-petition that called for the States Assembly to amend Jersey law and allow for assisted dying.<sup>24,35</sup> The States Assembly will consider more detailed proposals on assisted dying in November 2022 and, if legislation is passed, could implement an "assisted dying service" from May 2023.<sup>24</sup>
- **Oireachtas (Republic of Ireland):** In 2020-2021, the Joint Committee on Justice undertook pre-legislative scrutiny of the Dying with Dignity Bill 2020, a PMB introduced by Gino Kelly, accompanied by a public consultation. The bill aimed to legalise assisted dying for terminally ill, mentally competent residents on the island of Ireland, including euthanasia "in the case of a person for whom it is impossible or inappropriate to ingest orally."<sup>29</sup> The Committee decided that the bill should not progress.<sup>30</sup> However, it recommended that an Oireachtas Special Committee be established to examine the topic of assisted dying. One media report suggests that this Special Committee will be convened in September 2022.<sup>31</sup>

# 3 Key ethical debates

There is longstanding ethical debate across the UK concerning the legalisation of any form of assisted dying. There is also ethical debate about who should have access to assisted dying and under what circumstances. Ethical considerations also shape debates about the practical considerations raised by assisted dying.

This section briefly describes key ethical considerations put forward. There is a spectrum of ethical positions, and many stakeholders acknowledge the validity of some of the arguments both for and against assisted dying.

#### 3.1

Ethical debate centres on two first principles - personal autonomy and the sanctity of human life - and which of those principles should be given precedence when they conflict.

### Personal autonomy and the sanctity of life

In 2005, the House of Lords Select Committee on Assisted Dying for the Terminally III Bill observed that the ethical debate centred on two "first principles": personal autonomy and the sanctity of human life. Debates focused on questions about which of those principles should be given precedence when they conflict.<sup>7,36</sup>

Over the past two decades, the debate on assisted dying has been driven in part by legal challenges to the current regime, brought by people suffering from terminal illness or catastrophic injury. They have argued that various aspects of the existing law constitute violations of their human rights, as protected by the European Convention on Human Rights (ECHR) (see Commons Library briefing on <u>The law on assisted suicide</u>). In its judgements dealing with assisted dying cases, the European Court of Human Rights (ECHR) main focus has been on Article 2 (the right to life) and Article 8 (the right to respect for private life) of the ECHR.<sup>37–39</sup> It allows Member States a large "margin of appreciation" in balancing these interests in the regulation of end of life issues.<sup>39</sup>

There is also debate on the ethical distinctiveness of assisted dying compared to some other practices in end of life care that are legal, including withdrawing or withholding life-sustaining treatment and some forms of palliative sedation, in which medications are used to relieve otherwise intractable suffering at the end of life.<sup>40–43</sup>

The dominant view is that withdrawing or withholding life-sustaining treatment is ethically and clinically distinct to assisted dying, because withdrawing life support allows the patient to die but does not actively cause death. Some researchers have queried the ethical difference between 'allowing' and 'doing' but agree that withdrawing life-sustaining treatment is distinct to assisted dying based on a moral and conceptual distinction between foreseeing and intending.<sup>44</sup> Similarly, the dominant view is that palliative sedation is ethically and clinically distinct to assisted dying, because

it is not intended to end the patient's life. However, some ethicists have noted that actual practice in some countries of some forms of palliative sedation, such as continuous deep sedation until death (see 7.3), do make the ethical boundaries become less clear.<sup>42</sup>

### Arguments for and against legalisation

Analysis of debate in the House of Lords on the Assisted Dying Bill 2021-2022 found that the principal arguments for and against the Bill were:<sup>45</sup>

compassion;

3.2

- the relationship with palliative care;
- autonomy, choice and control; and,
- legal and social effects, including pressure and coercion and the relationship between patients and doctors and the public and the healthcare system.

There were shared concerns on both sides of the debate in these areas but understanding of the concerns differed considerably.

Key arguments in support of legalisation include that it could reduce suffering, provide "emotional insurance"<sup>46</sup> for those who take comfort in knowing that the option exists, and that it would provide a "safe, transparent and compassionate"<sup>40</sup> option compared to the current legal situation.<sup>6,47–49</sup> Proponents also argue the current law has led to inequalities, as only some people can afford and have the physical ability to travel to Switzerland for an assisted death, as well as some people ending their life earlier than they would want, because they have to be well enough to travel.<sup>46,47</sup>

Key arguments against legalisation include that it is unnecessary if patients' end of life care needs are properly met, that autonomy should not be prioritised when its exercise threatens the rights or interests of others, and that legalisation could devalue the lives of people living with disabilities and exert pressure on vulnerable people to end their lives.<sup>14,52–54</sup> Opponents also argue that it could have adverse effects on healthcare services, professionals and families, including negative impacts on doctor-patient relationships as well as healthcare professionals and families feeling conflicted.<sup>48,55</sup>

There is disagreement as to what extent concerns could be dealt with by legislating for adequate safeguards.<sup>54,56–58</sup>

There is also debate on whether, if legalised, doctors or the court should be the arbiter of patients' requests for an assisted death.<sup>59,60</sup> Keep Assisted Dying Out of Healthcare (KADOH), an informal group of healthcare professionals, argues that, if legalised, assisted dying should be separate from mainstream healthcare.<sup>61</sup>

There is debate among proponents on whether physician-assisted suicide only or also euthanasia should be permitted, and who should be eligible. Supporters of physician-assisted suicide for the terminally ill only, and not euthanasia, such as Dignity in Dying, argue that enabling a person to self-administer drugs to control the time and manner of their death is ethically different from directly administering drugs to a person with the intention of ending their life.<sup>47</sup> Others, including Humanists UK and My Death, My Decision, part of the Assisted Dying Coalition, consider not permitting euthanasia is discriminatory against those who are physically unable to end their own lives. They argue that euthanasia should also be legalised.<sup>62,63</sup>

## UK stakeholder perspectives

This section reviews public, religious, disability rights and medical perspectives on the legalisation of assisted dying in the UK. Quantitative data are not available on the perspectives of other stakeholders, such as minority ethnic groups.

### Public attitudes

There are limited robust data on UK public perspectives on assisted dying and how these vary between different groups. Robust data on UK public perspectives on assisted dying and variations between different groups are limited. Most of the available data are based on opinion polls. Three polls from 2018 and 2019 suggest that over three-quarters of UK adults support legalising some form of assisted dying.<sup>64,65,60</sup>

The British Social Attitudes (BSA) survey is an independent representative survey that repeats questions over time to measure changes in attitudes. Data from the BSA suggests that support for assisted dying for terminally ill patients has been stable for over 30 years.<sup>66</sup> However, support for other forms of assisted dying is less clear cut. The latest survey in 2017 found 77% of respondents supported assisted dying for terminally ill patients.<sup>66</sup>

These data are indicative. However, research indicates that the explanatory context, question wording and order and response options can influence reported attitudes to assisted dying.<sup>67</sup> Further, public understanding of the term 'assisted dying' is low in the UK; a 2021 poll found that more than half of respondents understood the term to refer to medical practices that are currently legal, such as refusing life-prolonging treatment and hospice care.<sup>68</sup>

Public attitudes towards the legalisation of assisted dying are also known to be significantly affected by their awareness of the ethical and practical complexities.<sup>69</sup> Opinion polls and surveys that do not capture this complexity may not accurately reflect public attitudes.<sup>70</sup> As noted by the House of Lords 2005 Select Committee on Assisted Dying for the Terminally III Bill, opinion polls and survey data are useful to understand how many people agree or disagree with a specific proposition, but they do not explore in-depth the key factors that shape how people perceive complex and sensitive issues.<sup>7</sup>

Efforts are increasingly being made for people to explore the complex issues around assisted dying.<sup>7,70</sup> One way is through Citizens' Juries, which seek to bring together a small group of people representative of the demographics of a particular geographical area to hear from expert witnesses on either side of the debate, consider issues in-depth and make policy recommendations prior to legislative change. The Jersey Assisted Dying Citizens Jury (see Box 1) found that most members agreed assisted dying should be permitted in Jersey under specific circumstances, subject to "stringent safeguards."<sup>35</sup> The Scottish National Party indicated in its 2021 election manifesto that it would

4.1

hold a Citizens' Assembly on assisted dying.<sup>71</sup> The Oireachtas Joint Committee on Justice also stated in 2021 that it had considered establishing a Citizens Jury (Box 1).<sup>30</sup>

### 4.2 Religious stakeholders

Perspectives on assisted dying vary across religious groups and leaders. Many faith leaders, including those of Roman Catholicism, Anglicanism, Eastern Orthodoxy, Jewish Orthodoxy and Islam have expressed public opposition to assisted dying on the grounds of the intrinsic value of each person and risks to vulnerable groups.<sup>72–74</sup> In July 2022, the General Synod of the Church of England reaffirmed its opposition to assisted dying.<sup>75</sup> Some others, such as the Religious Alliance for Dignity in Dying, support assisted dying for the terminally ill on the grounds of personal autonomy and to reduce suffering.<sup>49</sup>

Some poll data suggests that there may be differences of opinion between religious clergy and laity.<sup>76</sup> The 2017 BSA survey found that the main differences in views towards assisted dying occur by religious affiliation, but that the majority of people with a religion supported assisted dying for terminally ill patients (67%).<sup>66</sup>

### 4.3 Disability rights stakeholders

Academic analysis in 2021 of the position statements on assisted dying of 140 disability rights organisations in England, Wales and Scotland found that the vast majority (93%) do not currently have a clear public position.<sup>77</sup> Of these 140 organisations, 10 had a public position; 5, including Scope, were opposed to a change in law on assisted dying and 5, including Disability Rights UK, had adopted a neutral position.

The researchers recommended that wherever the legalisation of assisted dying is considered, the perspectives of people living with disability should be captured using robust methods and that disability rights organisations should be engaged.

The above analysis excluded campaign groups established specifically to influence the assisted dying debate. Two UK-based disability rights campaign groups are opposed to any change in the law to allow assisted dying. These are Not Dead Yet UK<sup>78</sup> and Care Not Killing.<sup>79</sup> By contrast, Disabled Activists for Dignity in Dying supports a change in the law to allow terminally ill, mentally competent adults the choice of an assisted death "within upfront safeguards."<sup>80</sup>

# 4.4 Medical stakeholders

Professional UK medical bodies have different perspectives on assisted dying and use different definitions.<sup>81,82</sup> No medical Royal College has expressed support for changing the law on assisted dying in the UK. Some have moved from opposing assisted dying to a neutral stance, in the context of mentally competent adults who are terminally ill and make a voluntary request, meaning that they neither support nor oppose a change in UK law. This includes the Royal College of Nursing in 2009<sup>83</sup> the Royal College of Physicians (RCP) in 2019<sup>84</sup> and the British Medical Association (BMA) in 2021.<sup>85</sup> In 2020 the RCP clarified its position, stating that "it does not support a change in the law to permit assisted dying at the present time."<sup>84</sup> The Royal College of General Practitioners and the World Medical Association are opposed to the legalisation of assisted dying.<sup>86,87</sup>

### 5

## **International experience**

Assisted dying is legal in at least 27 jurisdictions worldwide. Some form of assisted dying is legal in at least 27 jurisdictions worldwide: Austria, 6 Australian states (New South Wales, Queensland, South Australia, Tasmania, Victoria, Western Australia), Belgium, Canada, Colombia, Italy, Luxembourg, the Netherlands, New Zealand, Spain, Switzerland, 10 US states (California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, Washington) and the District of Columbia.<sup>88–90</sup>

This POSTbrief focuses on jurisdictions with most data available on outcomes: Belgium, Canada, the Netherlands, Oregon (United States), Switzerland and Victoria (Australia). Boxes 2-7 outline how assisted dying functions within the health service of these jurisdictions. Most other US states have closely followed the Oregon model (Box 5).<sup>91</sup> The Commons Library briefing on <u>The law on assisted suicide</u> contains further information on the legal context in some jurisdictions.

Internationally, eligibility criteria vary. For example assisted dying may be:

- Restricted to adults (including Canada, Oregon, Switzerland and Victoria), or also include children with parental consent (including Belgium and the Netherlands).
- Restricted to people with terminal illness (including Oregon and Victoria), or also include those experiencing "constant and unbearable" suffering that cannot be relieved, but who are not terminally ill.<sup>92</sup>
- Where it is permitted for people experiencing "constant and unbearable" suffering that cannot be relieved, but who are not terminally ill, it can be restricted to suffering arising from serious physical illness only (including Canada until 2023), or also include those whose suffering arises from psychiatric illness (including Belgium, Canada from 2023 and the Netherlands).<sup>92,93</sup>

Doctors have a role in confirming the individual meets the eligibility criteria and/or in prescribing lethal drugs in all jurisdictions discussed, although in Canada this role can also be undertaken by nurse practitioners.

In some jurisdictions, healthcare professionals are only permitted to prescribe lethal drugs for the patient to take (including Oregon and Switzerland), whilst in others, healthcare professionals can also inject lethal drugs (including Belgium, Canada, the Netherlands, and Victoria). In Victoria, a doctor is permitted to administer lethal drugs only if a person is physically unable to administer or digest medicine themselves. In these jurisdictions healthcare professionals are required to report assisted dying to relevant institutions.

In all the jurisdictions discussed here except Switzerland, assisted dying is funded in line with other healthcare costs, through general taxation, social insurance and private insurance, together with out-of-pocket costs. Switzerland is the only country where assisted dying is not restricted to citizens or residents. Between 1998-2021, 498 UK citizens travelled to Switzerland to receive assisted dying by private organisations, such as Dignitas (23 in 2021).<sup>94</sup>

In Boxes 2-7, data on the sex and age of people receiving an assisted death is reported. By comparison, in 2019, the median age of deaths registered in England and Wales was 81.9 years and the largest number of deaths occurred in the 80-89 years age group (34.3%). 50% were male and 50% were female.<sup>95</sup>

#### Box 2. Belgium Act on Euthanasia 2002

- **Law:** Euthanasia is permitted. Physician-assisted suicide is not explicitly regulated for, but it is not prohibited; the Federal Control and Evaluation Commission has accepted that cases fall under the law.<sup>96</sup>
- **Eligibility:** Mentally competent adult citizens or residents experiencing "constant and unbearable" physical or psychological suffering that cannot be cured. Since 2014, no age limit applies; minors must possess "capacity of discernment", suffering must be physical, and death must be expected in the short term. Parental consent is required for those under the age of 18 years.
- **Funding:** In line with other healthcare costs.
- **Procedure:** Request must be voluntary, persist over time, be well considered and made in writing. Two doctors must confirm eligibility criteria. When death is not expected in the short term an additional doctor must be consulted.
- **Reporting:** Doctors should report the death to the Federal Control and Evaluation Commission (FCEC) which assesses compliance with the law. Non-compliance cases should be referred to the public prosecutor.
- Data: In 2021, 2699 cases of assisted dying were reported;<sup>97</sup> estimates suggest that nearly all cases (>97%) are euthanasia.<sup>98</sup> This is an increase of 10.4% from 2020 and 2.4% of total deaths in Belgium in 2021.<sup>99</sup> 50.8% were male and 49.2% were female. The largest number of assisted deaths occurred in the 80-89 years age group (29.3%). No assisted deaths for under 18s were reported. No data are available on ethnicity.<sup>97</sup>

#### Box 3. Canada 2015 amendment to Criminal Code

- Law: Physician-assisted suicide and euthanasia are permitted.
- **Eligibility**: Mentally competent adult citizens or residents experiencing "intolerable" physical or psychological suffering. The psychological suffering must stem from underlying physical illness. From 2023, those whose only medical condition is a mental illness, and who otherwise meet all eligibility criteria, will also be eligible.
- **Funding**: In line with other healthcare costs.
- **Procedure**: Physicians may offer assisted dying as an option for treatment to potentially eligible patients.<sup>100</sup> Patient request must be made in writing and signed by two independent witnesses. Two independent doctors or nurse practitioners must confirm eligibility.
- **Reporting**: Doctors and nurse practitioners must report all written requests to the provincial/territorial or federal health department who can refer non-compliance to the police.
- **Data**: In 2020, 7595 cases of assisted dying were reported, which is the most recent data available; more than 99.9% of cases were euthanasia. This is an increase of 34.2% from 2019 and 2.5% of total deaths in Canada in 2020. 51.9% were male and 48.1% were female. The average age (not specified if median or mean) of assisted death was 75 years.<sup>101</sup> No data are available on ethnicity.

#### **Box 4. Netherlands Termination of Life on Request and Assisted Suicide Act 2001**

- Law: Physician-assisted suicide and euthanasia are permitted.
- **Eligibility**: Mentally competent citizens or residents experiencing "constant and unbearable" physical or psychological suffering with no prospect of improvement.<sup>102</sup> Children aged 12–16-years eligible with parental consent. Government approved plans in 2020 to extend to children aged 1-12 years with parental consent. Separate to the Act, euthanasia of infants under 1 year is permitted with parental consent and is regulated through the Groningen Protocol.<sup>103,104</sup>
- **Funding**: In line with other healthcare costs.
- **Procedure**: Request must persist over time. A written request is not required. Patients with advanced dementia can make a written request in advance. Two doctors must confirm eligibility criteria. One doctor must be present at the time of death.
- **Reporting:** Doctors must report the death to the municipal coroner who informs regional review committees, who assess compliance with law. Non-compliance cases are referred to the public prosecutor.
- **Data:** In 2019, 6361 cases of assisted dying were reported, which is the most recent available data; More than 95% of cases were euthanasia. This is an increase of 3.8% increase from 2018 and 4.2% of total deaths in the Netherlands in 2019. 52% were male and 48% were female. The largest number of assisted deaths occurred in the 70-79 years group (32.7%).<sup>105</sup> Ethnicity data are not reported. No data are available on ethnicity.

#### Box 5. Oregon Death with Dignity Act 1994

- **Law:** Physician-assisted suicide is permitted. Euthanasia is not permitted by US federal law.
- **Eligibility:** Mentally competent adult citizens or residents who are terminally ill and likely to die within 6 months.
- **Funding:** In line with other healthcare costs.
- **Procedure:** Request must be made orally then in writing. Requests must be signed by two independent witnesses. Two doctors must confirm eligibility. A doctor prescribes lethal drugs for self-administration
- **Reporting**: Doctors must inform the Oregon Health Authority of written prescriptions. The Authority notifies the Oregon Medical Board of any suspicions or non-compliance with the law.
- **Data**: In 2021, 238 cases of physician-assisted suicide were reported.<sup>106</sup> This is a decrease of 2.9% from 2020<sup>107</sup> and 0.59% of total deaths in Oregon in 2021. It is an increase of 26.6% from 2019.<sup>108</sup> In 2021, 55.9% were male and 44.1% were female. The median age was 75 years, and most were of White ethnicity (95%).

# Box 6. Switzerland 1942 decriminalisation of assisted suicide

- **Law:** Physician-assisted suicide is permitted for "non selfish" motives. Euthanasia is not permitted.
- Eligibility: Adult citizens or residents and foreign adults.
- **Funding**: NGOs and individuals.
- **Procedure**: Individual organisations have their own internal processes. Swiss law does not require doctors to be involved, but only doctors can prescribe lethal drugs, so in practice they are involved in every case.
- **Reporting**: No central regulating process exists, but police must be notified of all "unnatural deaths" and can investigate them.
- **Data**: Precise numbers are not known because recorded cases often do not differentiate between individual and assisted suicides. Data released by the Swiss Federal Office for Statistics (excluding foreign citizens travelling to Switzerland for non-healthcare assisted dying) show that 1196 Swiss residents died from physician-assisted suicide in 2019.<sup>109</sup> This is an increase of 1.7% from 2018 and 1.8% of total deaths in Switzerland in 2019.<sup>110</sup> 40.4% were male and 59.6% were female. Available data provide the proportion of deaths in those aged under and over 65 years: 88% were over 65 years. No data are available on ethnicity.

#### Box 7. Victoria Voluntary Assisted Dying Act 2017

- **Law:** Physician-assisted suicide is permitted. If a person is physically unable to administer or digest the medicine themselves, euthanasia is permitted.
- **Eligibility:** Mentally competent adult citizens or residents who are terminally ill and likely to die within 6 months, or 12 months in the case of neurogenerative disease.
- **Funding:** In line with other healthcare costs, although state funding precluded for some aspects
- Procedure: Requests must be initiated by the patient and made in writing. They must be signed by two independent witnesses. Two doctors must confirm eligibility.
- **Reporting**: Doctors submit forms throughout the process to the Voluntary Assisted Dying Review Board which reviews cases for compliance and can refer them to the police.
- **Data:** From July 2020 to June 2021, 201 cases of assisted deaths were reported; 85.6% of cases were physician-assisted suicide.<sup>111</sup> This is an increase of 61.7% from July 2019 to June 2020<sup>112</sup> and 0.49% of total deaths in Victoria between July 2020 to June 2021.<sup>113</sup> It is important to note that the Act only commenced in June 2019, and therefore the percentage increase stated above is compared with the first year of implementation in which barriers to access were reported.<sup>114</sup> Demographic data are provided aggregate from June 2019 to June 2021. 53.6% were male and 46.3% were female and 0.1% self-described. The median age was 73 years.<sup>111</sup> No data are available on ethnicity

### 5.1

### Demand for and access to assisted dying

Annual data and research from Oregon, Belgium, the Netherlands and Canada suggests that motivations for assisted dying include: loss of autonomy and dignity, being less able to enjoy life, fear of being a burden on others, current experience of pain and fear of future pain.<sup>101,106,115,116</sup>

Uptake of assisted dying varies across jurisdictions where it is a legal option, according to what the law permits. Where both euthanasia and physicianassisted suicide are legal and eligibility criteria include those with nonterminal illness (Belgium, Canada, the Netherlands) there tends to be higher proportions of assisted deaths (2.4% - 4.2%) than where eligibility is restricted to those with terminal illness (Oregon, Victoria) (under 1%) (see Boxes 2-7).<sup>4,117</sup> There are no official figures on total assisted deaths in Switzerland, but some data suggest that population death proportions are over 1% (Box 2).<sup>118</sup> One analysis of international data from 2017 concludes that assisted dying is used in a small percentage of cases.<sup>115</sup> However, some research suggests that there is underreporting of assisted dying in some jurisdictions.<sup>98,119–121</sup> For example, studies suggest that approximately half (52%) of all estimated cases of assisted deaths were reported in Belgium in 2007<sup>98</sup> and three-quarters (77%) in the Netherlands in 2010.<sup>120</sup> Possible explanations given in the literature include: doctors not perceiving their acts as assisted dying, but as a form of palliative sedation (see section 7.3), and not considering it necessary to report deaths as such; wanting to avoid the administrative burden of reporting to a review committee; believing they have not complied with legal care criteria; privacy concerns; and a lack of clear guidelines.<sup>98,119,120</sup>

A systematic review of assisted dying in selected European countries and US states in 2013 found that in jurisdictions where assisted dying has been legal for longer periods (Belgium, the Netherlands, Switzerland and Oregon), the total number of reported cases and the percentage of reported assisted deaths of all deaths increased over time. The authors note however that this may be because of more complete reporting to the authorities.<sup>121</sup> A study in 2021 similarly reports a consistent increase over time in these jurisdictions.<sup>122</sup> In jurisdictions where assisted dying legislation was introduced more recently (Canada, Victoria), there is a higher annual growth rate of cases, but some experts suggest that uptake will stabilise over time and level out at a figure similar to that in other jurisdictions.<sup>123</sup>

Factors affecting trends in growth noted in the literature include the sociocultural context, eligibility criteria, form of regulation and whether doctors proactively offer assisted dying as an option to potentially eligible patients.<sup>4,118,100,122,124</sup> There are different perspectives on whether trends in growth are perceived as a concern or as removing barriers to access (see 6.1).

Research on demographic characteristics suggests that individuals who die with assistance tend to be "older, White, educated, and diagnosed with cancer."<sup>121,125,126</sup> Some research suggests that there is unequal access to assisted dying in some jurisdictions where it is a legal option, arising in part from some healthcare professionals being personally unwilling to provide it and legislative restrictions in some jurisdictions, which prevent health professionals initiating conversations about assisted dying.<sup>57,127–130</sup>

# **Key practical considerations**

Key practical considerations raised in the context of assisted dying are outlined below, with reference to data from jurisdictions where assisted dying is legal (see Boxes 2-7). Many of these issues are interrelated and are raised in ethical debates.

### 6.1 Extension of legislation and eligibility criteria

Key practical considerations raised in the context of assisted dying are interrelated and are raised in ethical debates.

6

There are different perspectives on whether it is difficult to prevent incremental extension of legislation and eligibility criteria once assisted dying is legalised and whether this is perceived as a concern or as removing barriers to access.

Several jurisdictions have made subsequent amendments to legislation or changes to eligibility criteria, including:

- In 2014, Belgium amended its law to remove age restrictions; parental consent is required for those under 18 years. Minors must possess "capacity of discernment" (regardless of their biological age) and fulfil several other due care criteria. These include that suffering must be physical and death must be expected in the short term.<sup>131,132</sup>
- In 2019, Oregon amended its law to create exception to the mandatory 15-day waiting period between the patient's initial oral request and the writing of a prescription for patients with less than 15 days to live.<sup>133</sup>
- In 2020, the Dutch government approved plans to allow euthanasia for terminally ill children aged between 1 and 12 years, with parental consent. Media reports suggest that the current law will not be changed, but doctors will be exempt from prosecution for carrying out an approved euthanasia on someone in this age range.<sup>134</sup> New regulations for the practice are expected in autumn 2022.<sup>135</sup>
- In 2021, Canada passed legislation to amend the Criminal Code (Medical Assistance in Dying) to repeal the provision that required a person's natural death to be reasonably foreseeable to be eligible for an assisted death.<sup>136</sup> This was in response to the 2019 Superior Court of Québec's ruling that the provision was discriminatory.<sup>137</sup> Canadians whose only medical condition is a mental illness, and who otherwise meet all eligibility criteria, will be eligible from 2023.<sup>138</sup> The requirement for a minimum 10-day reflection period was also removed for those whose natural death is reasonably foreseeable.

Some researchers and other stakeholders, such as Living and Dying Well, are concerned that legalisation of assisted dying can create a 'turning point' and contribute to it becoming normalised, creating pressure to widen its scope to categories that were not envisaged when it was first accepted, which could put vulnerable people at risk.<sup>53,139–141</sup> In 2021, UN human rights experts expressed concern about legislation that enabled access to assisted dying for those who are not terminally ill. They argued that under "no circumstance should the law provide that it could be a well-reasoned decision for a person with a disabling condition who is not dying to terminate their life with the support of the State."<sup>142</sup> In Belgium<sup>143</sup> and the Netherlands,<sup>144</sup> some academics and doctors have also raised concerns about the application of assisted dying legislation and monitoring of practice, including how eligibility criteria are interpreted.

Other researchers and stakeholders have argued that if access to assisted dying is perceived as a benefit for those who are terminally ill, to not extend it to other groups who feel they are suffering unbearably, but who are not terminally ill, can be perceived as inequitable or discriminatory.<sup>145,146</sup> Some academics argue that some provisions framed as safeguards in legislation, including some eligibility criteria, can create significant barriers to equal access for marginalised groups.<sup>57,147,148</sup>

## 2 Determining prognosis

In some jurisdictions assisted dying is permitted only for people who have a terminal illness. However, determining prognosis of a progressive or life-threatening condition and judging how long the person has left to live can be difficult (see POSTnote on <u>Palliative and end of life care</u>).<sup>7,149–153</sup>

Definitions of terminal illness also vary across jurisdictions. For example, in Victoria it is defined as "a disease, illness or medical condition that— (i) is incurable; and (ii) is advanced, progressive and will cause death; and (iii) is expected to cause death within weeks or months, not exceeding 6 months".<sup>154</sup> In Oregon, it is defined as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months".<sup>155</sup> This is reported to include diseases where the person is likely to die within 6 months, with or without further treatment.<sup>156,157</sup>

In other jurisdictions eligibility criteria also include people who are not terminally ill but who are experiencing "unbearable" or "intolerable" suffering arising from physical illness or injury, or in some cases, also where it arises from psychiatric illnesses. Debate focuses on how to evaluate the degree of suffering and whether doctors have the necessary expertise to assess when suffering is "unbearable" or "intolerable".<sup>158,159</sup> There is also debate as to whether an individual's subjective experience of suffering should be a sufficient condition for permitting assisted dying.<sup>160–164</sup>

For patients with mental disorders, debate also focuses on how to assess whether suffering is irremediable<sup>163</sup> or whether it could be relieved over time.<sup>139,165–167</sup> Research suggests that it may be particularly challenging to assess whether suffering may be relieved in patients with personality disorders, and that not all patients appear to receive some standard treatments.<sup>168,169</sup>

# 6.3 Mental capacity

All jurisdictions restrict assisted dying to people who have the mental capacity to make the decision and who have made a voluntary request. In healthcare, capacity is usually determined by doctors or nurse practitioners, and patients with diagnosed psychiatric conditions may be referred to psychiatrists.<sup>170</sup> In England and Wales, the Mental Capacity Act (MCA) 2005<sup>171</sup> applies to those aged 16 years or over, who are presumed to have capacity to make decisions about their own care unless it is established that they lack capacity to make a particular decision at the time it needs to be made.<sup>172</sup>

Assessing capacity for assisted dying requests can be complex. For example, research indicates that a terminally ill person's request for an assisted death may stem from emotional distress and not necessarily imply a genuine wish to hasten death.<sup>173–176</sup> Research in Oregon indicates that palliative interventions were significantly associated with changes of mind about assisted suicide among dying patients.<sup>177</sup> Assessing capacity for assisted dying requests can be particularly challenging where the person has psychiatric disorders, such as severe depression, which can impair decision-making capacity.<sup>163</sup>

Patients with life-limiting illnesses can suffer depression and anxiety (see POSTnote on <u>Palliative and end of life care</u>). Research suggests that depression in older adults is frequently under-recognised and under-treated.<sup>178–180</sup> Recent robust data on the prevalence of psychiatric illness in those who request assisted dying on the basis of terminal or physical illness are limited. A 2008 study in Oregon found that some terminally ill patients who had an assisted death had untreated clinical depression.<sup>181</sup> A 2011 systematic review of the prevalence of depression in granted and refused requests for assisted dying found that most studies estimated that a quarter to a half or requests came from patients with depressive symptoms or clinical depression.<sup>182</sup> It also found convincing evidence that depression was a significant factor in refusing requests for assisted dying in the Netherlands.

Suffering arising from psychiatric illnesses reported in cases of assisted dying include depressive disorders, posttraumatic stress and other anxiety disorders, psychotic disorders and personality disorders.<sup>168,169,183</sup> Studies in Belgium<sup>169</sup> and in the Netherlands<sup>183</sup> on the characteristics of assisted deaths for psychiatric conditions both suggest that most people had more than one condition and that the most frequent diagnoses were depression and personality disorder.

There is disagreement about the influence that psychiatric illness, such as depression and personality disorder, may have on an individual's capacity to request to end their life.<sup>160,181,184,185</sup> Because symptoms of some mental disorders fluctuate, someone may lack capacity to make a particular decision at one point in time, but may be able to make the same decision at a later point in time.<sup>186</sup>

Academic research in Oregon suggests that the ethical view of psychiatrists may influence their clinical opinions regarding patient competence to requests assisted dying.<sup>187</sup> There is also debate on who is best placed to

assess capacity and identify potential coercion in requests for assisted dying and whether the courts should have a role in assessing requests.<sup>59,168,188</sup>

#### Advance directives for euthanasia

In Belgium and the Netherlands, a person can make an advance directive to express their wish for euthanasia at a later date when they may no longer be able to request it. For example, because they are in an advanced state of dementia, or are unconscious because of an illness or treatment for an illness.<sup>189</sup> Such cases are few in number. In Belgium in 2021, there were 17 cases of euthanasia with an advance directive; 0.6% of the total.<sup>97</sup> Equivalent data from the Netherlands are not available.<sup>105</sup>

The practice of relying on advance directives to authorise euthanasia is controversial.<sup>190–193</sup> Some bioethicists have argued that when written by a previously well-informed and competent person, advance directives for euthanasia should be implemented, and that a "sliding scale", which considers both autonomy and the capacity for enjoyment, provides the best justification for determining when.<sup>192</sup> Other bioethicists have raised concerns about whether processes duly ensure that the person has capacity at the time that an advance directive for euthanasia is made, and how it should be balanced against contemporaneous statements and actions.<sup>194</sup> Data suggest that it is difficult for doctors to judge whether patients with advanced dementia who lack capacity are in unbearable suffering with no prospect of improvement and apply advance directives.<sup>144,191</sup>

#### Assisted dying in minors

In the Netherlands, minors may themselves request an assisted death from the age of 12, although the consent of the parents or guardian is mandatory until they reach the age of 16 years. 16- and 17-year-olds do not need parental consent in principle, but their parents must be involved in the decision-making process.<sup>195</sup> In 2020, the Dutch government approved plans to extend its law to also include terminally ill children aged between 1 and 12 years.<sup>134</sup> Separate to the Termination of Life on Request and Assisted Suicide Act 2001, euthanasia of infants under 1 year with parental consent is permitted and regulated through the Groningen Protocol, which was devised in 2005 to regulate existing practice and make it more transparent.<sup>103,104</sup>

In 2014 Belgium amended its law to allow euthanasia for terminally ill minors; parental consent is required for those under 18 years. Minors must possess "capacity of discernment" (regardless of their biological age), and fulfil several other due care criteria, including that suffering must be physical and death must be expected in the short term.<sup>131,132</sup>

Cases are low. In the Netherlands, the latest data are from 2019 and no cases of euthanasia in minors between the ages of 12 and 17 years old<sup>105</sup> or infants aged under 1 year were reported.<sup>196</sup> In Belgium in 2021, no cases of assisted deaths in those aged under 18 were reported.<sup>97</sup>

The practice of assisted dying for those aged under 18 years is controversial.<sup>104,197–199</sup> In England and Wales, those aged under-16 years are presumed unable to make decisions for themselves unless it is established that they are 'Gillick competent' to make the decision in question, otherwise

a person with parental responsibility can consent for them (see forthcoming POSTnote on Mental Health Act Reform: Children and Young People). The capacity of children under the age of 16 years to make the decision to end their lives and the role of parental consent in assisted dying in minors are contested.<sup>199–203</sup> Some research suggests that doctors involved in the treatment of severely-ill children in the Netherlands feel a duty to relieve suffering, irrespective of the patients age or competency to decide.<sup>204</sup> There have been calls for more research on the legality and morality of child euthanasia.<sup>205</sup>

6.4

### Coercion and risks for vulnerable groups

A key area of concern raised by some stakeholders is whether vulnerable groups, including older people, people with disabilities and people who are socio-economically disadvantaged, are more at risk of being pressurised, manipulated or forced to request or accept an assisted death, than the general population. This may arise because of, for example, social and family pressures, because they have internalised negative social attitudes toward themselves, and impairments in decision-making capacities.<sup>45,128,206</sup> In 2021, UN human rights experts raised concerns that, even when restricted to those with a terminal illness, "people with disabilities, older persons, and especially older persons with disabilities may feel subtly pressurised to end their lives" due to social attitudes and lack of appropriate services and support.<sup>142</sup>

There are limited empirical data on the impact of assisted dying on vulnerable groups in jurisdictions where it is legal. A 2007 study on data from Oregon and the Netherlands concluded that there was no current evidence that assisted dying had a disproportionate impact on vulnerable groups.<sup>128</sup> The study conclusions about assisted deaths in Oregon have been contested however, including its estimates of assisted deaths in the elderly, and on the basis of research published since on untreated depression among those who have had an assisted death.<sup>207</sup> Concerns about potential abuses in the Netherlands have been raised in relation to particular cases and reported in academic literature.<sup>144,194</sup> Some research suggests that in Belgium, the use of life-ending drugs without explicit request of the patients occurred predominantly among groups of vulnerable patients.<sup>208,209</sup>

Several studies have noted a need for detailed monitoring of assisted dying practice, including improved official reporting data in some jurisdictions, as well as further research on official reporting data in different jurisdictions.<sup>115,210–212</sup> Research also suggests that in parts of the US, Canada and the UK, vulnerability and abuse, such as coercion and elder abuse (including financial abuse)<sup>213,214</sup> are poorly understood by healthcare professionals.<sup>207,215,216</sup> There is disagreement as to whether requiring a High Court judge to confirm decisions by doctors to approve assisted deaths would be sufficient to protect vulnerable people.<sup>54</sup>

# 6.5 Role of healthcare professionals

Another area of debate is whether assisting dying is compatible with the role of healthcare professionals.

Proponents of assisted dying, such as Healthcare Professionals for Assisted Dying and My Death My Decision, argue that it is compatible with their healthcare role of respecting patient autonomy, in line with the latest World Medical Association Declaration of Geneva, which sets out the ethical principles of the medical profession.<sup>46,217,218</sup>

Opponents, such as Care Not Killing, argue that assisted dying is incompatible with the principle of respect for human life. Care Not Killing point to the Canadian Parliamentary Budget Officer's (PBO) 2020 report<sup>171</sup> on the predicted costs and savings of expanding access to assisted dying for patients whose death is not expected in the relative near term in Canada. They contend that such economic calculations "forces patients, families and health authorities to consider the fiscal prudence of simply living."<sup>170</sup>

#### Impacts on healthcare professionals

Research on the effects of their involvement in assisted dying on healthcare professionals in jurisdictions where assisted dying is part of healthcare suggests that healthcare professionals have a range of experiences. It can lead to emotional distress,<sup>219,220,221,222</sup> conflict with perceptions of professional responsibilities,<sup>223</sup> impact on relationships with other doctors<sup>224</sup> and increase workloads.<sup>223</sup> It can also reduce distress from being able to offer and witness "good death" dying experiences,<sup>221,225</sup> provide comfort from knowing the requests of patients are being met,<sup>220</sup> and support "satisfying and gratifying" work from being able to help patients relieve suffering.<sup>225</sup>

In Switzerland, where assisted dying exists outside of routine healthcare funding, one study found doctors wanted clearer institutional frameworks and better collaboration with Right-to-Die Societies.<sup>226</sup> Some research in Oregon suggests that legalising assisting dying has contributed to increased palliative care training.<sup>149,227</sup> Research in Canada has identified the need for better training for healthcare professionals.<sup>228</sup>

#### **Conscientious objection**

All jurisdictions permit healthcare professionals to opt out of participating in assisted dying on the grounds of conscientious objection.<sup>92</sup> Healthcare professionals may choose not to participate in assisted dying because it conflicts with their personal beliefs or values, and also for personal reasons such as the emotional toll on them and perceived reputational stigma from colleagues.<sup>229</sup> Research in Victoria and in rural areas of Canada suggests that conscientious objection can result in some patients who are eligible not being able to access assisted dying.<sup>229,230</sup> A study in Victoria suggests conscientious objection could be problematic for junior doctors due to perceived risks to career progression.<sup>231</sup> Conscientious objection in medicine has been challenged in the courts.<sup>232</sup> This has led some doctors to query the adequacy

6.6

of the protection they would receive if assisted dying were legalised in the  $\rm UK.^{233}$ 

### Efficacy and safety of drugs used to end life

In jurisdictions where it is legal, the methods used to assist dying are intended to be humane, and the drugs used should have a high level of efficacy, bringing about death quickly, as well as a high degree of safety, bringing about death without distressing adverse effects.<sup>234,235</sup> Drugs used for medical purposes are required to undergo a stringent approval process in order to assess efficacy and safety, but none of the drugs used for assisted dying are approved by a regulatory authority for medicines for a lethal purpose.<sup>234</sup> In some jurisdictions, medical professional associations publish guidelines; however, there is not consensus on the most effective drug or drug combination for ending a human life and specific drugs, doses and monitoring vary.<sup>234–236</sup> Drugs include:

- Sedatives and hypnotics: to induce unconsciousness and depress breathing.
- Opioids: to induce unconsciousness and depress breathing.
- Cardiotoxic agents: that produce toxic responses in the heart muscle.
- Neuromuscular blockers: to paralyse muscles to prevent movement, including breathing.
- Antiemetics: to prevent or reduce nausea and vomiting.<sup>234–236</sup>

Reported complications in oral ingestion include vomiting, regurgitation, seizures, prolongation of death and regaining consciousness after ingesting the lethal medications.<sup>115,234,235,237</sup> Reported complications in intravenous administration include difficulty in obtaining or maintaining intravenous access and the person dying too slowly or too quickly.<sup>238</sup>

Determining the rate of problems and complications related to assisted dying is difficult to assess however, because data on the drugs used and complications are not reported in all jurisdictions. What is classified as a complication varies between jurisdictions and in some jurisdictions a healthcare provider is not always present at the time of death.<sup>115,234</sup>

For example, in Oregon in 2021, complications were reported in 2.5% of deaths. The presence or absence of complications was reported as unknown in 68% of deaths as no healthcare professional was present. One person was reported to have regained consciousness after ingesting the lethal medications, but this was not classified as a complication.<sup>106</sup> Research also indicates that doctors reporting on assisted dying deaths can be low in some jurisdictions (see 5.1).<sup>234</sup>

# 7 Wider impacts

# 7.1 Social and cultural impacts

There is very little research on the social and cultural impact of legalising assisted dying.

A key area of concern put forward by some bioethicists is that legalising assisted dying could change how we value some human lives<sup>140</sup> and that it could "have the effect of creating lives that are societally deemed to be not worth living".<sup>239</sup> In 2021, UN Human Rights experts expressed concern about enabling access to assisted dying for people who are not terminally ill. They argued that it could normalise "ableist assumptions about the inherent 'quality of life' or 'worth' of the life of a person with a disability."<sup>142</sup>

There is no empirical research on whether assisted dying has changed societal or cultural perspectives towards, for example, older people or people with disabilities, in jurisdictions where it has been legalised. However, some experts point to how value-judgements can adversely affect healthcare decision making, including how older people, people with dementia and people with a learning disability have been treated in regard to the application of 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions during the pandemic<sup>189</sup> and under the former Liverpool Care Pathway (LCP) for care in the final days of life.<sup>134</sup>

An empirical study on Oregon nurses' perspectives in 2001 found that families of hospice patients who received prescriptions for lethal drugs were more accepting of and prepared for the patient's death, although they were "somewhat more likely" to be distressed than were the family members of other hospice patients.<sup>240</sup>

Based on theoretical research, which logically explores systems of beliefs, some anthropologists argue that assisted dying could affect cultural meanings attributed to dying, including how different cultures prepare for death and the value they attribute to caregiving at the end of life.<sup>241</sup> However, the authors conclude that assisted dying is not so much a cause but rather a symptom of changes to the cultural meanings attributed to dying in post-industrial Western societies, in part due to medical advances.

### 7.2 Link to suicide rates

Questions have been raised as to whether access to assisted dying affects overall rates of suicide.

A link has been found between diagnosis of severe health conditions and clinical depression and suicide.<sup>242–244</sup> Studies suggest that the first year after diagnosis carries a higher risk for completed suicide.<sup>243</sup> Recent experimental statistics from the Office for National Statistics (ONS) based on data from 2017 to 2020 suggest that suicide rates among people diagnosed with severe health conditions in England were twice as high as in the general population during the first year after diagnosis. ONS note that "suicide rates in patients increased sharply after the initial diagnosis for the severe health conditions, but the increase in the suicide rate slows over time" measured up to 24 months.<sup>245</sup>

There are few studies examining the association between assisted dying and rates of suicide. Studies in the US and Europe (Switzerland, Luxembourg, the Netherlands, and Belgium) have found that legalising assisted dying correlates with increases in overall rates of "self-initiated deaths" (assisted dying and suicide combined).<sup>246–249</sup> When measuring suicide rates only, these studies generally did not show a statistically significant correlation between legalisation of assisted dying and suicide rates. Some researchers have called for more high-quality research to determine whether there is no association between introduction of assisted dying and suicide rates, or whether there might be a small positive association.<sup>247</sup>

Some proponents of the legalisation of assisted dying in the UK, such as Dignity in Dying and the Assisted Dying Coalition, suggest keeping assisted dying illegal in the UK has led to unsafe deaths by suicide.<sup>47,250</sup> Opponents, such as Care Not Killing, suggest that attention should be focused on suicide prevention strategies and increasing appropriate services and support.<sup>251</sup> Some researchers have argued that suicide prevention interventions should be offered to all those who are eligible for assisted dying.<sup>252,253</sup> Some research has also called for guidance on media reporting on assisted deaths.<sup>252</sup>

7.3

### Palliative and end of life care services

Palliative and end of life care (P&EOLC) aim to improve the quality of life of people with terminal illness (<u>see POSTnote 675 on P&EOLC</u>). There is debate on whether legalising assisted dying has an adverse or beneficial impact on palliative and end of life care resources and services.

Proponents of assisted dying, such as Dignity in Dying, argue that P&EOLC can flourish alongside assisted dying.<sup>157</sup> Opponents, such as Care Not Killing and Not Dead Yet UK, argue that demand for assisted dying in the UK is fuelled by a lack of access to good P&EOLC and have called for an urgent focus on improving P&EOLC.<sup>78,251</sup> Internationally, a frequently expressed concern is that legalising assisted dying could stunt the development of P&EOLC services and erode its culture.<sup>254,255</sup>

Evidence is mixed. A systematic scoping review in 2020 suggests that the relationship between P&EOLC and assisted dying is varied and that impacts in any jurisdiction may not be the same as in other jurisdictions, even within the same country.<sup>256</sup> The authors note a lack of evidence on the relationship between assisted dying and P&EOLC in the Netherlands and US states other

than Oregon. A study published in 2021 on the relationship between assisted dying and P&EOLC in Flanders (Belgium), Oregon and Quebec (Canada) similarly found no clear and uniform relationship.<sup>257</sup>

A study examined data on governmental funding of P&EOLC services between 2002-2011 in Belgium, the only country where the authors state they could find these data. Analysis indicated that Belgium government expenditure for P&EOLC doubled between 2002 and 2011.<sup>255</sup> The study also analysed the number of P&EOLC services (such as palliative home care teams, hospital palliative care units and hospices) between 2005 and 2012 for seven European countries (Belgium, Iceland, Ireland, Luxembourg, the Netherlands, Sweden and the UK). It found that the rate of increase in the number of P&EOLC services among the compared countries was the highest in the Netherlands and Luxembourg. Separate analysis of P&EOLC speciality services in 51 countries of the WHO European region between 2005 and 2019 suggests that the Netherlands and Switzerland had a consistent increase in specialised P&EOLC service provision over this period, but that growth in Belgium has stalled since 2012.<sup>258</sup> By contrast, there was a reduction in specialised P&EOLC services in the UK. Some Australian states, including New South Wales, Victoria, Western Australia and Queensland, received funding boosts for P&EOLC when assisted dying was legalised.<sup>259–262</sup>

The systematic scoping review suggests that Belgium is the only jurisdiction where P&EOLC specialty has developed in tandem with assisted dying.<sup>256</sup> It suggests that in Oregon and Washington in the US, Switzerland and Canada the relationship between assisted dying and P&EOLC is more complex. For example, some studies suggests that the legalisation of assisted dying in Oregon has supported more open conversation and careful evaluation of end-of-life options, more appropriate P&EOLC training of doctors and efforts to reduce barriers to access to hospice care.<sup>133,263–265</sup> Other studies in Oregon suggest that hospice workers can feel unclear about their role and professional boundaries.<sup>266,267</sup> Tensions between P&EOLC and assisted dying are reported in Canada, including challenges in communication, confusion about whether assisted dying is an intervention or a last resort, inadequate provision of P&EOLC for those requested an assisted death and consumption of P&EOLC resources to support assisted death.<sup>221,268,269</sup> Researchers have called for more research on the potential impact of assisted dying on P&EOLC across different jurisdictions, including indicators of quantity and quality of care and whether patients are nudged towards assisted dying because of insufficient P&EOLC.<sup>255,256</sup>

Some studies have shown that some forms of palliative sedation, such as continuous deep-sedation until death, have increased in the Netherlands<sup>270</sup> and Belgium<sup>271</sup> following the legalisation of assisted dying, in some cases, without the explicit request of the patient. Continuous deep-sedation until death is a highly debated medical practice, particularly regarding its potential to hasten death and its proper use in end-of-life care.<sup>272,273</sup> In this context, there is debate on whether "life-ending acts without explicit patient request" represent non-voluntary termination of life.<sup>208,274</sup> Some researchers have called for further training for physicians on standards of decision-making and the effects of high-dose opioids in terms of life-shortening potential<sup>274</sup> and the need for the involvement of patients and relatives in the decision-making process.<sup>272</sup>

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## Contributors

Members of the POST board\*

Professor Sam H. Ahmedzai, University of Sheffield

Zeynab Al-Khero, Not Dead Yet UK and parliamentary Researcher at the House of Lords to Baroness Campbell of Surbiton\*

Ruth Campbell, Nuffield Council on Bioethics

Professor Kenneth Chambaere, Ghent University and Vrije Universiteit Brussel\*

Dr John Chisholm CBE, British Medical Association\*

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Dr Tony Wainwright, University of Exeter\*

Professor Ben P. White, Queensland University of Technology\*

Professor Lindy Willmott, Queensland University of Technology\*

Dr Gillian Wright, Care Not Killing\*

 $\ast$  denotes people and organisations who acted as external reviewers of the briefing.

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