# **Assisted Dying**

An International Survey

A report from the Swedish National Council on Medical Ethics (Smer)

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## Preface

An important task for the Swedish National Council on Medical Ethics (henceforth, "the council") is to stimulate public debate on important issues in medical ethics and to act as a bridge between science, the public, and political decision-making. With this role in mind, we are presenting here an international survey of the rapid developments around the issue of assisted dying.

The present report supplements the state of knowledge report on assisted dying published by the council in 2017. As with the previous one, the council hopes this report will help to keep our medical ethics debate on the matter evidence-based, factual, and nuanced. While the report does include an ethical analysis of the different ways in which assisted dying has been permitted in the jurisdictions described, it does not come to a conclusion or recommendation regarding what would be the right course of action for Sweden.

A reference group, consisting of council members Per Landgren and Sofia Nilsson, and experts Titti Mattsson and Mikael Sandlund, was tasked with producing the report. Main author is research officer Henrik Ahlenius. Secretariat staff members Lotta Eriksson, Michael Lövtrup and Carolina Östgren have also contributed. As part of its research, the council has obtained facts from ethics councils in other countries as well as from experts in various fields. These are listed in Annex 1. The decision to publish the report was made at a meeting of the council on 21 March 2024.

Stockholm, April 2024

Sven-Eric Söder, Chair

# Content

1	Introduction	9
1.1	Defining 'assisted dying': practitioner- and self-administered	10
1.2	Procedures not classified as assisted dying	11
1.3	The council's previous treatment of the issue	12
1.4	Structure of the report	13
2	Australia	15
2.1	The process towards new legislation	16
2.2	Implementation of the Act	17
2.3	Eligibility criteria for assisted dying	18
2.4	The assessment process	
2.5	Why do people request assisted dying?	23
2.6	How assisted dying is provided	24
2.7	Medical and demographic data	25
2.8	Statistics from Australia	25
3	Spain	27
3.1	The process towards new legislation	27
3.2	Implementation of the LORE	28
3.3	Eligibility criteria for assisted dying	29

3.4	The assessment process	29
3.5	Time, place, and method	30
3.6	Medical and demographic data	31
4	New Zealand Aotearoa	35
4.1	The process towards new legislation	35
4.2	Implementation of the Act	
4.3	Eligibility criteria for assisted dying	39
4.4	The assessment process	40
4.5	Place and method	41
4.6	Medical and demographic data	43
5	Portugal	45
5.1	The process towards new legislation	45
5.2	Eligibility criteria for assisted dying	46
5.3	The assessment process	47
6	Update on Benelux, Canada, Colombia, Switzerland, and USA	51
6.1	The Netherlands	52
6.2	Belgium	55 55
6.3	Luxembourg	57

6.4	Canada	1	58
	6.4.1	Changes since 2017	59
	6.4.2	Medical and demographic data from Canada	60
6.5	Colom	bia	62
6.6	Switzer	rland	
	6.6.1 6.6.2	Changes since 2017  Medical and demographic data	63
	0.0.2	from Switzerland	64
6.7	USA: 7	The Oregon model	65
	6.7.1	Changes in the Oregon model since 2017	
	6.7.2	Medical and demographic data from the USA .	66
7	Other i	nternational developments	69
7.1	Austria	1	69
7.2	Germa	ny	71
7.3	Italy		72
7.4	Ecuado	or	72
7.5		st of Latin America: Argentina, Chile, Cuba, o, and Uruguay	73
7.6	France		74
7.7	Ireland		75
7.8	United	Kingdom	76
7.9	Denma	rk	78
7.10	Finland	ł	78
8	Ethical	perspectives	81
8.1	Termin	nal disease or chronic suffering	81
	8.1.1	Uncertain prognoses	82
	8.1.2	Mental illness	
	8.1.3	Different scopes and rationale for	
		the legislation	83

Content Smer 2024:4

Patient	judgement and decision-making capacity	. 84
8.2.1	Advance directives	. 84
		0.5
8.3.1		
8.3.2		
8.3.3	The burden on staff	. 88
8.3.4	Patient capacity and remaining life	. 88
8.3.5		
Patient-	initiated or healthcare-initiated discussion	. 90
The role	e and recruitment of healthcare professionals	. 92
8.5.1	Opt-in or opt-out	. 92
Conclu	sion	. 93
8.6.1	Facts and values	. 94
rences		.97
×		
ex 1 Co	onsulted experts	109
	Practiticassisted 8.3.1 8.3.2 8.3.3 8.3.4 8.3.5 Patient-The role 8.5.1 Conclus 8.6.1	Practitioner-administered or self-administered assisted dying

## 1 Introduction

Although assisted dying is one of the oldest debates in medical ethics it is now more topical than ever. This is so largely because of an inherently positive development, namely our improved capacity to cure and alleviate medical conditions, which in turn is part of the explanation we now enjoy longer lives than previous generations did. However, a downside to our longevity is that dying too has become more protracted. In a developed country, people tend to die in hospitals, hospices, nursing homes, and other healthcare facilities. Compared to in the past, death nowadays does not come quite as often in the form of a sudden unforeseen incident or as the end of an inevitable course of events. More often, death now comes as something enmeshed with a string of medical decisions and balancing of various factors, the precise timing of which largely depends on these decisions and factors. Death and dying are thus becoming matters in which ethics is playing a bigger role precisely because we have much more control over death and dying than before. Consequently, it is of importance that we think about and discuss how we want to die, and what kind of death we are prepared to furnish for others.

The present report is a contribution to that conversation. Its main purpose is to inform Swedish societal debate about developments internationally regarding assisted dying — in the law and in actual practice. Assisted dying is currently accepted in 15 countries, including nine European. Other countries seem to be following suite. The extent to which these trends are desirable rather than regrettable merits discussion, and this report provides part of the basis for such a discussion.

In 2017, the council published the report Assisted dying. A state of knowledge report. That report described the law and practice in countries that at the time permitted assisted dying in some form. These were Belgium, Canada, Colombia, Luxembourg, the Netherlands, Switzerland, and a handful of US states. There was a particular focus

Introduction Smer 2024:4

in that report on the 'Oregon model', which was presented and evaluated in detail. The report also described the legal situation in Sweden, as well as what was known about the opinions of both the public and Sweden's healthcare professions. This report is a supplementary sister volume to the 2017 report. Over the past six years, assisted dying has become accepted in yet more countries, the Canadian legislation has been amended, and additional states in the USA have adopted the Oregon model. Also, draft legislation is currently being considered in several countries in Europe and in Latin America. Consequently, there is now quite a lot of new knowledge, experience, and trends to summarise and ponder.

#### 1.1 Defining 'assisted dying': practitionerand self-administered

The term 'assisted dying' is used by the Swedish National Council on Medical Ethics to denote an intervention that is provided following an explicit request from a patient where the intention is that the intervention should cause the patient's death. With this definition, we can then distinguish between two different forms of assisted dying. The form of assisted dying referred to in this report as practitioner-administered assisted dying is defined as a person other than the patient, typically a physician or nurse practitioner, performing the decisive act that leads to the patient's death. (Note that in the following in this report, the terms physician, doctor and (medical) practitioner are used synonymously.) When, on the other hand, this decisive act is performed by the patient themself, for example with the aid of a lethal substance (medication) prescribed for them, it is termed selfadministered assisted dying. So 'assisted dying' is the umbrella term, and the two sub-forms are 'practitioner-administered assisted dying' and 'self-administered assisted dying'.

What is called 'self-administered assisted dying' in this report is sometimes referred to as 'physician-assisted suicide'. The council has chosen to use the term 'self-administered assisted dying', which does not include the emotionally charged word 'suicide'. Suicide is often a desperate and rash act that frequently stems from mental illness. Proponents of assisted dying in some form wish to be able to discuss the issue in a way that does not carry this emotional baggage, as it

Smer 2024:4 Introduction

has the potential to lead us to prejudge a request for assisted dying as irrational or see it as an expression of mental derangement of some kind.

- 'Assisted dying' is defined in this report as an intervention that is given after an explicit request from a patient, where the intention is that the intervention should cause the patient's death.
- 'Practitioner-administered assisted dying' is defined in this report as a form of assisted dying as described above, where someone other than the patient performs the decisive act that leads to the patient's death.
- "Self-administered assisted dying' is defined in this report as a form of assisted dying as described above, where the patient themself performs the decisive act that leads to the patient's death.

In the Benelux countries, as well as in Spain, Portugal, and Latin America, the equivalent of 'euthanasia' is used to denote what in this report is called 'practitioner-administered assisted dying'. Indeed, in some jurisdictions, practitioner-administration is so dominant that the term 'euthanasia' is used to talk about assisted dying more broadly, and self-administration is rare enough as to be mentioned specifically. While perhaps not a taboo term, by contrast in the Anglophone world 'euthanasia' is used somewhat less often and the general trend is a terminology usage in line with the one suggested here: physician-or practitioner-administered assisted dying on the one hand, and patient- or self-administered assisted dying on the other.

## 1.2 Procedures not classified as assisted dying

The definition above includes three essential elements for something to be called assisted dying: that it is voluntary, intentional, and active. Procedures where one or more of these elements is missing are thus not assisted dying as the council defines the term. A patient who dies after refusing treatment does not die through assisted dying, as this does not constitute an intervention that has been administered, and because there is no intention of the healthcare staff to cause the patient's death. According to the proposed definition, other situations where decisions are made to withhold treatment or discontinue

Introduction Smer 2024:4

treatment should not be called assisted dying, because such decisions are not interventions that have been administered nor, typically, is death intended (even though it may be foreseen) in these situations. The same applies to a case where the pain relief administered to the patient accelerates their death by suppressing respiration. In such a case, the intention is to relieve symptoms – not to cause the death of the patient. Finally, palliative sedation, a procedure where the patient's level of consciousness is lowered using tranquillizing and sedating medication should be kept distinct from assisted dying. Sedation where the patient is woken up at certain intervals is called intermittent palliative sedation, and sedation that involves the patient sleeping until death occurs is called continuous or terminal palliative sedation. Since these procedures do not in themselves accelerate the advent of death, and are typically used for the purpose of relieving symptoms, they do not constitute assisted dying as defined above.

#### 1.3 The council's previous treatment of the issue

Questions of self-determination and end-of-life quality of life have been an obvious focus of the council's attention and its work over the years. In 1989, P.C. Jersild, at the time an expert on the council, led the drafting of a report on the Netherlands, where assisted dying was practised. The entire council visited the Netherlands in 2006, meeting with officials, researchers, and physicians, along with defenders and opponents of assisted dying. On two previous occasions, the council has recommended that the Swedish Government investigate with an open mind whether assisted dying in any form should be legalised. On both occasions, the Government of the day - one a Social Democrat government and the other a centre-right government – rejected the proposal. In 2008, the council adopted a position on assisted dying whereby it should be accepted for patients with decision-making capacity who are at the end of their lives and are suffering from "a progressive and untreatable disease capable of causing foreseeable physical or mental suffering that is unbearable".

In 2017, the council published Assisted Dying. A state of knowledge report, which described the legislation and practice in the jurisdictions that at that point in time practised assisted dying. The report also gave an overview of the general debate on assisted dying, and

Smer 2024:4 Introduction

listed the various reasons for and against it. In light of the rapid developments internationally in recent years, and after the Swedish Society of Medicine (SLS) and the Swedish Medical Association jointly wrote to the council with a request to update the 2017 report, the council decided in 2023 to produce a supplementary state of knowledge report with a focus on developments internationally.

#### 1.4 Structure of the report

The main focus of this report is the account of the legalisations of practitioner-administered assisted dying that have taken place since the last state of knowledge report on this topic was published in 2017. Such legalisations have occurred in Australia's six states, in New Zealand, Portugal, and in Spain. These developments are described in Chapters 2–5 chronologically by the date of the legalisation. Chapter 6 provides an update on legislative amendments and current statistics from the countries and federal states covered already in the 2017 report. This group includes Benelux, Canada, Colombia, and the US states that have legalised assisted dying modelled on Oregon's legalisation. In addition, a number of jurisdictions have permitted or initiated processes towards legalisation – a development described in Chapter 7.

Chapter 8 presents an ethical analysis of the various laws described in the previous chapters. This analysis is not intended to provide a comprehensive treatment of the issue of assisted dying, and therefore it does not result in an all-things-considered recommendation from the council. Chapter 8 thus confines itself to highlighting points of common interest and the differences between the models in question and the ethical considerations of which they are an expression.

This compilation is mostly based on publicly available information from government agencies in the countries concerned that describe the legislation and procedures in that country or federal state. Research literature and news articles have also been used as sources. In the course of this project, the council was assisted by a number of foreign experts and by contacts serving on equivalent councils in the various countries, for which we are deeply grateful. A list of the consulted experts can be found in Annex 1.

# 2 Australia

Australia is a federation of states, each of which has far-reaching powers of self-determination. Both the federal government and the state governments, as well as more regional actors, share in healthcare responsibilities, but it is up to each state parliament to decide on the issue of assisted dying. In recent years, all six states (starting in 2019 in Victoria and ending in New South Wales in 2023) have legalised what is termed *voluntary assisted dying (VAD)* in Australia. This nomenclature covers both procedures in which the patient is given the means to end their own life, that is 'self-administered assisted dying', and procedures in which the physician (or, in some states, a nurse practitioner) administers the lethal substance, that is, 'practitioner-administered assisted dying'.

In 2016, the Australian Medical Association (AMA) issued a position statement on assisted dying stating that doctors should not be involved in interventions that have as their primary intention the ending of a person's life. The position statement stressed, however, that it was recognised that there are divergent views within the medical profession and that the issue should be "ultimately a matter for society and government". Since assisted dying was legalised in all the states of Australia, the AMA's resistance has waned. Its submission before the New South Wales Parliament, the most recent state to legalise VAD, does not include the wording stating that doctors should not be involved. On the other hand, it emphasises healthcare professionals' freedom to decline personally to participate in VAD and the fact that assisted dying is up to society and government to decide on.

<sup>&</sup>lt;sup>1</sup> Australian Medical Association 2016.

<sup>&</sup>lt;sup>2</sup> Australian Medical Association New South Wales 2021.

Australia Smer 2024:4

#### 2.1 The process towards new legislation

Australia has long had a lively debate around assisted dying – among academically schooled moral philosophers, in public debate, and in its legislative assemblies at both the federal and state level. When the first opinion poll on the issue was conducted in 1962, 48 percent of Australians polled were in favour of practitioner-administered assisted dying. Since then, support has been growing steadily, and 75–85 percent of the population were in favour of the legalisation long before it became a reality.

Between 1993 and 2017, more than 50 bills to legalise assisted dying were tabled in the country's various parliaments. In 1995, both forms of assisted dying became legal in the Northern Territory through the Rights of the Terminally Ill Act. At this time, practitioner-administered assisted dying was being practised in the Netherlands without being officially permitted under a time-honoured praxis of dropping the charges for doctors who followed an established process. On the other hand, the Northern Territory in Australia was the first jurisdiction in the world to explicitly permit practitioner-administered assisted dying in law. However, the NT is not a state but a territory, with more limited autonomy than Australia's states. The Act was in force about a year before it was annulled by the Parliament of Australia in 1997. During the brief existence of the Act, three people died by assisted dying.<sup>3</sup>

Since then the question has been dealt with many times, without proceeding all the way to legalisation in any of the state parliaments until more recently. Between 2015 and 2016, the Parliament of Victoria commissioned a thorough analysis of legalising assisted dying. The Panel took more than 1 000 written submissions into account, and the parliamentary committee responsible held a number of public hearings, debates and lectures aimed at illuminating the issue from all sides. The vote on the bill on 29 November 2017 prompted intense, emotional parliamentary debate, which in one instance lasted non-stop for over 24 hours. The legislation enacted comprised 142 pages

<sup>&</sup>lt;sup>3</sup> The facts in this and the previous paragraph come from Willmott et al. 2016. The ban on Australia's territories having the power to decide on assisted dying legislation was lifted in 2022, and legalisation is currently being investigated in both the Australian Capital Territory and the Northern Territory.

<sup>&</sup>lt;sup>4</sup> See Parliament of Victoria (2016) and State of Victoria, Department of Health and Human Services (2017).

<sup>&</sup>lt;sup>5</sup> Preiss & Towell 2017.

Smer 2024:4 Australia

and detailed the eligibility criteria for VAD, the application and review process, and the rights and obligations of healthcare professionals. As the first state with a carefully crafted (and parliamentary viable) piece of legislation, Victoria's Act then became the model for subsequent Australian states to legalise VAD, even though they have each chosen a slightly different form in some respects.

## 2.2 Implementation of the Act

The Voluntary Assisted Dying Act 2017 entered into force 18 months after its adoption, on 19 June 2019. In the interim, a series of measures were taken to prepare the healthcare system and to inform staff and the public about the implications of the new legislation. A new independent government agency, the Voluntary Assisted Dying Review Board, was created. The Review Board's remit is to review VAD activities, monitor compliance with the legislation, and propose corrections and improvements. One of the preparations needed included training physicians and other healthcare staff. Regardless of their attitude towards assisted dying, all were to be taught about their professional rights and obligations under the new Act, and about patients' rights. The physicians who wish to participate in VAD must complete specified training to make them qualified for the role. Easy-to-understand and standardised forms were designed, as well as information material for patients and the public more broadly. Procedures for the fast and secure handling of the lethal substances were developed, as well as a secure online service for all documentation, assessments and decisions regarding those patients who have requested assisted dying. Victoria's ambition was to develop the "safest and most conservative model in the world", and the challenge was to design legislation, procedures and safeguards that lived up to this ambition without making assisted dying inaccessible in practice.6

<sup>&</sup>lt;sup>6</sup> Premier of Victoria 2017.

Australia Smer 2024:4

## 2.3 Eligibility criteria for assisted dying

The Australian states do not have identical legislation, but in general, one can say that all the Acts say that a patient may be eligible for assisted dying only if they:

- have a current and persistent wish to receive assisted dying
- are 18 years or older
- · are capable of making their own decisions
- act voluntarily and without coercion or undue influence
- are permanent residents in the state
- have been diagnosed with an advanced and progressive disease, illness, or medical condition that, according to medical experts, is likely to lead to the patient's death within six (in some cases twelve) months, and
- are experiencing suffering that, in the person's own judgement, is unbearable and cannot be alleviated satisfactorily.<sup>7</sup>

In all states, the person must be *dying*. Chronic, unbearable suffering is not sufficient. Five states require that death is likely to occur within six months but, in the case of neurodegenerative diseases, voluntary assisted dying can be granted even if death is expected to occur only after twelve months. The reason for the exception is that these conditions can cause serious impairment of bodily and cognitive functions more than six months before the disease is estimated to lead to the patient's death. Queensland has a general 12-month limit regardless of the underlying condition.

<sup>&</sup>lt;sup>7</sup> Tasmania does not require the disease to be progressive, that is, that the patient's condition is steadily worsening. The various Acts often list Australian citizenship among the criteria, but upon closer inspection it turns out to be neither necessary nor sufficient. Citizenship is not a necessary condition because the Acts give permanent and legal residents the same opportunities to apply for assisted dying as Australian citizens in the same state. Nor is it sufficient because the states do not accept Australian citizens who reside in, for example, Canberra (the Australian Capital Territory) or the Northern Territory, where assisted dying is not currently permitted, travelling to a state to apply for assisted dying. Some states allow exceptions to the residence rule in particularly distressing circumstances, for example when the person has family in the state. Now that all six states have legalised assisted dying, the risk of national 'assisted dying tourism' would seem to be less. In the most recent evaluations, the reviewers in both Victoria and Western Australia propose that the requirement for residency should be reexamined. For more information on the legislation in each of the states, see Waller et al. 2023.

Smer 2024:4 Australia

#### 2.4 The assessment process

All states have rules concerning which healthcare professionals are permitted to discuss assisted dying with a patient and how such a discussion should be initiated and what it must contain. Victoria and South Australia prohibit licensed medical professionals such as physicians and nurses from *initiating* conversations about VAD. The patient must be the one who brings up the subject. In the other four states, physicians, and in some cases nurse practitioners, may bring up assisted dying with a patient, but always with the requirement that they must inform the patient about other possible treatment options and palliative care, and what the different options might mean for the patient.

In all the states, the VAD process is initiated by a patient talking to a physician and unambiguously expressing a request for assisted dying. If the physician who receives this request agrees to take care of the patient, they become the patient's coordinating medical practitioner. The coordinating medical practitioner follows the patient throughout the process and is the person with whom the patient has the most personal contact. The patient is also supported by a care navigator from the state health department. A patient can choose whether to first contact the state care navigator service for advice and referral to a qualified medical practitioner, or to directly contact a medical practitioner themself. In addition to the coordinating medical practitioner, the patient meets with and is assessed by a consulting medical practitioner, who is typically a specialist in the medical condition that the patient is suffering from.

The coordinating medical practitioner makes the first assessment of whether the patient meets the requirements under the Act and is therefore eligible for assisted dying. The medical practitioner must have access to the patient's entire medical record and be able to contact the patient's previous healthcare providers. The medical practitioner must also assess the patient's decision-making capacity and rule out that their request for assisted dying might originate in pressure from or the wishes of others. If the coordinating medical practitioner assesses that the patient meets the criteria for assisted dying, the patient must then be assessed by the independent consulting medical practitioners. Both the coordinating and consulting medical practitioners may call in other specialist doctors if they deem that the

Australia Smer 2024:4

assessment requires their opinions. In Victoria (as in South Australia), a third assessment is always required for patients with neurodegenerative diseases who are expected to live longer than six but less than twelve months. This prognosis must be determined by a specialist doctor in neurology.

#### 2.4.1 Decision-making capacity

In the Australian states, there are detailed instructions and tools for doctors involved in the application process for VAD. For example, the guide to support doctors in Queensland in assessing decision-making capacity and excluding undue influence from others contains the following points:

Ask the person to describe in their own words:

- the problem with their health now
- their end-of-life options including further active treatment, palliative care, and voluntary assisted dying
- the possible benefits and risks (or discomforts) of the options
- what they expect will happen if they choose voluntary assisted dying
- what they expect will happen if they do not choose voluntary assisted dying
- how they decided to accept or decline the other options
- what makes [voluntary assisted dying or the chosen option] better than [alternative options]?

To ensure that the patient's request is truly voluntary and free from undue influence, the doctor may talk to the patient alone and seek to establish:

- · why they are applying for voluntary assisted dying
- whether any of their friends, family or carers know they are considering voluntary assisted dying, and what they think about it

Smer 2024:4 Australia

• if the patient feels safe or is feeling any pressure from others to request voluntary assisted dying, and

• what support they would have if they choose not to proceed with voluntary assisted dying.

Some "red flags" that the doctor is asked to watch out for are:

- The patient fails to remember or understand their medical condition or prognosis
- The patient does not accept the diagnosis, for example due to delusions or denial
- The patient cannot recount the possible options, and their consequences (including no treatment), and their benefits and risks
- The patient cannot remember their prior choices or express them in a consistent way
- The patient engages in a decision-making process that does not lead logically to the outcome communicated
- The patient makes an unusually quick decision
- The decision does not appear to be based on the patient's expressed beliefs or values, or rejects alternative options without explanation
- The patient frequently reverses their decision
- The patient's conversations seem more constrained when in the company of others
- Friends, family, or carers are encouraging the person to seek voluntary assisted dying
- The patient seems to feel unsafe or uncomfortable with family or carers
- The patient has inadequate support at home for their condition
- The patient appears to respond inconsistently to questions
- The patient has a family member or carer who constantly speaks or communicates for them
- Evidence of domestic violence (for example, signs of physical or verbal abuse).

Australia Smer 2024:4

If either the coordinating or consulting medical practitioner has doubts about the patient's decision-making capacity, a psychiatrist must make a special assessment. If, after these examinations, both the coordinating and the consulting medical practitioner – at least two, but sometimes four or more – come to the conclusion that the patient meets the criteria for assisted dying, the patient must be asked if they wish to proceed with or discontinue the process. If the patient wishes to proceed, they must sign a written request for voluntary assisted dying and have it witnessed by two eligible witnesses who sign the document in the presence of the patient. The coordinating medical practitioner now carries out a final assessment, reviews the documentation and verifies that the patient has undergone the statutory assessment process and has been found to meet the criteria to be eligible for VAD. In Queensland and Western Australia, this completes the assessment process. In New South Wales, South Australia, Tasmania and Victoria, the entire case is then reviewed by a state health department review board before final approval is given. After approval, the lethal substance is made available to the coordinating medical practitioner through specially licensed pharmacies.

<sup>&</sup>lt;sup>8</sup> The process in Tasmania is a little different.

Smer 2024:4 Australia

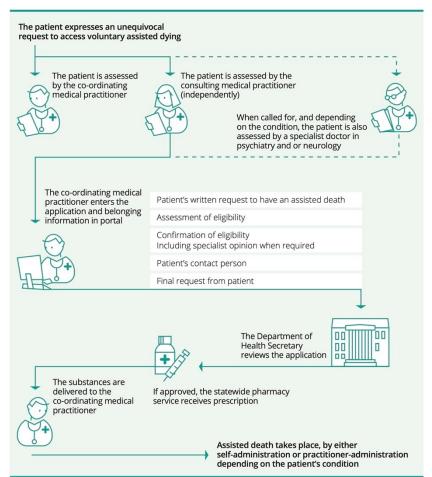


Figure 2.1 the VAD process in the state of Victoria

## 2.5 Why do people request assisted dying?

A patient may have many reasons for requesting assisted dying, but the most common is a reduced capacity to do the things that they feel make life worth living. Loss of independence is another common reason. Inadequate pain relief, or concern about inadequate pain relief, is a reason in just under half of these patients, but is not the most common reason. Australia Smer 2024:4

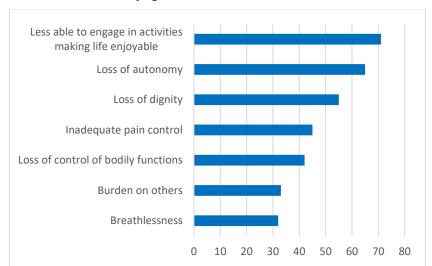


Figure 2.2 Australian patients' reasons for requesting voluntary assisted dying

## 2.6 How assisted dying is provided

In all six states, both self-administered and practitioner-administered assisted dying are permitted, but the legislations govern each of these procedures differently. South Australia and Victoria permit practitioner-administered VAD only if the patient is 'physically incapable' of taking the lethal substance themself. In Queensland, Tasmania and Western Australia, VAD is also seen as the primary option, but doctors in these states have greater scope for taking the patient's preferences and general condition into account. Only in New South Wales is the choice entirely free for the patient, and no special conditions apply to either option. The legislation currently being drafted in the Australian Capital Territory, that is, Canberra and its surrounding area, also lacks the presumption for self-administered assisted dying and thus leaves the patient free to choose.

If assisted dying is to be self-administered, the lethal substance can be given to the patient, and they have the right to take it in any way they choose. However, there are special rules on how the lethal substance must be stored and how any unused lethal substance must be returned securely. In the case of practitioner-administered assisted dying, all states except Tasmania require that there is an independent

Smer 2024:4 Australia

witness present who can corroborate that the patient's request to receive assisted dying has been unambiguous right to the very last moment.

The patient can choose themself where to receive the lethal substance, for example in their own home. Actors in aged care and healthcare are entitled to abstain from participating in VAD, and if a patient at such an institution requests and is assessed eligible for VAD, the state care navigator and the coordinating medical practitioner may need to take steps to move the patient to a place that accepts the procedure. This institutional form of conscientious objection is the subject of debate in Australia because it can place practical obstacles in the way of a person requesting VAD.

## 2.7 Medical and demographic data

All patients who die through VAD in Australia have a terminal illness that is estimated to lead to death within six or in some cases a maximum of twelve months. Cancer dominates as an underlying condition in all states, accounting for at least 58 (Tasmania) and at most 78 percent (Queensland) of patients. Neurodegenerative diseases are the reason in 10–15 percent of patients, and about the same proportion have a variety of respiratory illnesses such as chronic obstructive pulmonary disease (COPD). Men make up about 55 percent of the patients. About 80 percent are receiving palliative care, and about 15 percent of these have been receiving palliative care for over a year. About half of the patients who request voluntary assisted dying are in the age range of 65-81 years. The median age varies between 72 and 76 years. The proportion of deaths through voluntary assisted dying compared to the total number of deaths varies between the states. The highest percentage is in Western Australia, where voluntary assisted dying accounted for 1.4 percent of deaths in the most recent period for which figures are available.

#### 2.8 Statistics from Australia

The six states legalised assisted dying in the following order, starting from the first: Victoria (19 June 2019), Western Australia (1 July 2021), Tasmania (23 October 2022), Queensland (1 January 2023), South

Australia Smer 2024:4

Australia (31 January 2023), New South Wales (28 November 2023). Since VAD was introduced in the state of Victoria in 2019 and subsequently in the other five states, 1 667 individuals have died by VAD in Australia.<sup>9</sup>

Table 2.1 Deaths through assisted dying in Australia from 2019 to June 2023

	2019/2020	2020/2021	2021/2022	2022/2023	Total
Victoria	129	202	275	306	912
Western Australia	_	_	191	255	446
Queensland	-	_	_	245	245
Tasmania	_	_	-	25	25
South Australia	-	_	_	39	39
<b>New South Wales</b>	_	_	-	_	_
National	129	202	466	870	1 667

<sup>&</sup>lt;sup>9</sup> Statistics and other facts are derived from the review board reports in each state: Voluntary Assisted Dying Board Western Australia 2023, Voluntary Assisted Dying Commission Tasmania 2023, Voluntary Assisted Dying Review Board Queensland 2023, Voluntary Assisted Dying Review Board South Australia 2023, and Voluntary Assisted Dying Review Board Victoria 2023. No data has yet been published from New South Wales.

# 3 Spain

As the fourth country in the EU – after the Netherlands, Belgium and Luxembourg – Spain legalised practitioner-administered and self-administered assisted dying in 2021. The issue had been under consideration by the country's parliament since 2017 and after several rounds of negotiations and revisions, the legislation (the Organic Law 3/2021 for the Regulation of Euthanasia in Spain, hereinafter LORE) was enacted on 24 March 2021 and entered into force on 25 June of that year.

#### 3.1 The process towards new legislation

As in most other countries, the issue of assisted dying had been debated for a long time in Spain, often based on individual high-profile patient cases. Since the 1980s, a series of court cases, political debates and legislative amendments had paved the way for the legalition of assisted dying. Spain's 17 regions have a certain degree of autonomy and eleven of them had used this autonomy in the 2010s to accept terminal sedation, where patients are sedated until the point of death.<sup>1</sup>

The traditional dominance of the Catholic Church in medical ethics in Spain has gradually waned and a secular tradition of ideas focusing on quality of life and *self-determination* in particular has gained ground. The text of the LORE refers explicitly to assisted dying as an individual right enshrined in the Spanish constitution. The preamble states that a Law that simply permits assisted dying

<sup>&</sup>lt;sup>1</sup> Ministerio de Sanidad 2022.

Spain Smer 2024:4

does not sufficiently respect the right of self-determination of those who find themselves in a situation of serious, chronic and incurable suffering ... which cannot be alleviated in ways they find acceptable ... To this end, this Law regulates and decriminalises practitioner-administered assisted dying in certain clearly defined cases; with criteria that ensure absolute freedom in the decision and exclude any kind of external pressure.<sup>2</sup>

#### 3.2 Implementation of the LORE

The LORE legalising assisted dying came into force three months after it was passed in the Spanish Parliament (Cortes Generales). In Spain, healthcare is administered by the country's regions and cities under national regulation. Following the adoption of the LORE in March 2021, the regions were tasked with developing a workable praxis compliant with the LORE's guidelines and requirements. The most important parts included setting up the infrastructure needed for the assessment process to function, and to establish a register of healthcare professionals who, for reasons of conscience, did not want to participate in providing assisted dying care. The work of the regions was supported and coordinated by Spain's national Ministry of Health. The work was based on a set of guiding principles that expressed certain basic norms or ideals in this context: to create equivalent assisted dying care across the nation, to ensure transparency, to promote thoroughness in the documentation and assessment processes, to ensure confidentiality in the handling of sensitive personal data, to ensure legal certainty for healthcare professionals, and to enable smooth cooperation and information exchange between various government agencies and individual actors. All regions must prepare an annual report on how assisted dying is practised, which is submitted to the Ministry of Health. In addition to the reports from each of the regions, the Ministry of Health compiles a report for the whole country.

The Spanish LORE provides an *opt-out* system for physicians and other healthcare professionals: they are free to refrain from participating in assisted dying on moral grounds, but this requires that they actively opt out of participating. The presumption is that physicians will participate both in assessing applications and in providing assisted dying. This design is in line with the LORE's rationale

<sup>&</sup>lt;sup>2</sup> Ministerio de la Presidencia, Justicia y Relaciones con las Cortes 2021: Chapter 1, p. 34038.

Smer 2024:4 Spain

that the right to assisted dying entails that it should be not only permitted but also accessible.

#### 3.3 Eligibility criteria for assisted dying

Under the Spanish LORE, a person may be eligible for assisted dying provided that they:

- are aged 18 years or older
- are able to make their own decisions
- are a citizen or permanent resident for 12 months
- express a voluntary and persistent request to be provided with assisted dying care, and
- are suffering from a serious, chronic and incapacitating disorder or incurable illness causing persistent and unbearable physical or mental suffering.

## 3.4 The assessment process

A patient who is considering requesting assisted dying can turn to any health centre or family doctor of their choice. The presumption is that any physician can assist, unless they have chosen to invoke their right of conscientious objection. If the physician does not wish to participate in assisted dying care, the LORE requires that they inform the patient of this and help the patient to find another physician. Otherwise, the physician can take on the care of the patient and then becomes the responsible physician (médico/a responsable) for the patient, who will follow the patient throughout the process. At their first meeting, the physician and the patient will talk about what assisted dying is, what other options there are, and why the patient is requesting assisted dying. The physician will also inform the patient that they still have the right to palliative care and other healthcare options. If, after this initial conversation, the patient wishes to proceed with an application for assisted dying, the physician and patient will write the application together. The physician and other members of the patient's care team will then consult with each other, and Spain Smer 2024:4

decide whether the patient appears to provisionally meet the criteria for assisted dying. This consultation must take place within two days of the initial meeting with the patient, and the patient is notified of the outcome within five days.

In cases where the patient is deemed to meet the criteria, a period of 15 days from the initial meeting and completed application then begins for the patient to reflect on and consider their decision. If the patient wishes to proceed after this period of reflection, they must then submit a second written application for assisted dying. After their second, confirmatory, application, the patient will meet with another physician, called the *consulting physician* (médico/a consultant/a). As a rule, the consulting physician must be a specialist in the condition that has led the patient to request assisted dying, and they may not be part of the same care team as the responsible physician. The consulting physician will talk to and examine the patient, study their medical record and contact other healthcare providers.

The consulting physician sends their assessment to the responsible physician. If they both agree that the patient is eligible, the responsible physician then submits all the documentation to a review board that conducts a final review of the case, and either approves or rejects the application. The chair of the review board engages a lawyer and a physician (who are independent in relation to the two physicians involved thus far) to familiarise themselves with the case and make an assessment. The review board may want to talk to the patient, as well as the physicians and other staff in the care teams that have been in contact with the patient. The chair of the review board has two days in which to find a suitable duo to review the case, and these two (the physician and the lawyer) in turn have seven days to conduct their review.

Throughout the process, from the initial application to the review board's decision, the patient must be kept informed of their appeal options with regard to decisions that go against them. There are specific instructions and time frames for appeal processes.

## 3.5 Time, place, and method

Spain's 2022 National Report notes that the legal framework in the LORE concerning minimum and maximum time limits have generally been adhered to. In 2022, in 82 cases the responsible physician in-

Smer 2024:4 Spain

voked the option to derogate from the rule that 15 days must pass between the first and the second requests for assisted dying, with reference to the rapid deterioration of the patient. On average, it took 75 days (median: 56) from a patient's initial request for assisted dying to the death of the patient through assisted dying. Patients who die before the assessment is completed do so on average 27 days after the initial application (median: 20).

Patients who are deemed eligible for assisted dying are free to choose between practitioner-administered assisted dying and self-administered assisted dying. Most people choose practitioner-administered assisted dying. In 2022, self-administered assisted dying was chosen by five patients. The patient also chooses where the procedure is to take place. Sometimes, it cannot be done in a place other than a hospital or other healthcare facility. This occurred in just under half of the cases. Half of the patients choose to have the procedure at home.

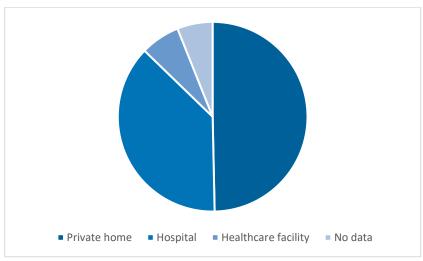


Figure 3.1 Place of assisted dying

## 3.6 Medical and demographic data

During the first 18 months of the operation of the LORE, that is, the second half of 2021 and all of 2022, 701 patients applied for assisted dying in Spain. Of these, 363 died by assisted dying. 184 of those who had requested assisted dying died during the process. Just under

Spain Smer 2024:4

20 percent had their application rejected. The proportion of applicants who subsequently died by assisted dying varies regionally from 27 percent to at most 80 percent.

Table 3.1 Patients requesting assisted dying in 2022

Demographics of assisted dying in	f patients requesting 1 2022 (N= 528)	Number of persons	Percentage
Sex	Women	245	46.4
	Men	281	53.2
	Data lacking	2	0.38
Age groups	Under 30 years	4	0.76
	30-39 years	13	2.46
	40-49 years	36	6.81
	50-59 years	68	12.88
	60-69 years	121	22.91
	70-79 years	122	23.11
	80+ years	97	18.37
	Data missing	67	12.69
Diagnoses	Neurodegenerative	205	38.83
	Cancer	192	36.36
	Multimorbidity	40	7.58
	Respiratory diseases	16	3.03
	Cardiovascular		
	diseases	7	1.33
	Other	68	12.88

Spain differs from other countries where assisted dying is permitted in that patients with neurological diseases are the biggest group. In the first half of the year following the legalisation, the proportion was even greater. But the trend thereafter has become more similar to other countries, with a growing proportion of cancer patients. According to the national report published in 2023, one possible explanation could be that a large group of patients with chronic but not acutely life-threatening neurological conditions had been waiting to be able to request assisted dying. More than 40 percent of the patients are over 70 years old, and just under half of them are 80 years old or older. More men than women request assisted dying. Since the LORE was introduced, 49 patients who died by assisted dying have donated their organs to a total of 135 patients. There is no information in-

Smer 2024:4 Spain

dicating that patients with only a mental illness have died from assisted dying in Spain.

Spain accepts advance directives in which an approved request for assisted dying may remain in force even if the patient's decision-making capacity has subsequently declined. Of the 528 applicants in 2022, 14 patients had such an advance directive. All of them had a legal representative previously appointed by the patient.<sup>3</sup>

<sup>&</sup>lt;sup>3</sup> The statistics and other facts concerning assisted dying practice in Spain come from Ministerio de Sanidad 2023. The report sometimes mentions the number of applicants in 2022 as 576 and sometimes 528. The difference of 48 cases concerns applications that are not registered in the special database in which all assisted dying applications should be documented. These cases may refer to instances where the patient changed their mind or died during the process.

## 4 New Zealand Aotearoa

Both forms of assisted dying have been legal in New Zealand since 7 November 2021. In 2019, the New Zealand Parliament passed a law called the *End of Life Choice Act 2019* on the condition that the legislation would subsequently be approved in a binding referendum. As the first and so far only country in the world to do so, New Zealand subsequently held a referendum on assisted dying the following year, in which the proposal to accept the legislation was supported by 65 percent of voters. After another year of preparations, the new Act came into force in November 2021.

## 4.1 The process towards new legislation

The question of whether to permit assisted dying had been raised by individual members of parliament on a number of occasions since 1995, but the bills had never won a majority of votes in the parliament. The question was raised again in 2015 in connection with a specific patient's case. Counsel acting for New Zealand lawyer Lecretia Seales, a 40-year-old woman diagnosed with an aggressive brain tumour wrote to the High Court at Wellington with an urgent question: Would it be deemed a criminal act under the *Crimes Act* if her doctor helped her to die, and if it were, wouldn't that be inconsistent with her human rights under the Bill of Rights Act? The High Court found that the current Crimes Act did not permit her to be killed, or helped to take her own life, and that this was not inconsistent with the bill of rights that is also part of the New Zealand Constitution. "The changes to the law sought by Ms Seales", the judge explained, "can only be made by Parliament. I would be trespassing on the role of Parliament and departing from the constitutional role of Judges

<sup>&</sup>lt;sup>1</sup> Lundy 2015.

New Zealand Aotearoa Smer 2024:4

in New Zealand if I were to issue the criminal law declarations sought by Ms Seales" Seales died without assisted dying the following day.

Immediately after the High Court's decision and the death of Ms Seales, political initiatives aimed at stimulating debate on the legalisation of assisted dying were taken. Maryan Street, a former MP and human rights activist, along with Seales' surviving husband co-authored a petition to Parliament accompanied by 8 974 signatures, requesting an inquiry into the issue of assisted dying. The leader of the liberal ACT party, David Seymour, announced that he would work for the legalisation of assisted dying, and it was his bill (*End of Life Choice Act*) that after several rounds in Parliament was finally passed by 69 votes for and 51 against.

The drafting of the issue in Parliament prior to the vote attracted exceptional interest. The Justice Committee responsible for drafting the new law received up to 40 000 submissions of various kinds from organisations and the general public. In order to ensure that the Committee would acquire a view of the question that illuminated all sides of the issue, four smaller sub-committees were set up which listened to a total of 1 350 statements or testimonies from individual citizens at public meetings held across the country. Voting on the bill was classified as a 'conscience vote', which meant that MPs did not have to vote in accordance with their party line.

#### 4.2 Implementation of the Act

Following the referendum, the Ministry of Health (Manatū Hauora) was tasked with implementing the legislation and having an assisted dying service in place in New Zealand Aoteroa. A particular focus of this work was collaborating with and designing assisted dying care so that it looked after the interests of two traditionally vulnerable groups: the Māori indigenous population and people with disabilities. Representatives of aged care and palliative care were also involved in the process as well as physicians and other healthcare professionals from different backgrounds and work environments – all "to ensure that a broad spectrum of perspectives and concerns were considered within the implementation work programme." A special group had

<sup>&</sup>lt;sup>2</sup> High Court of New Zealand Wellington 2015.

<sup>&</sup>lt;sup>3</sup> New Zealand Parliament 2020.

<sup>&</sup>lt;sup>4</sup> Ministry of Health 2022, p. 4.

Smer 2024:4 New Zealand Aotearoa

overall responsibility for the preparations. This group consisted of representatives of the Ministry of Health's management, various leaders with special responsibility for Māori health, the healthcare regions, the Council of Medical Colleges, and others.

Table 4.1 Timeline of implementation in New Zealand Jan-Dec 2021

Jan-Mar 2021	Apr-June 2021	July-Sept 2021	Oct-Dec 2021
Governance Group and advisory network established Treaty analysis Assessment of workforce interest Key system-level policy settings defined (e.g. service provision, accountability, funding) Budget Bid	Medications selected Initial consultation with the Privacy Commissioner Funding and accountability arrangements defined Workforce training and support needs assessed, and first training module launched	The Support and Consultation for End of Life in New Zealand (SCENZ) Group established Forms, systems and processes to support com- pliance developed Operational processes and guidance developed Standards of Care and Clinical Guide- line developed Medications procured and available	Assisted dying secretariat established, including Registrar (assisted dying) Review Committee appointed by Minister All training available and workforce forum held Public information available Processes and systems in place to support operation and oversight of assisted dying service.

When the new End of Life Choice Act entered into force in 2021, a reform was under way that would result in the closing down of the country's 20 regions and the centralisation of healthcare responsibilities in one and the same new central government agency: Te Whatu Ora Health New Zealand. This meant that when the assisted dying service was introduced in 2021, responsibility for the service lay directly within the Ministry of Health, and thus was never something that was managed regionally. Since March 2023, the new central government agency has operational responsibility for the assisted dying service and the Ministry has had a more strategic task focusing on compliance with, and further development of, the legislation.

New Zealand Aotearoa Smer 2024:4

Since the Act's entry into force, various reviews have been carried out. The most important are the reports produced by the Registrar (assisted dying) and presented to the Ministry of Health. The first report was published in June 2022 and covers the period from 7 November 2021 to 31 March 2022. The second report was published in June 2023 and covers the period from 1 April 2022 to 31 March 2023. The new Te Whatu Ora Health New Zealand, which took over operational responsibility for assisted dying, compiles quarterly and annual reports that are presented to the Ministry and the public. After the first year of operation of the service, that is for the period November 2021 to November 2022, the Ministry of Health commissioned an external audit by the company Malatest International.

#### **4.2.1** Equity

In the implementation of the assisted dying service, the Ministry of Health placed great emphasis on the service being "person-centred, equitable and accessible to all New Zealanders". In order to achieve this, it was decided to:

- maximise the size, spread and diversity of the assisted dying workforce
- by allowing any willing and appropriately trained medical or nurse practitioner to access funding for providing assisted dying services
- providing funding for practitioners to travel to provide services, which means a person can receive care, regardless of where they live
- supporting the use of telehealth, where appropriate, in the process
- providing public information in various languages and formats
- supporting the use of interpreters to increase accessibility and support a culturally safe service for all people

<sup>&</sup>lt;sup>5</sup> Ibid. p. 6.

Smer 2024:4 New Zealand Aotearoa

 incorporating Te Tiriti o Waitangi principles in the assisted dying training, Standard of Care and Clinical Guideline for administering assisted dying medication to support practitioners to provide services that recognise and support Māori models of care

- supporting practitioners to provide culturally safe assisted dying services by creating a care plan and ensuring training resources reflect how the assisted dying process may look different depending on the person accessing the service
- ensuring feedback channels were in place to enable continuous quality improvement based on a person's experience of the service
- giving only two hospital pharmacies responsibility for fulfilling prescriptions of the assisted dying medications, and ensuring they are securely and speedily delivered anywhere in the country they are to be used.

## 4.3 Eligibility criteria for assisted dying

The assisted dying care offered by the New Zealand public health system is called the *assisted dying service*. The term covers both practitioner-administered assisted dying and self-administered assisted dying. In order to be eligible for assisted dying, the person must be:

- 18 years or older
- · competent to make an informed decision about assisted dying
- a citizen or permanent resident of New Zealand
- in an advanced state of irreversible decline in physical capability, and
- suffering from a terminal illness that is likely to end their life within six months
- experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable.

<sup>&</sup>lt;sup>6</sup> In Māori, the term 'Ngā Ratonga Mate Whakaahuru' is used, meaning "to die in a warm and comforting manner".

New Zealand Aotearoa Smer 2024:4

## 4.4 The assessment process

Under the Act, a discussion about assisted dying may not be initiated by healthcare staff. The patient must bring up the question themself. This can be done in several ways. The most common situation is that the person who is thinking about assisted dying, or just wants to learn more about what it is, talks to their own doctor. This doctor might be trained in providing the assisted dying service and on the approved Support and Consultation for End of Life in New Zealand (SCENZ) Group list, meaning that they are willing to be involved in providing the service. However, if this doctor is not willing to be involved in providing the service, whether due to conscientious objection or not, the Act requires the doctor to help the patient find another doctor who is. Patients can also turn directly to Te Whatu Ora Health New Zealand for guidance on which doctors in the area they can talk to about assisted dying. A doctor can choose whether they want to be involved in providing the service solely for their own patients or whether they are open to receiving patients referred to them by colleagues or Te Whatu Ora Health New Zealand. Similarly, patients can choose whether they want to initiate the process through their current doctor or whether they want to contact Te Whatu Ora Health New Zealand to be referred to another doctor. Te Whatu Ora Health New Zealand's website contains complete contact details for doctors willing to provide the service, and information explaining the process. A patient requesting assisted dying gets a contact person within Te Whatu Ora Health New Zealand, a care navigator who supports them throughout the process.

The Act establishes a formal process that must be adhered to in order to be eligible for assisted dying. It aims to protect the patient by ensuring that they meet all the criteria. The various steps must be taken in the specified order and centrally designed forms must be completed at each step in order to document the process.

Whether the patient visits their family doctor or contacts Te Whatu Ora Health New Zealand, anyone who wishes to apply for assisted dying will be entitled to an attending medical practitioner (AMP). This is the equivalent in other jurisdictions of the responsible physician. The AMP will follow the patient throughout the process, and is the doctor who makes the initial assessment of eligibility. The AMP may be the patient's family doctor, if that doctor is on the

Smer 2024:4 New Zealand Aotearoa

SCENZ Group list and if the patient wants their family doctor to provide the service. Or the AMP may be a doctor that the patient has been referred to by their family doctor, or a doctor that the patient has been referred to from the SCENZ Group list of approved doctors. Before a patient formally applies for the assisted dying service, they usually ask for a meeting to discuss the issue. The doctor will then inform the patient about what assisted dying involves, and about other options that may be relevant for end-of-life care, that palliative care exists and that assisted dying and palliative care are not mutually exclusive; and explain that even if the patient chooses to apply for assisted dying, they can change their mind at any time and halt the process. The AMP will encourage the patient to speak to their 'whānau', a Māori word for extended family. The doctor must also inform the patient that they have the right to go through the process on their own if they so wish.

If the AMP decides that the patient meets the criteria, the patient then meets with an independent medical practitioner (IMP). This is the equivalent of the consulting physician in other jurisdictions. The IMP is appointed via Te Whatu Ora Health New Zealand and does not have access to the AMP's notes. Both doctors must make their own independent assessments of whether the patient meets all the criteria. If they disagree, or if either of them is in doubt about whether the patient is competent to make an informed decision, the patient will also be evaluated by a psychiatrist. Both the AMP and the IMP have access to the patient's medical record and usually contact other healthcare providers with whom the patient has been in contact, for example to assess the patient's prognosis. After the IMP's assessment, the patient and the AMP meet again. If the assessment means that the patient is not deemed to meet the criteria, the AMP explains the decision and assists the patient to access other appropriate care. If the patient is deemed to meet the criteria, the process can continue. This means discussing the time and place of the assisted dying service.

## 4.5 Place and method

The assessment of a patient requesting assisted dying can take up to six weeks, but the average for those deemed to meet the Act's criteria is 18 days. A person who has been deemed to meet all the criteria

New Zealand Aotearoa Smer 2024:4

then chooses where the assisted dying service will be provided. In some cases, it cannot be provided in a place other than a hospital or hospice. But when the option exists, 80 percent choose to have the service provided at home or in another private, designated place. About one tenth take place in nursing homes, 7 percent in hospitals and 3 percent in hospices.

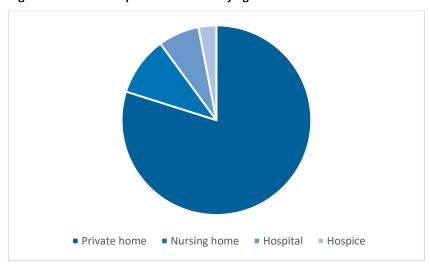


Figure 4.1 Chosen place for assisted dying

The patient also decides whether they want assisted dying in the form of practitioner- or self-administration. In New Zealand, this is a choice left to the patient, and there is no requirement that practitioner-administered assisted dying be provided only if it is physically difficult or impossible for the patient to take the lethal substance themself. The distinction between practitioner- and self-administered assisted dying plays a subordinate role in the New Zealand model. No specific terminology is used to distinguish between them. All that is said is that the lethal substance can be taken by the patient themself or be administered by a doctor or nurse practitioner, and that the patient chooses which method they will use. The patient can either swallow a lethal substance provided by a doctor or a nurse practitioner, or trigger an intravenous injection rigged by a doctor or a nurse practitioner, or a doctor or nurse practitioner can administer the lethal substance via a feeding tube or injection. An overwhelming

Smer 2024:4 New Zealand Aotearoa

majority, around 92 percent of patients, choose to have a doctor or nurse practitioner (under the supervision of a doctor) give them an injection. About 5 percent choose to swallow the lethal substance themself, 2 percent to trigger an injection themself, and 1 percent to receive the lethal substance via a feeding tube that the physician or nurse has set up and triggers.<sup>7</sup>

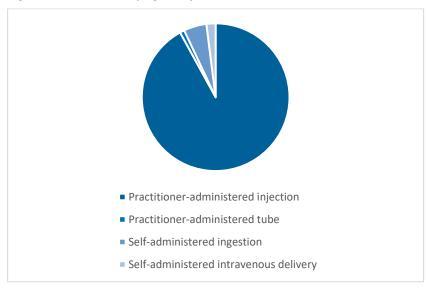


Figure 4.2 Assisted dying: four possible methods

# 4.6 Medical and demographic data

In the last 12-month period surveyed, 807 individuals formally requested assisted dying. More than half were women. About 80 percent were of European descent, and about 5 percent of Māori descent. This means that Europeans (representing about 70 percent of the total population) are slightly over-represented and Māori (representing over 15 percent of the population) are significantly under-represented. As in Australia, Benelux, Canada and the USA, various forms of cancer are the most common diagnosis. More than 75 percent of patients are over 65 years of age and over 18 percent are over 85. More than three-quarters were receiving ongoing palliative care at the time of applying for assisted dying.

<sup>&</sup>lt;sup>7</sup> Statistics and other facts come from the Ministry of Health 2022 and 2023.

New Zealand Aotearoa Smer 2024:4

Table 4.2 Patients requesting assisted dying 1 April 2022 to 31 March 2023

Demographic compos 1 April 2022 to 31 Ma	sition of applicants (N= 807) rch 2023¹	Number of persons	Percentage
Ethnicity	Māori	40	4.96
	Pasifika	5	0.62
	European/Pākehā	654	81.04
	Asian	15	1.86
	Other	109	13.51
Sex	Women/wāhine	420	52.04
	Men/tāne	387	47.96
	Non-binary	0	0
Age groups	18–44 years	8	0.99
	45-64 years	179	22.18
	65–84 years	471	58.36
	85+ years	149	18.46
Diagnoses	Cancer	546	67.66
	Neurodegenerative	88	10.90
	Respiratory diseases	41	5.08
	Cardiovascular diseases	51	6.32
	Other organ failure	25	3.10
	Other diagnoses	51	6.32
	Unknown	117	14.50
Receiving palliative	Yes	615	76.21
care at the time of	No	189	23.42
application?	No data	3	0.37

<sup>&</sup>lt;sup>1</sup> If a patient has stated multiple ethnicities, they are in more than one category. The same patient may also have more than one diagnosis. The value 'unknown' diagnoses includes those who have not yet undergone an initial assessment, or those who have withdrawn their application before the initial assessment; those who died before the completion of this assessment, or those who were found not to be suffering from a fatal illness.

Of the 807 patients who requested assisted dying during the 12-month period, 328 died by assisted dying and 111 were still in the assessment process. That the other 368 did not die through assisted dying may have many explanations. In 202 cases, the patient died during the assessment process, 48 patients lost their decision-making capacity, 17 chose to halt the process, and still others were found not to meet all the criteria. The most recent report states that the relatively high number of people who die during the application process is mainly because these are very fragile patients who are close to death – not to delays in the process.

# 5 Portugal

The Portuguese parliament has supported a bill that would permit practitioner-administered assisted dying and self-administered assisted dying multiple times, but the bills were never finally passed into law because the President used his constitutional powers to block them or send them back for a constitutional review. In May 2023, the president's options for delaying the matter were exhausted, and he finally signed off on the law that will make Portugal the European Union's fifth Member State to have legalised assisted dying in both forms.

## 5.1 The process towards new legislation

The Portuguese assisted dying debate is more recent than in many other places, and the process leading to its legalisation was rapid, even bearing in mind the dispute between the parliament and the president in recent years. During the country's long period of dictatorship in 1926–1974, an authoritarian form of Catholic conservatism reigned supreme as an official social philosophy, and in such a climate there was little debate on medical ethics. Since then, Portugal has developed rapidly into a modern Western democracy. The country joined the EU in 1986, and around the same time, various committees and councils were initiated, which after a few years were established as Conselho Nacional de Ética para as Ciências da Vida (CNECV), the National Council of Ethics for the Life Sciences.

It was also CNECV that initiated Portuguese debate on assisted dying with an opinion published in 1995. However, the debate did not lead to any concrete proposals for changes in the law or adjustments in praxis, at least not in the immediate future at the time. After the turn of the millennium, however, much has happened in healthcare and other sectors of society in Portugal. A string of changes

Portugal Smer 2024:4

have been implemented: same-sex marriage, the right to abortion and the decriminalisation of narcotics for personal use are some examples. In the medical-ethics sphere, in 2012 Portugal enacted a law on advance healthcare directives or living wills. These instruments give patients the right to decide on their care in the event that they lose their decision-making capacity. These advance healthcare directives can include the right to refuse proposed treatment, but not to receive assisted dying, that is, active interventions intended to cause the death of the patient.

## 5.2 Eligibility criteria for assisted dying

Under the Portuguese legislation, a person may be eligible for assisted dying provided that they:

- are aged 18 years or older
- are able to make their own decisions
- are citizens or legal residents of the country, who
- confirm their intention to request assisted dying in writing on two occasions, and have a
- physical, serious, chronic and incapacitating disorder, injury or incurable illness causing
- persistent and intense suffering that the patient finds unbearable.

There is no explicit requirement that the patient must be close to death; rather, the patient's expression of their will, their quality of life and the absence of any reasonable hope of achieving an improvement are the decisive factors. On the other hand, unbearable suffering as a consequence of a *mental* illness is not accepted as the sole reason. Unlike neighbouring Spain, Portugal does not accept advance healthcare directives or that the patient appoints a legal representative or agent who is given the power to make decisions on behalf of the patient. If a person who has been found eligible for assisted dying loses their decision-making capacity before assisted dying has taken place, the process is halted.

Smer 2024:4 Portugal

## 5.3 The assessment process

Like Spain, Portugal has chosen a type of *opt-out* system for physicians, where they are expected to be involved in providing assisted dying if they have not actively chosen to exercise their right to abstain. The law permits the doctor to be the first to address the subject, but they may not *suggest* assisted dying or try to *persuade* the patient to choose it. The doctor who first takes on a patient who intends to apply for assisted dying becomes the patient's *supervising physician*. (In other jurisdictions this is termed the responsible or coordinating physician.) As a rule, the patient should be able to choose who they wish to have as their supervising physician, for example, it may be the person's regular family doctor. In connection with discussions about assisted dying, the physician must also inform the patient about their right to palliative care and about any other treatment options.

If the patient wishes to proceed after receiving this introductory information, they must then sign a written application for assisted dying. If – given the patient's medical history, current condition, prognosis and decision-making capacity – the supervising physician concludes that the patient meets the criteria to be eligible for assisted dying, they draw up a document describing in detail the clinical picture and confirming that the patient has been provided with information about their prognosis, other options available and palliative care, and that the patient, fully understanding all of this, requests assisted dying. The document is signed by both the physician and the patient. In addition, the physician must arrange an appointment with a psychologist for the patient, in order to further ensure that the patient understands their situation and the various options they have to consider, and to rule out that the patient's wish is due to any undue influence from others. The visit to the psychologist is almost 'mandatory' unless the patient explicitly refuses the appointment. The patient must also be informed that throughout the entire process, they are entitled to consult with a psychologist provided by the healthcare system. Contact with the psychologist serves the purpose of helping to assess the patient's decision-making capacity, the independence of their request and their mental state, but also to ensure that there is sufficient time for the patient to think through their decision.

Portugal Smer 2024:4

At this stage of the process, the supervising physician must contact a second, specialist physician (consulting physician in other jurisdictions) who specialises in the condition that has caused the patient to apply for assisted dying. The specialist physician and the supervising physician must not belong to the same care team. Depending on the patient's health status, the supervising physician may make the assessment that additional specialist doctors should be involved. If the specialist physician makes the assessment that the patient does not meet the criteria, the process must be halted and the patient informed of this decision and the underlying reasons for it by the supervising physician. However, if the specialist physician makes the same assessment as the supervising physician, the supervising physician contacts the patient and asks if they are still interested in applying for assisted dying. If the answer to this question is yes, the patient must now sign a second written application.

If any of the physicians involved doubt the patient's decision-making capacity, a psychiatrist is called in to conduct a special psychiatric assessment. If the psychiatric assessment ends up showing that the patient does not have the requisite decision-making capacity, the application process must be halted, and the patient informed of this decision and the reasons for it. If the psychiatrist makes the assessment that the patient does have the requisite decision-making capacity, the supervising physician must again ask the patient if they wish to continue with their application and, if they again say yes, the supervising physician draws up a third written application from the patient. The psychiatrist's opinion is added to the dossier that documents the entire application process.

If both the supervising physician and the specialist physician and, where applicable, the psychiatrist agree that the patient meets the criteria, the entire application is then submitted to a special review board (Comissão de Verificação e Avaliação or CVA). The review board consists of two lawyers, one physician, one nurse and one bioethicist appointed by CNECV, Portugal's equivalent of The Swedish National Council on Medical Ethics. The review board may question the supervising physician and the specialist physician or ask them to submit supplementary documentation. If the review board rejects the patient's application, the process is halted immediately. If the review board approves the application, it is up to the supervising physician to notify the patient and ensure again that the patient wishes to proceed. This

Smer 2024:4 Portugal

final expression of the patient's willingness to proceed must also be documented in writing.

It is only after the review board has approved the application that the supervising physician and the patient together make a decision on the time, place and method of assisted dying. The patient can choose the time and place themself, for example in their own home. In terms of method, the law states that self-administered assisted dying is the standard procedure, and practitioner-administered assisted dying can only be considered if, due to their condition, the patient is unable to swallow the lethal substance themself. Immediately prior to the decisive act, whether self-administered or practitioner-administered, the patient must unequivocally express their wish to proceed with the assisted dying procedure before at least one identified witness. Family members who the patient wishes to be present may be present, on the condition that the physician deems this appropriate.

In spring 2024, the new law had not yet been implemented. Consequently, there is nothing to report concerning how the law has been applied, how many people have requested assisted dying, and so forth.

# 6 Update on Benelux, Canada, Colombia, Switzerland, and USA

The council's 2017 state of knowledge report presented and analysed the US 'Oregon model'. In addition, the report described the legislation in other countries where assisted dying at the time was permitted, that is, Belgium, Luxembourg and the Netherlands (the "Benelux model"), Canada, Colombia, and Switzerland.

The Oregon model and the system in Switzerland only permit self-administered assisted dying, while Benelux, Canada, and Colombia also permit practitioner-administered assisted dying. This chapter provides an update on the situation in these countries and federal states.

#### 6.1 The Netherlands

The Netherlands has been practising assisted dying in both forms for longer than any other country in the world. In the 1970s, despite assisted dying being against the law, an informal praxis was established whereby physicians were not prosecuted if they had assisted a patient to die provided that they had followed a certain process. The criteria for assisted dying were formally codified in the 'Rotterdam Judgment' of 1981: that the patient is well aware of and capable of making their own decisions, that the request for assisted dying is entirely voluntary, that the patient's suffering is unbearable and there is no hope of improvement, that an additional physician makes the same assessment, that the patient is informed of their prognosis and what options are available, and that the patient has been given a period of time to reflect on their decision. During the 1990s, legal certainty for physicians providing assisted dying was strengthened, but it was only in 2002 that the Netherlands enacted its Termination of Life on Request and Assisted Suicide Act explicitly permitting assisted dying and protecting the procedure from criminal prosecution provided that the set process has been followed. The eligibility criteria listed are largely the same as those listed above. One change, however, is that advance directives are now permitted, meaning that under certain circumstances patients who have lost their decision-making capacity can be given assistance to die if they have previously formulated an assisted dying instruction in their advance directive and otherwise meet the criteria. Notably, there is no requirement that death is imminent, nor that the patient's suffering is due to a *physical* illness or injury.

Support for assisted dying is very high in the Netherlands, where 87 percent of the population are of the opinion that practitioner-administered assisted dying should remain legal, while 8 percent are of the opinion that it should be illegal. A large majority, between 75 and 80 percent, also accept assisted dying for terminally ill minors, assisted dying for patients with dementia under their advance directives, and assisted dying in the case of non-physical suffering in connection with a mental illness. These figures for the general population are largely consistent with the attitudes of the Dutch medical profession. More than half of doctors in the Netherlands have provided assisted dying. For general practitioners, the figure is 75 percent. About one quarter of all doctors have not provided assisted dying, but could consider doing so. 18 percent say they are unwilling to provide this service. Of these, 99 percent say that they would refer the patient to someone else.

#### 6.1.1 Changes since 2017

An issue that has been discussed for many years in the Netherlands is how one should view minors who are suffering unbearably without any hope of improvement. Children from the age of 12 have the option to request assisted dying, but their parents must give their consent. Young people between the ages of 16 and 18 in principle do not need the consent of their parents, but the Act states that the parents must be involved in the decision-making process. In 2023, the regulatory framework was amended so that infants and children aged 1–12 years may also be eligible for practitioner-administered assisted dying. "This concerns a very small group of children who are expected

<sup>&</sup>lt;sup>1</sup> Statistics Netherlands 2019.

<sup>&</sup>lt;sup>2</sup> ZonMw 2023, p. 139.

to die in the foreseeable future and who are suffering unbearably without hope and for whom palliative care is inadequate," the statement reads on the Government of Netherlands website where the decision was announced.<sup>3</sup> Practitioner-administered assisted dying for newborns had been possible in the past if the following conditions were met:

- In the light of prevailing medical opinion, the child's suffering must be unbearable and with no prospect of improvement. There must be no doubt about the diagnosis and prognosis.
- The parents must have been fully informed of the diagnosis and prognosis.
- Both the physician and the parents must be convinced that there is no reasonable alternative solution given the child's situation.
- The parents must have given their consent for the termination of life.
- At least one other, independent physician must have examined the child and given a written opinion on compliance with the due care criteria listed above.
- The termination must be provided with all due care.4

Since the regulatory framework for children aged 0–1 year and 1–12 years, respectively, concerns individuals who do not have the capacity to make their own decisions, they are not covered by the general assisted dying legislation, but come under the same legislation as regulates late-term abortions.

## 6.1.2 Medical and demographic data from the Netherlands

In 2022, 8 720 people died by assisted dying in the Netherlands. This represented 5.1 percent of all deaths in the country that year, and was an increase compared to the previous year, when 7 666 people died by assisted dying. The trend over time is also that more people are dying through assisted dying: the proportion in 2015 was 4.5 percent. The

<sup>&</sup>lt;sup>3</sup> Rijksoverheid 2023. Note that The Swedish National Council on Medical Ethics defines 'assisted dying' as an intervention that must be done at the patient's explicit request. In this instance, the Dutch legislation highlights instead the motive of mercy.

<sup>&</sup>lt;sup>4</sup> Government of the Netherlands n.d.

majority (over 97 percent) die through practitioner-administered assisted dying and the remainder, some 100 individuals per annum, die through self-administered assisted dying.

Just under 90 percent of those who die through assisted dying have either cancer (58 percent), neurodegenerative conditions such as multiple sclerosis or Parkinson's disease (7 percent), cardiovascular disease (4 percent), respiratory diseases (3 percent) or a combination thereof (16 percent). In 2022, patients with a mental illness who were granted assisted dying numbered 115 cases, or 1.3 percent of all deaths through assisted dying. The number was similar the year before. One person aged between 12 and 16 died by assisted dying in 2022. The number of men and women who die through assisted dying in the Netherlands is almost exactly the same. About 80 percent of those who choose assisted dying die in their own home. Residential aged care homes and hospices are the next most common places. 1.8 percent of assisted dying deaths take place in hospitals.<sup>5</sup>

The Dutch assisted dying legislation is now more than 20 years old. During this period, 91 565 documented cases of assisted dying have taken place. In 133 of these cases, a review has shown that deviations from the criteria for proper care have occurred. In one case, this led to a criminal investigation.<sup>6</sup>

## 6.2 Belgium

Belgium legalised assisted dying in both forms in the same year as the Netherlands, that is, in 2002. Unlike the Netherlands, it is more accurate to say that in doing so, the country *introduced* assisted dying, while the Netherlands formally legalised an informal but wellestablished praxis. The two Acts are similar (hence the 'Benelux model', which also includes Luxembourg, whose Act in this area is in turn based on the Belgian Act). The Belgian Act is more detailed than the Dutch Act. As in the Netherlands, assisted dying can be provided to patients who are not near death, to patients whose suffering stems from a mental illness, and to patients who are minors.

<sup>&</sup>lt;sup>5</sup> The facts in this section come from RTE 2023.

<sup>&</sup>lt;sup>6</sup> Ibid.

#### 6.2.1 Changes since 2017

One of the changes that have taken place in recent years concerns the validity of the advance directives that patients can draw up regarding their end-of-life care and assisted dying in the event that their decision-making capacity has deteriorated. In 2019, the validity of the instructions in these advance healthcare directives was extended from five to ten years, and in 2021 it was decided that advance healthcare directives were to remain valid indefinitely. Another change concerns physicians who are unwilling to participate in assisted dying. Since 2020, they are now required to provide information about what assisted dying is and how the process works, and arrange a referral to another physician who is willing to participate in providing the service. A final amendment concerns the possibility for institutions to prevent assisted dying. For example, a residential aged care home run by an opponent of assisted dying cannot legally prevent a patient from requesting and receiving assisted dying there.<sup>7</sup>

#### 6.2.2 Medical and demographic data from Belgium

In 2023, 3 423 individuals died by assisted dying, representing 3.1 percent of all deaths in the country. The number went down in 2020, which is believed to have been on account of the pandemic, but the trend over time is that assisted dying is becoming more common. As in the Netherlands, the number of men and women dying through assisted dying is roughly equal, but the proportion of women is slightly higher (51.4 percent). In Belgium too, various types of cancer are also the most common underlying diagnosis (55.5 percent). 713 patients (20 percent) with various serious medical conditions where death was not considered imminent were granted assisted dying. A little over half of this group suffered from multiple chronic, untreatable diseases. Just under 20 percent had a neurodegenerative disease. 48 individuals, or 1.4 percent of the total number in 2023, were granted assisted dying on the basis of a mental illness. No minors died by assisted dying in 2020–2022, but one minor died by assisted dying in 2023. The number of individuals under the age of 30 who have died by assisted dying has been around 5-10 per annum in recent years. 70 percent of the patients were over 70 years old and 42 percent were

<sup>&</sup>lt;sup>7</sup> de Hert et al. 2023b.

over 80 years old. 99.4 percent of the deceased actively wanted to die through assisted dying and 0.6 percent were unconscious patients who died by assisted dying in accordance with their advance healthcare directive. The most common place for assisted dying is the patient's own home, although not as common as in the Netherlands (49 and 80 percent, respectively). 32 percent die in hospitals, including palliative care wards, and around 18 percent in care homes. Belgium does not prohibit foreign nationals from requesting assisted dying, but there is also no requirement to keep specific statistics on the nationality of patients, making it difficult to estimate the number of foreign nationals in the figures. In 2021-2023, there were 189 documented cases of foreign national patients dying through assisted dying, with an increasing trend each year. No-one in this group had a mental illness. The foreign national patients were mainly in the 50-89 age range, had serious physical illnesses and were assessed as being near death. Most in this group were French-speaking, but patients from Germany, the UK and South Korea also travelled to Belgium to access assisted dying.8

### 6.2.3 Belgium before the European Court of Human Rights

The European Court of Human Rights has repeatedly taken up cases in which plaintiffs have argued that citizens' rights are being violated because they do not have access to assisted dying and are instead forced to live on or die in a way they consider unacceptable. The Court has consistently held that our rights are not violated by the fact that our country does not authorise assisted dying. However, the Court has not addressed how a system that actually permits assisted dying relates to our rights. In 2022, a Belgian man took his country to the European Court of Human Rights after his mentally ill mother died by assisted dying without her relatives having been informed that this had happened. According to her son, Belgium had failed in its obligation to protect the woman's life. The Court's examination of the case resulted in a ruling that a Member State may

<sup>8</sup> The facts concerning Belgium come from the Commission fédérale de contrôle et d'évaluation de l'euthanasie 2022, 2023, and 2024. Belgium publishes short reports annually and larger compilations every two years.

<sup>&</sup>lt;sup>9</sup> European Court of Human Rights 2022 and 2023 (the latter also includes a summary of other assisted dying cases).

legalise assisted dying, but it must be done in a manner that is compatible with Article 2 of the European Convention on Human Rights on the right to life. According to the Court, legislation authorising assisted dying must be formulated so that it:

- 1. clearly and precisely defines the criteria that must be met for a person to be eligible for assisted dying
- 2. provides a procedure to ensure that the request is voluntary
- 3. includes safeguards to protect vulnerable groups, and
- clarifies in detail the steps that the person entrusted with the assessment of the request must take to be considered to have fulfilled their duty of good care.

The Court found that Belgium's legislation complied with the Convention in these respects, and that the handling of this particular case adhered to the law. The woman had sought assisted dying on her own initiative. A range of treatment options had been tried without success. She was assessed by several different psychiatrists, who came to the same conclusion: that she had decision-making capacity and had unbearable suffering that could not be alleviated. Despite the doctors' attempts to persuade her, she refused to contact her family, and she would not allow anyone in the care team to do so either. According to the Court, there was nothing more that society could or should have done.<sup>10</sup>

## 6.3 Luxembourg

Luxembourg's assisted dying legislation dates to 2009. The eligibility criteria for assisted dying have not subsequently been changed. Unlike Belgium and the Netherlands, Luxembourg does not permit assisted dying for minors. Since its legalisation in 2009, 170 patients have died by assisted dying in Luxembourg. In 2022, 34 patients (17 men

<sup>&</sup>lt;sup>10</sup> European Court of Human rights 2022, de Hert et al. 2022 and de Hert et al. 2023a. However, the Court ruled against Belgium on another point, namely its administrative practice of anonymising the doctors involved. In certain cases, this allowed doctors to assess their own performance in an assisted dying case under review, without anyone else's knowledge, as had happened in this particular case. Anonymity was originally intended to protect the doctors involved from stigma or harassment, but the practice now needs to change. The issue of assisted dying in cases of unbearable suffering caused by mental illness is discussed in Chapter 8.

and 17 women) died by assisted dying, representing 0.8 percent of the country's deaths that year. 22 (around 65 percent) of these individuals had cancer. 15 died at home, 13 in hospital and four in a nursing home or hospice. In 2021–2022, one patient died by self-administered assisted dying and the others by practitioner-administered assisted dying. As in neighbouring Belgium and in the Netherlands, Luxembourg's legislation permits assisted dying in the case of unbearable suffering caused by a mental illness, but unlike in those countries, it does not occur in practice.<sup>11</sup>

#### 6.4 Canada

Canada legalised assisted dying in both forms in 2016. The path to legalisation came through a high-profile court case in which a patient suffering from amyotrophic lateral sclerosis (ALS) challenged the ban on assisted suicide in force at the time. The case eventually reached the Supreme Court of Canada, which ruled unanimously that laws prohibiting physician-assisted dying "infringes the right to life, liberty and security of the person" in a manner that is not supported in the Constitution of Canada. The Court instructed the government to formulate a legal framework for assisted dying that took this judgment into account.

The criteria for eligibility for assisted dying under the legislation put in place in 2016 were that the patient must:

- be eligible for health services funded by a province or territory, or the federal government in Canada
- be at least 18 years old and
- mentally competent
- make a voluntary request for medical assistance in dying that is not the result of outside pressure or influence
- be in an advanced state of decline that cannot be reversed, and which causes

<sup>&</sup>lt;sup>11</sup> Ministre de la Santé et de la Sécurité sociale 2023; Statista 2024.

- unbearable physical or mental suffering from their illness, disease, disability or state of decline that cannot be relieved under conditions that they consider acceptable and where
- death is reasonably foreseeable.

In addition to these criteria, the law states that the patient should be informed about what assisted dying involves, what other options may be relevant, that they retain their right to palliative care, and that they can change their mind at any time. The procedure requires the patient to be assessed by two people, either doctors or nurse practitioners. The Canadian model does not have any presumption of either self-administered assisted dying or practitioner-administered assisted dying; rather the patient chooses themself. One exception is the province of Quebec, where only practitioner-administered assisted dying is permitted. Quebec is also different from the other provinces in that assisted dying may only be administered by doctors, not by nurse practitioners.

#### 6.4.1 Changes since 2017

The requirement that only people whose natural death is 'reasonably foreseeable' may be considered for assisted dying was challenged in yet another court case, which resulted in the law being amended to include chronic conditions of unbearable suffering with no hope of cure or relief. The revised Act, which was preceded by intense debate and investigation, entered into force in 2021. The amendment introduced two 'tracks' in the assessment of a request for assisted dying: one for patients who are close to natural death, and another for patients who are not. Some specific safeguards were introduced for this latter group:

- at least one of the two people assessing the patient's condition must have *expertise* in the condition that is causing the patient's suffering
- the assessment should last at least 90 days to give the patient time to reflect on their decision

• the patient has received all available information on the types of treatment that might relieve their suffering and *the assessors and the patient agree* that the patient has seriously considered these options.

Along with the amendment to the criteria to include non-terminal conditions, an option was also introduced for patients to approve assisted dying through an advance healthcare directive, even if their decision-making capacity had deteriorated after they had been approved for assisted dying but before the assisted dying was provided. This option only applies to patients whose natural death has been deemed reasonably foreseeable, and is revoked if the patient appears to oppose assisted dying through speech, facial expressions or body language.

A special case of non-terminal but potentially chronic conditions that has been much discussed in Canada concerns individuals whose suffering is from a *mental illness* and who request assisted dying on that basis. In the context of the expansion to include non-terminal conditions, an explicit exemption was made for mental illness as the sole basis for an assisted dying request, to allow for more detailed consideration of this difficult issue. According to a decision, as of March 2024 this group of patients would also be able request and be approved for assisted dying, provided that they met the other requirements under the Act regarding decision-making capacity, unbearable suffering that cannot be relieved and so forth. However, following the recommendation of a special joint committee, the government decided in February 2024 to postpone the implementation again until 2027 at the earliest to investigate the issue in further detail.

# 6.4.2 Medical and demographic data from Canada

The number of patients dying through assisted dying has increased by around 30 percent per year since its introduction. In 2022, 13 241 individuals died by assisted dying, representing 4.1 percent of the total number of deaths in Canada that year. The trend over time is illustrated in the table below.

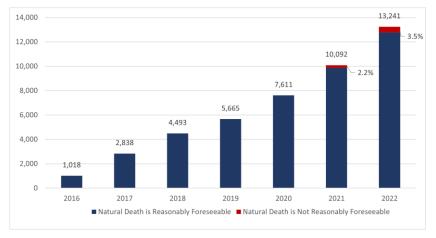


Figure 6.1 Number of patients who died by assisted dying in 2016–2022

After it became possible to be granted assisted dying for non-terminal conditions in 2021, this group of patients accounted for 2.2 percent (2021) and 3.5 percent (2022) of the total number of assisted dying cases. As stated above, self-administered assisted dying is not permitted in Quebec, but it is also very uncommon in Canada's other provinces. In 2022, only seven patients chose this option, while the remaining 13 234 patients died by practitioner-administered assisted dying.

As in most other states and countries (with the exception of Spain) in which assisted dying is legal, cancer is the predominant underlying reason for requesting assisted dying. In Canada, various cancers account for around 63 percent of cases. Other diagnoses include cardiovascular diseases (19 percent), respiratory diseases and neurodegenerative diseases (both around 13 percent). The distribution between women and men is fairly even, with men slightly overrepresented (51.4 percent compared to 48.6 percent women). 95 percent were over 56 years of age and 85 percent were over 65 years of age. 1.3 percent of the patients were in the age range 18–45, and 3.2 percent were in the age range 46–55. The average age was 77. Canada does not permit assisted dying for patients under the age of 18.

Only a small proportion of patients who died by assisted dying had a chronic but non-fatal condition. This patient group of 463 individuals, or 3.5 percent of the total number of assisted deaths, display a different medical and demographic profile from the average. Neurological diseases are the most common underlying condition (50 percent), followed by 'other conditions' (37 percent) and multiple comorbidities (24 percent). Cancer was the underlying condition in 8 percent of cases. The average age of this group was 73, that is, slightly lower than the average age of patients who died by assisted dying overall. Of the patients who requested and were granted assisted dying for a non-terminal condition, 59 percent were women and 41 percent were men.<sup>12</sup>

#### 6.5 Colombia

In 1997, the Constitutional Court of Colombia ruled that it is not a criminal offence for a doctor to administer assisted dying to a dying and severely suffering patient who expressly requests it. Self-administered assisted dying on the other hand, remained illegal. Comprehensive legislation regulating practitioner-administered assisted dying was enacted in 2015. In summary, the criteria are that under certain conditions, a medical practitioner may administer assisted dying to a patient who has decision-making capacity and is severely suffering and close to death. In 2018, practitioner-administered assisted dying was also legalised for minors. Patients between the ages of 14 and 17 can request assisted dying without the consent of their custodian(s). Younger children require the consent of their custodian(s). In 2019– 2020, the law was amended to include non-terminal but chronic conditions that cause the patient unbearable suffering. In May 2022, self-administered assisted dying was also legalised. Since the law was passed in 2015 and up to 2022, 322 patients requested and died by assisted dying in Colombia (almost all practitioner-administered, which until recently was the only permitted form).<sup>13</sup>

<sup>&</sup>lt;sup>12</sup> Statistics, figures and other facts about Canada come from Health Canada 2023.

<sup>&</sup>lt;sup>13</sup> Regarding the legalisation of practitioner-administered assisted dying for minors, see Ministerio de salud y proteccion social 2018. For more information on assisted dying in Colombia, see Cook 2023.

#### 6.6 Switzerland

Practitioner-administered assisted dying is banned in Switzerland, but self-administered assisted dying has been practised for a long time. The legislation, which dates back to the 1940s, permits self-administered assisted dying, provided there is no self-serving motive on the part of the person offering the assistance, such as inheriting money. The specific Swiss model of self-administered assisted dying in use since the 1980s rests on this rather minimal regulation in the legislation along with individual judgments, guidelines by the Swiss Academy of Medical Sciences (SAMS), and the criteria set by the various memberdriven organisations offering self-administered assisted dying. Both the legislation and the assisted dying organisations accept that patients do not have to be close to death to be eligible for self-administered assisted dying, while such a condition is recommended by SAMS. Patients whose suffering is caused by a mental illness may be granted self-administered assisted dying, but they must have decision-making capacity and have been assessed by a psychiatrist. A person who has been granted self-administered assisted dying must retain their decision-making capacity throughout the process.

## 6.6.1 Changes since 2017

As stated above, the Swiss Academy of Medical Sciences has taken a somewhat more cautious approach than the legislation and case-law have actually required. In 2018, they issued new guidelines that 'seek to mediate between different viewpoints and values, and to ensure that the self-determination of all parties – patients, relatives and medical professionals – is respected and protected'. The new guidelines include a requirement for doctors to conduct at least two detailed discussions with the patient, *separated by an interval of at least two weeks*. This extended assessment or reflection period is a new element that was not previously required or in use. The guidelines also state that the patient's desire to end their life must be 'comprehensible' for the doctor given the patient's history and current situation. The Swiss Medical Association, with which more than 90 percent of the country's doctors are affiliated, accepted these guidelines in May 2022.<sup>14</sup>

<sup>14</sup> Swissinfo.ch 2022.

#### 6.6.2 Medical and demographic data from Switzerland

Between 1999 and 2018, 8 734 individuals died by self-administered assisted dying in Switzerland. Such deaths currently account for around 1.5 percent of the country's total number of deaths per annum. Women account for around 57 percent of these patients, and men around 43 percent. The median age of patients in recent years was 80. Just over 40 percent of the patients had cancer. The next most common conditions were various neurodegenerative diseases followed by cardiovascular diseases.<sup>15</sup>

Foreign patients are accepted by the organisation Dignitas, which assists around 200 non-Swiss citizens to die each year. Since its inception in 1999, a total of 1 449 Germans, 531 Britons, 499 French citizens and 36 Swedes have died by self-administered assisted dying at Dignitas. As in other countries in which some form of assisted dying is permitted, the trend in Switzerland is that the number of individuals requesting and being granted assisted dying is increasing over time.<sup>16</sup>



Figure 6.2 Number of patients who died through assisted dying 1999–2018

2007 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018

2003 2004 2005 2006

400

200

 $<sup>^{15}</sup>$  Graphs and facts from Montagna et al. 2023. Further facts and analysis can be found in Bartsch et al. 2019.

<sup>&</sup>lt;sup>16</sup> Lewy 2011; Dignitas 2023.

## 6.7 USA: The Oregon model

Oregon introduced a model for assisted dying in 1997 under its *Death with Dignity Act*. Under this Act, doctors are permitted to prescribe a lethal substance to a patient under three conditions: The patient is 1) 18 years of age or older, 2) has the ability to make and communicate health care decisions, and 3) has been diagnosed with a disease that is expected to produce death within six months. Several other states have since enacted similar legislation, and assisted dying is now legal in ten US states (California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Washington and Vermont) and in the Washington, DC metropolitan area. <sup>17</sup> The issue is under consideration, at various stages, in other states including Illinois, Kentucky, Massachusetts, Michigan, New York and Pennsylvania.

Having previously adopted a negative attitude towards doctors' involvement in self-administered assisted dying, the American Medical Association published a statement in 2019 which aimed at compromise, pointing out that the profession is divided and that there are legitimate ethical concerns among those who oppose as well as those who advocate self-administered assisted dying. In particular, the Association stated that doctors may play a part in self-administered assisted dying without violating the ethical obligations of their profession.<sup>18</sup>

## 6.7.1 Changes in the Oregon model since 2017

When the Oregon model was introduced in 1997, there was a requirement that at least 15 days must pass between the first and second requests for assisted dying. There was also a requirement for 48 hours to elapse between the last written request and the prescription of the lethal substances. Other states that have followed Oregon have had similar requirements, sometimes with longer time periods. This has made the model less well suited to address the interests of patients whose condition is rapidly deteriorating. A study in California found that around a third of those seeking assisted dying actually die during

<sup>18</sup> American Medical Association 2019.

<sup>&</sup>lt;sup>17</sup> Colorado, Hawaii, California, Maine, Montana, New Jersey, New Mexico, Oregon, Washington, Vermont and Washington, DC. Montana has a special legal design where there is no specific legislation permitting self-administered assisted dying. Instead, following a decision by the State Supreme Court, the process is decriminalised if it follows a certain procedure.

the waiting period. <sup>19</sup> The latest US state to legalise self-administered assisted dying, New Mexico, reduced these times and permits doctors to ignore them completely if the patient is at risk of dying or losing their decision-making capacity sooner. Hawaii, California, Oregon, Washington and Vermont have made similar adjustments. In Oregon, in the most recently reported period, the time rule was waived in 25 percent of the cases granted, which is a measure of the proportion of patients for whom the dying process is relatively rapid.

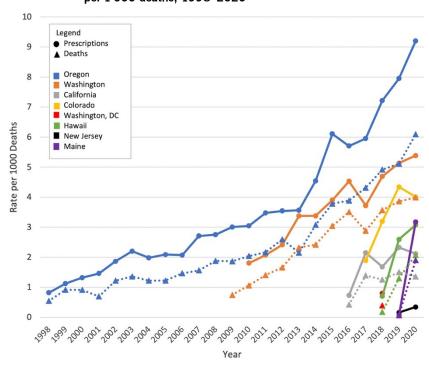
Another change relates to the requirement that only permanent residents of the state may request assisted dying there. Oregon and other states that have legalised self-administered assisted dying have sought to avoid becoming a destination for any kind of 'assisted dying tourism'. Vermont was the first state to abolish this requirement, following a court case in which a patient from Connecticut was eventually granted self-administered assisted dying. In Oregon too, such disputes have led to a ruling that the restriction is not compatible with the part of the US Constitution that prohibits states from discriminating against residents of other states in favour of their own residents. If the legal determination that the residency requirement violates federal law stands, it is likely that all states will abolish this requirement. As more states adopt similar legislation, the trend for patients to approach other states to gain access to self-administered assisted dying is also declining.

## 6.7.2 Medical and demographic data from the USA

As in other jurisdictions in which assisted dying is permitted, the trend in the USA is that the number of people requesting assisted dying is increasing over time and the proportion of people dying through assisted dying is rising. Although these trends are showing an increase, dying through assisted dying is still uncommon in the states concerned. In Oregon, where assisted dying has been available for over 25 years, 0.6 percent of all deaths are self-administered assisted dying. A relatively high number of those given access to the lethal substances never use them. Between 1998 and 2020, 8 451 individuals were prescribed lethal substances in the various US states and, of these, 5 329

<sup>&</sup>lt;sup>19</sup> Nguyen 2018.

have since used them.<sup>20</sup> The model does not require the person to whom the lethal substances are prescribed to be suffering; the main criterion is the imminence of death. Many patients want to ensure that they can end their lives themselves if their situation becomes unbearable but later find that this is not necessary. In a study examining the motives of those seeking self-administered assisted dying, loss of autonomy is the most common response, followed by reduced quality of life and loss of dignity.<sup>21</sup>



Figur 3 6.3 Prescriptions and number of deaths through assisted dying per 1 000 deaths, 1998–2020<sup>22</sup>

In 2022, 431 patients in Oregon were prescribed lethal substances to help them end their own lives. 278 patients died in this way during the year, including 32 who had received the lethal substance in 2021.

 <sup>&</sup>lt;sup>20</sup> Kozlov et al. 2022; Oregon Health Authority 2023 mentions the same reason, but reduced quality of life is listed as the most common reason.
 <sup>21</sup> Al Rabadi, Luai et al. 2019.

<sup>&</sup>lt;sup>22</sup> The figure is from Kozlov et al. 2022. Montana, with its slightly different system, and the latest state to legalise, New Mexico, are not included in this data.

84 patients died of other causes without having taken the lethal substance. For 101 patients, it is not yet known whether they took the lethal substance or not. Unlike in Switzerland, for example, patients can take the lethal substance at home without the supervision of medical staff. In such cases, there is no verification of decision-making capacity or that the death is planned. 16 patients lived longer than the predicted six months. 85 percent of patients who died by self-administered assisted dying were over 65 and just under 20 percent were 85 years or older. The median age was 75.

The most common underlying diagnosis was cancer of various types (64 percent), followed by cardiovascular diseases (12 percent) and neurodegenerative diseases (10 percent). The gender distribution was almost exactly even. Patients who die through assisted dying in Oregon tend to be white and well-educated. 96 percent classified themselves as white (the state average is 74 percent). 49 percent had at least a Bachelor's degree (the state average for the population over 25 is 36 percent, and this figure is lower for older people). 92 percent of patients died at home, and 90 percent were receiving ongoing hospice care.<sup>23</sup>

<sup>&</sup>lt;sup>23</sup> Oregon's statistics and facts come from Oregon Health Authority 2023.

# 7 Other international developments

Almost every developed country is discussing how to reconcile the increasing medicalisation of dying and patients' demands for self-determination with the traditional role of doctors and the protection of vulnerable groups. No country that has permitted assisted dying in any form has subsequently chosen to re-criminalise it. The trend is in fact for more countries to consider legalising assisted dying. Alternatively, 'decriminalisation' can take place without public and political deliberation through court rulings. This has happened in Italy and Germany, for example. Legalisation in Austria also started with a court ruling. This chapter describes the situation in jurisdictions that have permitted assisted dying in various constellations in recent years, as well as those in which the issue is currently being discussed at a high political level without a decision having yet been made.

#### 7.1 Austria

In December 2021, the Austrian Parliament enacted a law permitting assisted dying from 1 January 2022. The country's Constitutional Court had previously ruled that an existing law prohibiting assisted suicide violated citizens' right to self-determination and was therefore unconstitutional.

To be eligible for self-administered assisted dying under Austrian law, the patient must:

- be of legal age
- be an Austrian citizen or a permanent resident of the country
- have decision-making capacity and have an

- incurable disease that leads to death, or a severe chronic illness with persistent symptoms affecting all aspects of life and causing
- suffering that cannot be relieved.

Two doctors, one of whom must be a palliative care specialist, evaluate the patient's request for assisted dying. As in other countries' legislation, the doctor is required to inform the patient about other options, including palliative care and psychological counselling. A psychologist or psychiatrist must be called in if either of the first doctors to assess the patient has any doubts about the patient's decision-making capacity. If the patient has entered a terminal phase of their illness, this review may take at least two weeks. In the case of chronic illnesses that are not expected to lead to the patient's death within six months, the process must take at least 12 weeks. A person who is granted assisted dying will be able to collect the required lethal substances from specialised pharmacies. The wording 'suffering that cannot be relieved' depends on what the healthcare system is able to offer but, according to the directive, this is ultimately decided by the patient. Consequently, there is no requirement for patients to have first exhausted all other options in the assessment of a doctor. The criteria do not exclude suffering from mental illness as the sole basis for a request for self-administered assisted dying, but also state that the desire to take one's own life must not be caused by a mental disorder that impairs decision-making capacity.

Austrian doctors who do not want to play a part in assisted dying have a right of conscientious objection, and are not required to help patients find another doctor. Patients may contact the equivalent of the Swedish regions (which are responsible for healthcare in Sweden) for referral to doctors who do agree to participate in assisted dying. During the period 1 January 2022 to 1 October 2023, 266 individuals were granted self-administered assisted dying. 220 of these individuals collected the prescribed lethal substances, and in 23 cases these substances were later returned unused. Statistics on the number of deaths (maximum 197) from taking the lethal substances are not available.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> The facts presented concerning Austria come partly from direct contact with government agencies as well as from publicly available documents such as Bundesministerium Justiz 2024.

## 7.2 Germany

Because of the complicity of the German medical profession in the Nazi crimes against humanity in 1933–1945, there has been sensitivity in Germany around the idea of a doctor causing or helping to end a patient's life. Although this stance had long been self-evident, there has been no explicit support for it in the law, which has not criminalised assisted suicide since 1871. As recently as 2015, a law was passed making it illegal to provide assisted dying in an 'organised form'. This explicit prohibition met with resistance and was challenged with varying outcomes in lower courts. In 2020, the issue was taken up by the country's Constitutional Court, which, like its Austrian counterpart, ruled that a prohibition on assisted suicide was unconstitutional. In its ruling, the Court states not only that the individual has a right to end their own life, but also that this right includes a right to receive help from others in this endeavour.<sup>2</sup>

One consequence of the Constitutional Court's ruling is that German doctors who help a patient end their life do not risk legal consequences. However, unlike in Austria, there is no explicit legislation supporting and setting specific criteria for self-administered assisted dying. The Court has recognised certain fundamental rights and freedoms, including the right to end one's life and seek assistance to do so, but has left it up to the legislator to develop more specific regulation. However, in its ruling the Court states that there is no legitimate basis for paternalism regarding a person's desire to end their life. The specifics of a person's desire to end their own life are therefore irrelevant as long as the desire is not the result of a pathological or compulsive process, or a process that is otherwise unduly influenced.<sup>3</sup> Such a right, the ruling points out, is already inherent in patients' usual freedom to refuse proposed life-saving treatment. These arguments in the context of the ruling suggest that any future legislation in this area may be similar to the Swiss legislation, in which the only criterion is decision-making capacity.

<sup>&</sup>lt;sup>2</sup> Bundesverfassungsgericht 2020.

<sup>&</sup>lt;sup>3</sup> Ibid, Section 39.

## 7.3 Italy

As in Germany and Austria, the issue of assisted dying in Italy has been decided by courts rather than legislatures. A ruling by the country's Constitutional Court in 2019 decriminalised self-administered assisted dying under certain circumstances. Unlike in Germany, the Italian court sets out more specifically the criteria that must be met for self-administered assisted dying not to be a criminal offence, namely that the patient:

- has decision-making capacity
- has been diagnosed with an incurable disease that causes
- unbearable physical or mental suffering; and
- is being kept alive with the help of life-sustaining treatment.<sup>4</sup>

The last requirement is specific to Italy and is not found in other countries' legislation. The condition does not mean that the patient must be connected to a device; for example, the life-sustaining treatment may mean a drug that is keeping the patient alive. To date, only one patient is believed to have died by self-administered assisted dying in Italy, partly because the legal situation is seen as unclear.

#### 7.4 Fcuador

In February 2024, Ecuador's Supreme Court ruled in a case in which a woman with ALS sought help to end her own life. According to the Court's ruling, it is no longer a criminal offence for a doctor to end the life of a chronically ill patient with unbearable suffering on request. The Court calls on the legislator and the healthcare authorities to define the detailed criteria and procedures for regulating assisted dying in the country, but decriminalisation as such takes effect immediately. Ecuador thus became the second South American country to permit practitioner-administered assisted dying.<sup>5</sup>

<sup>&</sup>lt;sup>4</sup> Corte Costituzionale 2019; Cecchi et al. 2024.

<sup>&</sup>lt;sup>5</sup> Jackson 2024.

# 7.5 The rest of Latin America: Argentina, Chile, Cuba, Mexico, and Uruguay

In 2021 and 2022, four different bills aimed at legalising assisted dying were discussed in *Argentina*. However, the issue does not yet have a definitive solution and President Javier Milei, who took office in December 2023, opposes the legalisation of assisted dying.<sup>6</sup>

In spring 2021, the Chamber of Deputies (the lower house) of the National Congress of *Chile* approved a bill permitting both practitioner-administered assisted dying and self-administered assisted dying. The issue then proceeded to the Senate (the upper house), which is still considering it.<sup>7</sup>

As part of a review of the country's healthcare legislation, in December 2023 the *Cuban* National Assembly of People's Power enacted new regulations on patients' right to die with dignity, including the option to refuse treatment, receive palliative care or *interventions that end life*. If this legislation were to be implemented, Cuba would be the first non-democratic country to legalise assisted dying.<sup>8</sup>

In Mexico, both practitioner- and self-administered assisted dying are illegal acts. In 16 of the country's 31 states, patients may draw up legally binding advance healthcare directives, including instructions to refuse or withdraw treatment. In 2019, a parliamentary inquiry on assisted dying was carried out, producing a state of knowledge report highlighting the issue from ethical, international, legal, and professional point of views. A proposal for legalised practitioner-administered (not self-administered) assisted dying has been under review in the Congress of the Union since 2023. Under the bill, patients with decision-making capacity who are close to death or, because of an incurable but not immediately fatal illness, are experiencing unbearable suffering could be eligible for practitioner-administered assisted dying. As in other countries where assisted dying has been legalised, it is proposed to give doctors and other healthcare professionals the right to refrain from participating on the grounds of conscientious objection. With a population of over 125 million, if the bill were to be enacted, Mexico would become the world's most populous country with legalised assisted dying throughout the entire nation. According

<sup>&</sup>lt;sup>6</sup> Berdejo 2022.

<sup>&</sup>lt;sup>7</sup> AP 2021.

<sup>8</sup> Nelson & Acosta 2023.

to a poll published in 2023, more than 70 percent of Mexico's population are in favour of legalising assisted dying.<sup>9</sup>

In October 2022, a majority of the members of the *Uruguayan* Chamber of Representatives voted for the legalisation of assisted dying, including practitioner-administered assisted dying. This means that the issue proceeded to the second chamber of the legislature, the Chamber of Senators.<sup>10</sup> At the time of writing, the issue had not been settled.

### 7.6 France

There is a lively assisted dying debate in France, both at the highest political level and in the wider community. The French equivalent of The Swedish National Council on Medical Ethics, Le Comité Consultatif National d'Éthique pour les sciences de la vie et de la santé (CCNE, or the French National Advisory Ethics Council for Health and Life Sciences) has examined the issue in several reports and opinions. Terminal sedation has been legal since 2016 and can be administered to patients who are estimated to have only a few weeks left to live. On the other hand, both self- and practitioner-administered assisted dying are illegal. In the CCNE's latest report on the issue of assisted dying from 2022, it neither advocates nor advises against legalisation. Instead, CCNE stresses that if the legislator wishes to legalise assisted dying, it is important that respect for the right of self-determination is combined with investments in palliative care and the protection of vulnerable groups. 11 The French National Academy of Medicine endorsed the CCNE's proposal to focus on palliative care and to pay particular attention to vulnerable groups, but went further than the CCNE and explicitly advocated the legalisation of selfadministered assisted dying while maintaining that practitioner-administered assisted dying should remain illegal.<sup>12</sup>

In the autumn of 2022, President Macron initiated a citizens' convention where 184 randomly selected French people listened and spoke to lawyers, doctors, philosophers, religious studies academics and

<sup>&</sup>lt;sup>9</sup> Ramírez Coronel 2023; Dirección de Servicios de Investigación y Análisis, Subdirección de Análisis de Política Interior 2019; Comisión de Salud 2023.

<sup>&</sup>lt;sup>10</sup> Mercopress 2022.

<sup>&</sup>lt;sup>11</sup> CCNE 2022.

<sup>&</sup>lt;sup>12</sup> Académie nationale de médecine 2023.

other experts for a total of 27 days. The citizens' convention report, published in April 2023, strongly supported the legalisation of assisted dying. Over 75 percent of the citizen representatives were in favour of the legalisation of assisted dying in some form, and 40 percent of the citizens' forum wanted to see legislation that would give patients who meet the criteria for assisted dying a free choice between practitioner-administered assisted dying and self-administered assisted dying. 28 percent stated that self-administered assisted dying should be seen as the primary option, and practitioner-administered assisted dying should only be granted in exceptional cases, while 10 percent stated that only self-administered assisted dying should be legalised. 3 percent of the respondents stated that only practitioner-administered assisted dying should be legalised.<sup>13</sup>

As is evident, in France the question of assisted dying is not moving forward as it has done in Italy, Germany and Austria through court rulings, but is instead very much owned by the country's political leadership and general societal debate. In March 2024, President Macron announced that a proposal for legalised assisted dying will be presented in the National Assembly before the summer. The proposal is similar to Australia's Victoria model: it is limited to dying patients and there is a presumption for self-administered assisted dying while allowing practitioner-administered assisted dying if the patient is not physically able to administer the lethal substance themself. The bill is accompanied by investments in palliative care, as recommended by the CCNE.<sup>14</sup>

#### 7.7 Ireland

Both practitioner- and self-administered assisted dying are illegal in Ireland. In 2020, a member of Parliament presented a bill to legalise self-administered assisted dying called the *Dying with Dignity Bill*. The drafting committee reached the conclusion the following year that the Bill was flawed, partly because it did not provide adequate safeguards for vulnerable patients. However, the committee recommended that the issue received a more thorough investigation and

<sup>&</sup>lt;sup>13</sup> Economic, Social and Environmental Council 2023, p. 53.

<sup>&</sup>lt;sup>14</sup> Le Monde 2024; Franceinfo 2024. The bill as a whole: République française 2024. Unlike, for example, Belgium and Spain, the French legislation avoids the term 'euthanasia' and instead speaks of 'aide à mouir'.

during 2023 the Oireachtas Committee on Assisted Dying worked to produce decision guidance for the parliament. Their report was published in March 2024, recommending that Ireland should legalise assisted dying for patients with decision-making capacity and with a terminal illness who want assistance to help them die. The proposal has a presumption for self-administered assisted dying, with practitioner-administration as an option only if the patient is unable to take the lethal substance themself. Like France, if the proposal proceeds, Ireland, will follow a model similar to that in several of Australia's states.

## 7.8 United Kingdom

The closest British counterpart to The Swedish National Council on Medical Ethics, the Nuffield Council on Bioethics, initiated a multidisciplinary project in autumn 2023 to explore the public's attitude towards assisted dying. The Nuffield Council intends to conduct opinion polls, but more importantly it will organise a Citizens' Jury to explore the issue of assisted dying to unpack the ethical, practical, and societal considerations.<sup>16</sup>

There have been political initiatives and debates to legalise assisted dying over a long period in both the UK Parliament and the regional assemblies and parliaments in the various parts of the United Kingdom. In England, Northern Ireland and Wales, it is illegal to assist anyone who intends to take their own life. In Scotland, there is no explicit crime classification covering assisted suicide, but it is widely held that anyone helping someone take their own life is at risk of prosecution for murder or manslaughter.

From 2004 to 2005, a Select Committee was appointed to consider and report on the issue of assisted dying in the House of Lords as part of Parliament's consideration of the *Assisted Dying for the Terminally Ill Bill*. The Committee's final report notes that the issue ultimately boils down to a conflict between the right of self-determination on the one hand and the principle of the sanctity of human life on the other.<sup>17</sup> The bill and the final report were debated thoroughly before the bill was voted down in 2006. A similar bill was debated in

<sup>&</sup>lt;sup>15</sup> Houses of the Oireachtas 2024; Reilly 2023.

<sup>&</sup>lt;sup>16</sup> Nuffield Bioethics Council 2023.

<sup>&</sup>lt;sup>17</sup> House of Lords 2005.

Parliament in 2015, but it too failed to reach majority support. Legalisation proposals have also been under consideration in the Scottish Parliament, without winning a majority, but new similar proposals are already being drafted. In spring 2024, a Member's Bill for the legalisation of assisted dying will be discussed in the Scottish Parliament. The Member's Bill does not require unbearable suffering, but applies to patients from the age of 16 who have been diagnosed with an incurable, progressive disease that will lead to their 'premature death' (no more specific time frame is given).<sup>18</sup>

In the self-governing dependency of Jersey, in spring 2024, the States Assembly will vote on a bill that would permit assisted dying (in a previous vote the States Assembly has approved the legalisation of assisted dying 'in principle'). Under the bill, both patients with a terminal physical medical condition and patients with an incurable physical condition that causes them unbearable suffering may be eligible for assisted dying. For the former group, the assessment of a request should take two weeks (faster if death is feared to be closer than that) and for the latter at least 90 days. The choice between selfadministered assisted dving and practitioner-administered assisted dying is left up to the patient.<sup>19</sup> In order to avoid 'assisted dying tourism', assisted dying will only be available to permanent residents of the island. Steps toward legalisation have also been taken on the Isle of Man, another self-governing British Crown dependency. In October 2023, the parliament approved a proposal that would make assisted dying legal. Further steps in the process remain before the proposal can enter into force.

At the national level, the issue of assisted dying was discussed again in 2022 when a petition was debated in the UK's House of Commons. Of More than 150 000 people had signed the petition to legalise assisted dying for terminally ill adults with decision-making capacity. The Tory-led government has made it clear in a statement that it is neither for nor against legalisation, but believes that the matter should be decided in Parliament, where MPs should be free to argue and vote according to their own conscience regardless of party affiliation. Labour leader Keir Starmer wants legalisation and has promised that under a Labour government, the Parliament would debate

<sup>&</sup>lt;sup>18</sup> Scottish Parliament 2024.

<sup>&</sup>lt;sup>19</sup> Government of Jersey 2024.

<sup>&</sup>lt;sup>20</sup> UK Parliament 2022.

and vote on the issue. A further inquiry in the British Parliament was completed in February 2024. The inquiry's report, which is more of a state of knowledge report than a recommendation, considered more than 68 000 submissions from the public and 380 written expert opinions. It stresses the importance of the UK Parliament and the government preparing for the likelihood that assisted dying will be permitted in certain parts of the UK soon, and how this may affect the nation's other jurisdictions.<sup>21</sup>

### 7.9 Denmark

In May 2023, a petition to legalise assisted dying reached more than 50 000 signatures, which meant that the proposal reached the Danish Parliament. In connection with the media attention accompanying the petition, Prime Minister Mette Frederiksen expressed her support for a future legalisation of assisted dying. Shortly thereafter, the Danish Parliament tasked the Danish Council on Ethics, with submitting an opinion on the issue. Of the 17 members of the Council on Ethics, 16 were opposed to legalisation, as its report published in October shows.<sup>22</sup> The Council on Ethics position has no formal legal force, and so the issue remains open in Danish public debate and has not been legislated. The same autumn, the Danish government appointed a Committee to provide nuanced decision guidance for work on a 'Danish model for a more dignified death'. The Committee will publish its report in spring 2025.

### 7.10 Finland

In March 2024, a petition on legalising assisted dying reached the 50 000 signatures required for the matter to be raised in Parliament. A similar petition reached the Finnish Parliament in 2018, but the proposal was voted down. However, the led to an inquiry into palliative care, assisted dying and self-determination at the end of life. The inquiry, which presented its report in 2021, proposed investments in palliative care and legislative amendments, but did not present any recommendation regarding assisted dying. Rather, the final

<sup>&</sup>lt;sup>21</sup> Health and Social Care Committee 2024.

<sup>&</sup>lt;sup>22</sup> Det etiske råd 2023.

report proposed two possible legislative pathways for further discussion. One of these entailed legalising only self-administered assisted dying, with a presumption of hospice care, and self-administered assisted dying as a last resort. The second was to legalise both self- and practitioner-administered assisted dying with a generally more permissive design. Under both proposals, assisted dying would be available only to patients who were near death.<sup>23</sup>

In a study carried out by the Finnish Medical Association with Tampere University in 2023, 55 percent of Finnish physicians were in favour of legalising assisted dying.<sup>24</sup> The Finnish Medical Association had surveyed the opinions of Finland's physicians in 2020 as well. At that time, 50 percent of respondents were in favour of legalisation. The more recent result is thus in line with the trend that more and more physicians are positive to the legalisation of assisted dying, and that younger physicians are more positive than older physicians.

<sup>&</sup>lt;sup>23</sup> Sosiaali- ja terveysministeriö 2021.

<sup>&</sup>lt;sup>24</sup> Lääkäriliito 2024. This figure is the best available but since many refrained from responding, it should be viewed with caution.

## 8 Ethical perspectives

The different legal systems or models for assisted dying described above have much in common but also things setting them apart from one another. These differences may have historical and societal origins, such as how healthcare is structured in these countries. Some differences also have their roots in ethical considerations. Whatever the sources of these differences, the design of a model for assisted dying in fact has ethical implications, since the value conflicts that can arise rank interests and goals differently.

This chapter describes the differences between the models in terms of the criteria that must be met for a patient to be eligible for assisted dying, and in terms of the administrative and organisational differences in the process. Each description ends with examples of the ethical considerations that speak for or against the different designs.

## 8.1 Terminal disease or chronic suffering

New Zealand and Australia's states, as well as the Oregon model, all have the condition that only *dying* patients may be eligible for assisted dying. The limit can be an estimated six or a maximum of twelve months of remaining life. Benelux, Portugal, and Spain have instead chosen to focus on suffering without hope of improvement as the decisive factor, and patients with conditions that are unlikely to lead to death in the near future may be eligible for assisted dying if they otherwise meet the criteria in the law. The same is true of the Swiss model of assisted dying. Canada initially granted assisted dying only to patients where death was "reasonably foreseeable" but recently removed that requirement.

### 8.1.1 Uncertain prognoses

The further into the future a sick person's death is expected to occur, the less certain one can be that the condition from which the patient is suffering will indeed remain impossible to remedy. We do not currently know what treatment options will be offered years into the future. Criteria that relate to a short life expectancy can be seen as a safety mechanism to reduce the risk of patients missing out on opportunities for better quality of life further in the future. When Canada adjusted the criteria so that death no longer had to be "reasonably foreseeable", two separate assessment processes were introduced: one for patients applying for assisted dying who have terminal illnesses, and one for patients who have non-terminal chronic illnesses. The process for those who do not have a terminal illness requires a longer period of reflection, and additionally that not only the patient themself but also their health practitioners must be of the opinion that the patient has exhausted all reasonable options to try to improve their situation. Other countries where assisted dying may be considered when death is not imminent have similar requirements for a longer and more thorough assessment.

#### 8.1.2 Mental illness

A special case of non-terminal illness is the suffering caused by a *mental* illness. In 1994, the Supreme Court of the Netherlands ruled that the unbearableness of a patient's suffering is not dependent on the cause of the suffering, which means that patients with mental illness have been granted assisted dying there, provided that they show decision-making capacity and undergo unbearable suffering that cannot be remedied. Belgium, Luxembourg, and Spain are other countries that have legalised practitioner-administered assisted dying which does not exclude such patients if they otherwise meet the criteria. In practice, however, Luxembourg and Spain do not seem to grant assisted dying in cases of mental illness.<sup>2</sup> Canada has opened up the possibility that such patients may be eligible in principle for assisted dying, but the implementation of this position has been postponed on several occa-

<sup>&</sup>lt;sup>1</sup> Government of Canada 2024 (Section on Safeguards for persons whose natural death is not reasonably foreseeable).

<sup>&</sup>lt;sup>2</sup> Ministre de la Santé et de la Sécurité sociale 2023; Ramos-Pozón m.fl. 2023; Ministerio de Sanidad 2023.

Smer 2024:4 Ethical perspectives

sions. Following a recommendation from a special inquiry, it was decided in spring 2024 that the current procedures in place are not adequate to accommodate such patients in a legally secure manner. Thus, a change in this regard will not take place in Canada until 2027 at the earliest. In those jurisdictions where terminal illness is a criterion for assisted dying, patients with mental illness as the only underlying diagnosis are effectively excluded. Portugal's law does not require that death is imminent, but only physical illnesses and injuries can be grounds for being granted assisted dying there. The legislation proposed in Jersey is similar in this respect to the Portuguese legislation. Jurisdictions that only permit self-administered assisted dying may also differ with regard to this criterion. The USA's Oregon model applies an estimated remaining life expectancy of a maximum of six months as a criterion, which in practice excludes mental illnesses. In Switzerland and Austria however, patients with unbearable suffering caused by mental illness can be granted self-administered assisted dying.

What makes assisted dying where mental illness is the underlying diagnosis worthy of special attention is partly the concern that the illness as such may affect the patient's decision-making capacity, and partly the difficulty of saying with certainty that there is no prospect of improvement. Long-term prognoses are always less certain, but can be particularly uncertain when it comes to mental illnesses. Refractoriness to treatment in the guideline of the Dutch Association of Psychiatrists is operationalised as follows: "A patient's condition can only be considered refractory if the following interventions haven been proven ineffective: all applicable regular biological treatments; all applicable psychotherapeutic treatments; social interventions which can make the suffering more bearable."

## 8.1.3 Different scopes and rationale for the legislation

The question of permitting assisted dying only in the case of terminal illnesses or also in the case of prolonged unbearable suffering reflects differences in what is seen as the ethical basis for permitting assisted dying. On one view assisted dying is something that satisfies the interest of empowering patients already at the end of their lives to decide

<sup>&</sup>lt;sup>3</sup> Berghmans et al. 2013, p. 440.

their final fate. A somewhat different approach identifies quality of life and the healthcare system's obligation to alleviate suffering and, equally importantly, respect for the individual's general right of self-determination as the key issues. Both approaches emphasise the value of the right of self-determination but see its scope in this context as either limited to end-of-life decisions, or as more generally applicable.

## 8.2 Patient judgement and decision-making capacity

With the exception of the Netherlands, where it is permitted to end the life of a newborn in certain extreme circumstances for reasons of mercy, a patient assessed as having decision-making capacity and persistently requesting assisted dying is central in the laws that this report has focused on. Crucial importance is placed on the requirement to determine what the patient really wants, that their request is unwavering and persistent, that they have not been unduly influence by others, and that their request is well-considered. The decision-making capacity of patients applying for assisted dying must be confirmed by at least two doctors or nurse practitioners, and sometimes also by a psychiatrist.

#### 8.2.1 Advance directives

Procedures for determining the patient's decision-making capacity are similar in the different jurisdictions (see the example from the Queensland VAD Handbook in the chapter on Australia). However, an important difference between the different models is how one views decision-making capacity and expressions of will over time in relation to assisted dying. Portugal joins with the Australian states and New Zealand in requiring that assisted dying patients must be capable of making their own decisions all the way up to the final decisive act that ends their life. In Australia and New Zealand, there is some scope for speeding up the process if there are fears that the patient's decision-making capacity may be impaired or lost, but under no circumstances can assisted dying be provided to someone who is suspected of having lost their decision-making capacity. Spain has chosen to allow patients to stipulate that they want assisted dying, even if their decision-making capacity is impaired or lost entirely, either through

Smer 2024:4 Ethical perspectives

an advance directive, or by having nominated a legal representative or agent who may make decisions on their behalf should their decision-making capacity be lost or impaired. The Benelux countries also allow advance directives, and thus assisted dying for patients who no longer have the capacity to make their own decisions. In Canada, advance directives are accepted under certain circumstances, but it is also made clear that "the agreement to waive final consent will be invalid if the person, after having lost decision-making capacity, demonstrates refusal or resistance to the administration of MAID [assisted dying] by words, sounds or gestures." Thus, patients with decision-making capacity are granted the right to make life-changing decisions for their incapacitated future selves, who nevertheless have a kind of veto right.

When assisted dying is provided in the form of self-administered assisted dying, such as in the Oregon model or in Austria, the patient has the lethal substance themself and there is no practical way to check that the patient remains capable of making their own decisions at the point when they later choose to utilise it. In Switzerland, assisted dying is typically provided in a clinic, thus allowing for an assessment of the patient's current decision-making capacity. In New Zealand too, assisted dying is always provided under the supervision of healthcare professionals.

# 8.3 Practitioner-administered or self-administered assisted dying

One important difference concerns whether the legislation in the country permits both forms of assisted dying or just one. Where practitioner-administered assisted dying is permitted, self-administered assisted dying is generally also permitted, but several countries permit only self-administered assisted dying. This is the case, for example, in Switzerland, Austria, and in the US states that have legalised or decriminalised some variant of the Oregon model. The form of assisted dying now permitted in Germany and Italy subject to a court ruling also concerns self-administered assisted dying, not practitioner-administered assisted dying. The Canadian province of Quebec deviates

<sup>&</sup>lt;sup>4</sup> Government of Canada 2024 (Section: Final consent for persons whose natural death is reasonably foreseeable).

from this pattern, permitting only practitioner-administered assisted dying.<sup>5</sup>

In the jurisdictions that permit both practitioner- and self-administered assisted dying, in some of the regulatory frameworks there is a presumption for self-administration, and practitioner-administered assisted dying is only considered if self-administration is impossible or deemed less appropriate. This presumption exists in all the Australian states except New South Wales (the most recent state to legalise assisted dying). The presumption is strongest in South Australia and Victoria, where practitioner-administration can only be considered if the patient is physically incapable of taking the lethal substance themself. While the other Australian states have this built-in presumption, they allow the physician greater discretion, given the patient's condition and wishes. In practice, the choice is stated as being virtually free in Western Australia, for example. Portugal follows the 'Victoria model', where self-administered assisted dying is the only option unless the patient is unable to end their own life with the provided lethal substance.

New Zealand and Spain leave the choice of method up to the patient. In New Zealand, patients who have met the criteria for assisted dying are faced with choosing one of four possible procedures: swallowing a lethal substance that the physician gives them, that the physician administers the same lethal substance via a feeding tube, that the physician gives them a lethal injection, or that the patient triggers such an injection themself after the physician has put the cannula in place. It is thus self-administered or practitioner-administered assisted dying by something swallowed or something injected. None of these alternatives is presented as the primary choice. In Spain, the patient chooses between swallowing a lethal substance themself or having a lethal injection administered either by the physician or triggered by the patient themself after the physician has put the cannula in place. If anything, one could say that the Spanish law places practitioneradministration as the standard option. For example, an injection administered by a physician is first on the list of options in the clinical manual for healthcare professionals. The manual also recommends always preparing an access, even in the case of self-administered as-

<sup>&</sup>lt;sup>5</sup> Today, Colombia permits both practitioner- and self-administered assisted dying, but for a number of years only practitioner-administered assisted dying was permitted.

Smer 2024:4 Ethical perspectives

sisted dying, in the event that the patient vomits, and a different approach becomes necessary.<sup>6</sup>

#### 8.3.1 Voluntariness

There may be several reasons why the legislation in a particular jurisdiction has a presumption for self-administered assisted dying. In states where self-administration is the only permitted form of assisted dying, it may have been a legally less complicated process than permitting practitioner-administered assisted dying. However, Australia's states and Portugal do permit practitioner-administered assisted dying in certain circumstances and therefore have amended their criminal law. So for them, the presumption of self-administered assisted dying cannot be explained by it having been legally simpler to implement. Other reasons may be conceivable on the other hand. The first is that it is seen as a stronger form of guarantee that the patient's decision to end their life is fully their own and current. While all jurisdictions that permit practitioner-administered assisted dying require a clear statement that the patient definitely wants assisted dying before it can be provided to them, the patient themself performing the final lethal act can be seen as an additional guarantee of this.

## 8.3.2 Agency

Another reason for the presumption may be a stance which says that there is always something ethically troublesome about actively causing another person's death, regardless of the circumstances. Given the overall picture of the patient's suffering, clearly expressed request and a bleak prognosis, one might think that death is the least bad option, while it is also an *unfortunate and morally ambivalent situation*, where healthcare professionals should preferably not perform the direct act causing death if the patient can do this themself.

The idea that self-administered assisted dying is preferable from an ethical perspective can also be understood in light of the distinction between *doing something* and *allowing something to happen*. Practitioner-administered assisted dying clearly means that a person actively does something that directly leads to the death of another person, which,

<sup>&</sup>lt;sup>6</sup> Ministerio de Sanidad 2021, pp. 29-43.

according to some ethical outlooks, must be justified by stronger reasons than a decision that involves passively allowing the same outcome to happen. According to this stance, the physician's agency lies in supplying the lethal substance; the patient is then the agent of their own death.

#### 8.3.3 The burden on staff

Causing a person's death can be extremely difficult even with the conviction that it is ethically justifiable. Therefore, it may be reasonable not to encumber physicians and other healthcare professionals with this burden unless there are strong reasons, such as that the patient would not otherwise be able to end their life if they had requested assisted dying. The latest Dutch evaluation report describes and discusses physicians' attitudes towards practitioner- and self-administered assisted dying. A majority of physicians say that they prefer practitioner-administration, which they see as more reliable and safeguards the physician's control over the procedure. But the minority who prefer self-administered assisted dying are of the view that this method is a better guarantee that the patient really wants assisted dying and that the procedure is less emotionally burdensome for them as physicians.<sup>7</sup>

## 8.3.4 Patient capacity and remaining life

One possible reason *against* a presumption in favour of self-administered over practitioner-administered assisted dying is that such a presumption could shorten the patient's life more than they would wish. In one of the rulings that had a decisive impact on the assisted dying system in Canada, the Supreme Court concluded that the legislation must avoid putting patients in the position of choosing to die when they are *capable* of dying as opposed to when they *wish* to die.<sup>8</sup>

<sup>&</sup>lt;sup>7</sup> ZonMw 2023, pp. 268–71.

<sup>&</sup>lt;sup>8</sup> In Supreme Court of Canada 2015, the ruling states: "It is a crime in Canada to assist another person in ending her own life. As a result, people who are grievously and irremediably ill cannot seek a physician's assistance in dying and may be condemned to a life of severe and intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel. [...] The right to life is engaged where the law or state action

Smer 2024:4 Ethical perspectives

The Irish parliamentary inquiry, which in March 2024 recommended the legalisation of assisted dying, suggested that the practitioner-administered mode should be available as an option with reference to this consideration, among others. In the Australian states with a presumption for self-administration, it is possible to reassess a decision on the method of assisted dying if the patient's physical capacity deteriorates. Following such a review, a patient may be approved for practitioner-administered assisted dying at their preferred time. In systems where only self-administered assisted dying is available, the option of getting assistance to die after the patient has lost the capacity to perform the act themself is lacking.

### 8.3.5 Patient preferences

Victoria and South Australia adhere strictly to a policy where only applicants who are physically incapable of self-administration may receive practitioner-administered assisted dying. In these states, 15 percent of assisted dying patients die by practitioner-administered assisted dying and 85 percent by self-administered assisted dying. Queensland has the same presumption of self-administered assisted dying but allows more scope for the medical practitioner's overall assessment. There, 57 percent of assisted deaths are practitioner-administered, and 43 percent are self-administered. Western Australia has yet less strict application of this presumption, and more of a culture of choice. There, 82 percent of patients granted assisted dying are provided with practitioner-administered assisted dying and 18 percent are granted self-administered assisted dying. In New Zealand, whose system does not have a built-in presumption or primary option, 93 percent have opted for practitioner-administered assisted dying and 7 percent have opted for self-administered assisted dying. On the assumption that the patients granted assisted dying in these jurisdictions are by and large equal in their capacity to self-administer, it can be concluded that most patients who request assisted dying prefer practitioner-admin-

imposes death or an increased risk of death on a person, either directly or indirectly. Here, the prohibition deprives some individuals of life, as it has the effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable ..."

<sup>&</sup>lt;sup>9</sup> Houses of the Oireachtas 2024, p. 71.

<sup>&</sup>lt;sup>10</sup> For a comparative analysis of the various states, see Waller et al. 2023.

istered over self-administered assisted dying. <sup>11</sup> One reason why not only self-administered assisted dying but also practitioner-administered assisted dying should be available may thus be that it is the option that most prefer.

Table 8.1	Method of assisted dying: presumption in the law
	and patient preferences

Jurisdiction	Self-administered assisted dying (%)	Practitioner-administered assisted dying (%)
Victoria and South Australia	85	15
Queensland	43	57
Western Australia	18	82
New Zealand	7	93

## 8.4 Patient-initiated or healthcare-initiated discussion

New Zealand and some of Australia's states prohibit physicians and sometimes other licenced healthcare professionals from initiating any discussion of assisted dying. The initiative or interest must come entirely from the patient. In other Australian states, as well as in Portugal and Spain, physicians and sometimes other healthcare professionals are permitted to bring the subject up. However, they must always inform the patient about other options, such as palliative care and other possible medical treatments. Similar procedures apply in the Benelux countries.

In Canada, physicians and other healthcare professionals are allowed to initiate a discussion about assisted dying and provide information without a prior request from the patient. A document by the Canadian Association of MAiD Assessors and Providers (MAiD standing for medical assistance in dying) even proposes that physicians and nurse practitioners have a professional obligation to provide information on assisted dying when talking to patients who might be eligible for

<sup>&</sup>lt;sup>11</sup> In Benelux, the proportion of patients who die through self-administered assisted dying is even lower. In these countries, there is an informal but clear presumption of practitioner-administered assisted dying, while self-administered assisted dying is less well-known as an option. The proportions in these countries, then, are more likely a reflection of an existing culture or praxis and not of patients' preferences such as they would be revealed if the patients were presented with a choice where no option was framed as the primary option.

Smer 2024:4 Ethical perspectives

it. The main reason given for this recommendation is that it is a way to respect patient autonomy in making decisions:

To respect a patient's autonomy, healthcare professionals are commonly required to provide all of the medically effective and legally available treatments as options for patients, even if they are at odds with their personal values, so that the patient can make a considered choice among those treatment options (including provision, withholding, or withdrawal of treatment).<sup>12</sup>

There is also a fairness dimension to this issue. Highly educated, socially well-situated patients are more often aware of assisted dying legislation and the opportunities and rights they have under it. For this group, the decisions they will make do not depend on whether they happen to end up in front of a physician who mentions or does not mention assisted dying. But for those who are less aware of what the healthcare system can offer and what rights and opportunities patients have, the fact that healthcare professionals can spontaneously inform them about all options, including assisted dying, may support their decision-making and reduce the gap between them and those who were aware of the alternatives from the beginning.

What are possible reasons against the position that, under certain circumstances, the physician should be the one who brings up assisted dying and provides the patient with information? Because the physician has the social and verbal upper hand over many of their patients, and has more knowledge, the patient may interpret the fact that the physician mentions assisted dying as a kind of proposal or recommendation, which they may find it difficult to consider in a way that is not influenced by these factors. Therefore, it can be difficult to ensure that the patient is making a fully independent decision. Thus, autonomy and fairness considerations, depending on how these values are thought to play out in the situation, can be invoked both for and against the proposal.

<sup>&</sup>lt;sup>12</sup> Canadian Association of MAiD Assessors and Providers 2019.

## 8.5 The role and recruitment of healthcare professionals

All countries that permit assisted dying stress that no one who opposes it should be forced to participate. Hence, they all grant what is known as *conscientious objection* for healthcare professionals on this issue. But beyond this, the provisions and procedures diverge, and some jurisdictions can be said to give healthcare professionals a greater degree of freedom of conscience than others. The issue of freedom of conscience is best thought of as a conflict between, on the one hand, the importance of patient equal access and, on the other hand, tolerance of dissent and the value of people not being forced to go against ethical convictions that they see as key in the exercise of their profession.

## 8.5.1 Opt-in or opt-out

Australia and New Zealand have a kind of opt-in system that requires healthcare professionals to express interest and undergo training to be given a role in assisted dying. Most physicians and nurses in these countries have nothing to do with assisted dying and do not come into contact with assisted dying unless they themselves make the decision that they would like to participate in providing this service. This means that relatively few physicians work with assisted dying, for example by being the coordinating medical practitioner (AU) or attending practitioner (NZ) in an assisted dying process. However, the systems are designed so that patients should still not have any significant difficulties in finding a physician who wants to provide this service to them. If the patient does not know which physicians in their area provide this service, they can contact the public care navigator who has information about all physicians offering the service.

Portugal and Spain have instead chosen what one might call an *opt-out* system. Here too, health professionals have the right to refrain from providing assisted dying services. But they must do so by mak-

<sup>&</sup>lt;sup>13</sup> The terms 'opt-in' and 'opt-out' allude to the terms usually applied to various organ donor systems. In opt-in systems, one must actively register as a donor, and people who have not registered are presumed not to have given their consent to their organs being donated to others after death. In opt-out systems, everyone is assumed to be willing to donate their organs, and only those who do not want to donate their organs need to register their stance in relation to organ donation. Sweden has an opt-out system.

Smer 2024:4 Ethical perspectives

ing an active choice to have their conscientious objection recorded in a special register. It is assumed that physicians who have not taken this step are prepared to participate in assisted dying, for example by being a supervising or consulting physician.

In the Australian states of New South Wales, South Australia and Victoria, a physician who is a conscientious objector to participating in assisted dying is not required to provide general information about voluntary assisted dying (VAD) or assist the patient in finding another physician. In Queensland, Tasmania and Western Australia, however, physicians who are conscientious objectors to VAD are required to provide contact details to health agencies and other physicians who can assist the patient further in this matter. In Tasmania and Western Australia, the physician is also required to provide the patient with the state's VAD information folder. In both Portugal and Spain, physicians who invoke freedom of conscience regarding assisted dying have a duty to ensure that patients who wish to discuss assisted dying are connected with a doctor who has not invoked freedom of conscience on this matter.

Countries that have legalised assisted dying have all chosen the line that healthcare professionals should be given the right of conscientious objection as a way of respecting their reasonable expectations of what their profession entailed when they chose it. How this right is specifically protected may differ, and experiences from the different systems in the future might inform us about the advantages and disadvantages that each of the different systems have, from the perspective of both patients and healthcare professionals.

#### 8.6 Conclusion

The above comparison of the different assisted dying models illustrates that a fundamental challenge in designing legislation has been to strike a balance between *accessibility* for individuals who wish to receive assisted dying services and *safeguards* aimed at identifying rash decisions or protecting vulnerable groups. The safety aspect came into focus when the European Court of Human Rights took up the case of a mentally ill Belgian woman who died by assisted dying without her relatives being informed about it (see Section 6.2.3). According

to the Court, a law that permits assisted dying is to be designed in such a way that it:

- 1. defines clearly and precisely the criteria that must exist in order for a person to be eligible for assisted dying;
- 2. provides a procedure to ensure that the request is voluntary and
- 3. includes safeguards to protect vulnerable groups; and
- 4. clarifies in detail what steps the person entrusted to assess the request must take to be deemed to have fulfilled their duty of care.

The Court found that the assisted dying legislation in Belgium was not in breach of the European Convention on Human Rights. It is important to note, though, that the verdict does not mean it is a good thing to make assisted dying legal, nor does it imply specifically that Belgium's eligibility criteria are the right ones.

In both the European jurisdictions permitting assisted dying as well as in the other jurisdictions, there is debate which in various ways touches on what is usually termed the *slippery slope argument*, that is, a suggestion that legalised assisted dying will tend to, in some sense, "derail". Several different kinds of fears and hypotheses may underpin this argument. These include concerns that the eligibility criteria for assisted dying over time will be expanded in a problematic way, or that assisted dying *per se* risks giving people with high care needs the feeling that they are a burden on society and their families. Existing research shows that patients seeking assisted dying are often socially and economically better situated than the average, but there is a debate, particularly in Canada, that has at its core a suspicion that inadequate access to care may affect people's desire to seek assisted dying instead.<sup>14</sup>

#### 8.6.1 Facts and values

In the council's 2017 report, a distinction was made between *fact-based reasons* and *value-based reasons* in the assisted dying debate. Fact-based reasons build on or refer to a fact (or alleged fact), such

<sup>&</sup>lt;sup>14</sup> A summary is provided in Parliament of Canada 2023. The sharpest criticism is expressed in Coelho et al. 2023. See Landry 2023 and Redelmeir 2021 and Downie & Schüklenk 2021 for additional perspectives.

Smer 2024:4 Ethical perspectives

as "Assisted dying is unjustifiable because we cannot ensure that a request for assisted dying is unwavering and entirely voluntary" or "Assisted dying is justifiable because it gives patients a sense of security and control as they face the end of their lives". Slippery slope concerns are also fact-based reasons, the truth of which can be tested using scientific methods. Value-based reasons, on the other hand, are considerations that refer to or are based on some kind of ethical value or principle such as 'assisted dying is unjustifiable because it goes against the idea of the inviolability of human life', or 'assisted dying is justifiable because everyone has a moral right to decide for themselves how they wish to die'. The plausibility of such arguments cannot be established scientifically in any straightforward way but are part of the ongoing ethical discussion present in all human cultures.

Fact-based as well as value-based considerations are variously invoked both in support of and as reasons to reject assisted dying. On some ethical views, the value-based considerations are, if not entirely decisive, at least more fundamental. A supporter of the principle of the sanctity of human life, for example, will reject in principle all forms of assisted dying, even if the system were to work as intended without adversely affecting vulnerable groups or people's confidence in the healthcare system. Similarly, a supporter of certain forms of rights-based ethics, where people are seen as categorically free to make whatever decisions they want about their own care and their own dying, would not be prepared to give up this view even if it could be shown that people sometimes seek assisted dying because they do not want to be a burden to others or that legalised assisted dying would erode investment in palliative care. On a more pragmatic approach, that is, an approach that neither rejects nor accepts assisted dying in principle, the facts are instead decisive for the position taken. On such an approach, it is therefore particularly important to clarify what the relevant facts of the case are, and what we know about these facts.

The distinction between fact-based reasons and value-based reasons, and the associated debates about which value-based reasons are the most plausible and which fact-based reasons are supported by the available empirical evidence, is crucial for a fruitful exchange of views. In some respects, the descriptions of the features of the assisted dying legislations given above allows for an evaluation based on empirical evidence, for example, whether the systems under the legislation in each country or state make assisted dying accessible primarily

to socio-economically well-situated groups or, on the contrary, risk causing harm to already vulnerable groups; whether healthcare professionals and citizens are by and large satisfied with the design of the model used in their country or state; or what effect on suicide prevention the different regimes could have. Other differences in the legislation designs reflect, rather, philosophical or principled disagreements over matters such as the ethics of killing, the nature and value of autonomy as compared to other concerns, or how to assess moral responsibility for outcomes that agents directly and actively *cause* to happen compared to outcomes that agents *allow* to happen, but where the outcome in question has a prior natural cause or is caused by the actions of others.

The Swedish National Council on Medical Ethics recognises a value in describing the models introduced in recent years in countries around the world, including several EU Member States, thus updating our combined knowledge about the situation internationally. The requirements for any assisted dying legislation set by the European Court of Human Rights ruling are also important to bear in mind, as they represent an anchor point from which draft legislation can be both justified and criticised. The purpose of this report, as with the former, is to contribute to a more informed debate. Whatever one thinks about assisted dying, we can all agree that adequate information combined with well-rounded and in-depth ethical analyses and discussions are good things.

## References

- Académie nationale de médecine (2023). "Favoriser une fin de vie digne et apaisée: Répondre à la souffrance inhumaine et protéger les personnes les plus vulnérables". https://www.academiemedecine.fr/wp-content/uploads/2023/07/Avis-Fin-de-vie.pdf.
- Al Rabadi, Luai et al. (2019). "Trends in medical aid in dying in Oregon and Washington", *Jama Network Open*, Vol. 2, No. 8.
- American Medical Association (2019). "Opinion of the council on ethical and judicial affairs: physician-assisted suicide". https://www.ama-assn.org/system/files/2019-05/a19-ceja2.pdf.
- AP (2021). "Chile legislature OKs euthanasia bill, which heads to Senate", 21 April. https://apnews.com/article/latin-america-health-euthanasia-business-chile-f1cf977ecd2779adf24a7ceef3a20eb4.
- Australian Medical Association (2016). "AMA Position Statement: Euthanasia and Physician Assisted Suicide".

  https://www.ama.com.au/sites/default/files/documents/AMA\_
  Position\_Statement\_on\_Euthanasia\_and\_Physician\_Assisted\_
  Suicide 2016.pdf.
- Australian Medical Association New South Wales (2021). "Voluntary assisted dying". https://www.amansw.com.au/voluntary-assisted-dying.
- Bartsch, Christine et al. (2019). "Assisted suicide in Switzerland: an analysis of death records from Swiss institutes of forensic medicine", pp. 545–52 in *Deutsches Ärzteblatt*, Vol. 116. https://www.aerzteblatt.de/int/archive/article/209391.

References Smer 2024:4

Berdejo, Eduardo (2022). "Iglesia Católica rechaza proyectos para legalizar eutanasia en Argentina: Toda vida vale", Aciprensa, 20 August. https://www.aciprensa.com/noticias/95310/iglesia-catolica-rechaza-proyectos-para-legalizar-eutanasia-enargentina-toda-vida-vale.

- Berghmans, Ron et al. (2013). "Physician-assisted suicide in psychiatry and loss of hope", pp. 436–43 i *International Journal of Law and Psychiatry*, Vol. 36, No. 5–6.
- Bundesministerium Justiz (2024). "Sterbehilfe", https://www.bmj.gv.at/themen/Fokusthemen/Dialogforum-Sterbehilfe.html.
- Bundesverfassungsgericht (2020). "Leitsätze Zum Urteil des Zweiten Senats vom 26. Februar 2020", www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/DE/2020/02/rs20200226\_2bvr234715.html.
- Canadian Association of MAiD Assessors and Providers (2019). "Bringing up medical assistance in dying (MAiD) as a clinical care option", https://camapcanada.ca/wp-content/uploads/2022/02/Bringing-up-MAiD.pdf.
- CCNE (2022). Questions éthiques relatives aux situations de fin de vie: autonomie et solidarité. Avis 139 Comité consultatif national d'éthique pour les sciences de la vie et de la santé. English version available online: https://www.ccne-ethique.fr/sites/default/files/2023-01/Opinion%20139\_0.pdf.
- Cecchi, Rossana et al. (2024). "Medically assisted suicide in Italy: recent legal developments on a controversial topic", pp. 77–81 I Medicine, Science, and the Law Vol. 64, No. 1.
- Coelho, Ramona et al. (2023). "The realities of medical assistance in dying in Canada", pp. 871–8 in *Palliative & Supportive Care*, Vol. 21, No. 5. https://www.cambridge.org/core/services/aop-cambridge-core/content/view/3105E6A45E04DFA8602D54DF91A2F568/S1478951523001025a.pdf/the-realities-of-medical-assistance-in-dying-in-canada.pdf.

Smer 2024:4 References

Comisión de Salud (2023). Dictamen de la comisión de salud de iniciativas con proyecto de decreto que reforma diversas disposiciones de la ley general de salud en materia de muerte digna sin dolor, Camera de Disputados LXV Legislatura.

- Commission fédérale de contrôle et d'évaluation de l'euthanasie (2022). Commission fédérale de contrôle et d'évaluation de l'euthanasie: Dixième rapport aux chambres législatives (années 2020–2021).
  - https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/10\_rapport-euthanasie\_2020-2021-fr.pdf.
- Commission fédérale de contrôle et d'évaluation de l'euthanasie (2023). "Communiqué de presse de la commission fédérale de contrôle et d'évaluation de l'euthanasie: chiffres de l'année 2022", 17 February.
  - https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/cfcee-communiquepresse20230217-chiffreseuthanasie-2022.pdf.
- Commission fédérale de contrôle et d'évaluation de l'euthanasie (2024). "Communiqué de presse de la commission fédérale de contrôle et d'évaluation de l'euthanasie: chiffres de l'année 2023", 27 February.
  - https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/cfcee-communiquepresse20240227-chiffreseuthanasie-2023.pdf.
- Conseil économique, social et environnemental (2023). Rapport de la Convention Citoyenne sur la fin de vie, www.lecese.fr/convention-citoyenne-sur-la-fin-de-vie
- Cook, Michael (2023). "Colombian euthanasia cases rise steeply", Bioedge: Bioethics News from Around the World, 14 February, https://bioedge.org/end-of-life-issues/assisted dying/colombian-euthanasia-cases-rise-steeply.
- Corte Costituzionale (2019). Sentenza n. 242. https://www.cortecostituzionale.it/actionSchedaPronuncia.do? anno=2019&numero=242.

References Smer 2024:4

de Hert, M. et al. (2022). "Euthanasia of a person with a psychiatric disorder does not violate the European Convention on Human Rights (Mortier v. Belgium [no. 78017/17])", pp. 1–2 i European Psychiatry, Vol. 65, No. 1.

- de Hert, M. et al. (2023a). "The Belgian euthanasia law under scrutiny of the highest courts", pp. 1–2 in *The Lancet Regional Health Europe*, Vol. 24, January. https://www.thelancet.com/action/showPdf?pii=S2666-7762%2822%2900245-9.
- de Hert, M. et al. (2023b). "De belgische euthanasiewet doorstaat de mensenrechtelijke toets, behalve voor de a posterioricontrole (Mortier tegen België [No. 78017/17])", pp. 311–9 i *Tijdschrift voor geneeskunde en gezondheidszorg*, Vol. 79, No. 4. https://tvgg.be/uploads/file/files/23.006.pdf.
- Det etiske råd (2023). *Det etiske råds udtalelse om dødshjælp*. https://etiskraad.dk/alle-udgivelser/aktiv-doedshjaelp-og-doeende/udtalelse-om-doedshjaelp-.
- Dignitas (2023). "Accompanied suicides per year and country of residence". http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahrwohnsitz-1998-2022.pdf.
- Dirección de servicios de investigación y análisis, subdirección de análisis de política interior (2019). La eutanasia en México: Marco Teórico Conceptual, Marco Jurídico, Iniciativas presentadas, Derecho Comparado: Internacional y Local Estadísticas y Opiniones Especializadas, Cámara de Diputados LXIV Legislatura. https://www.diputados.gob.mx/sedia/sia/spi/SAPI-ISS-08-19.pdf.
- Downie, J. & Schüklenk, U. (2021). "Social determinants of health and slippery slopes in assisted dying debates: lessons from Canada", pp. 662–9 i *Journal of Medical Ethics*, Vol. 47. https://jme.bmj.com/content/medethics/47/10/662.full.pdf.
- European Court of Human Rights (2022). "Mortier v Belgium 7801/17". Judgment 4.10.2022. https://hudoc.echr.coe.int/fre?i=002-13802.

Smer 2024:4 References

European Court of Human Rights (2023). "End of life and the European Convention on Human Rights: Right to life and right to respect for private life". Factsheet: End of Life and the ECHR.

- https://www.echr.coe.int/documents/d/echr/fs\_euthanasia\_eng.
- Franceinfo (2024). "Aide à mourir soins palliatifs 'maisons d'accompagnement'... Que contient le projet de loi sur la fin de vie présenté en Conseil des ministres? 10 April. https://www.francetvinfo.fr/societe/euthanasie/aide-a-mourir-soins-palliatifs-maisons-d-accompagnement-que-contient-le-projet-de-loi-sur-la-fin-de-vie-presente-en-conseil-desministres 6477941.html.
- Government of Canada (2024). "Canada's medical assistance in dying (MAiD) law", https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html#s1-2.
- Government of Jersey (2024). "Assisted dying in Jersey". https://www.gov.je/Caring/AssistedDying/pages/assisteddying. aspx.
- Government of the Netherlands (n.d.). "Euthanasia and newborn infants".
  - https://www.government.nl/topics/euthanasia/euthanasia-and-newborn-infants.
- Health and Social Care Committee (2024). Assisted Dying/Assisted Suicide: Second Report of Session 2023–24. House of Commons. https://committees.parliament.uk/publications/43582/documents/216484/default.
- Health Canada (2023). Fourth Annual Report on Medical Assistance in Dying in Canada 2022.
- High Court of New Zealand Wellington (2015). "Seales v Attorney-General", https://nz.vlex.com/vid/seales-v-attorney-general-793576089.
- House of Lords (2005). Assisted Dying for the Terminally Ill Bill, Vol. 1: Report, Select Committee on the Assisted Dying for the Terminally Ill Bill. https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86iii.pdf.

References Smer 2024:4

Houses of the Oireachtas (2024). Joint Committee on Assisted Dying: Final Report of the Joint Committee on Assisted Dying. https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint \_committee\_on\_assisted\_dying/reports/2024/2024-03-20\_final-report-of-the-joint-committee-on-assisted-dying\_en.pdf.

- Jackson, Patrick (2024). "Ecuador becomes second Latin American state to decriminalise euthanasia", BBC 8 February. https://www.bbc.com/news/world-latin-america-68236545.
- Kozlov, E. et al. (2022). "Aggregating 23 years of data on medical aid in dying in the United States", pp. 3040–4 i *Journal of the American Geriatrics Society*, Vol. 70.
- Lääkäriliito (2024). "Eutanasiatutkimuksen ennakkotulokset: Enemmistö lääkäreistä on täysin tai osittain eutanasian laillistamisen kannalla, mutta kysymys jakaa edelleen lääkärikuntaa", 21 January. https://www.laakariliitto.fi/uutiset/ajankohtaista/eutanasiatutki muksen-ennakkotulokset-enemmisto-laakareista-on-taysin-taiosittain-eutanasian-laillistamisen-kannalla-mutta.
- Landry J.T. (2023). "Medical assistance in dying (MAiD) in Canada: Why Coelho and colleagues are incorrect to suggest the MAiD framework is in significant distress", pp. 1101–3 in *Palliative and Supportive Care*, Vol. 2, No. 6. https://www.cambridge.org/core/services/aop-cambridge-core/content/view/8A3BDF6652706ED7AD1199FD878E1FF D/S1478951523001384a.pdf/medical-assistance-in-dying-maid-in-canada-why-coelho-and-colleagues-are-incorrect-to-suggest-the-maid-framework-is-in-significant-distress.pdf.
- Le Monde (2024). "Fin de vie: Emmanuel Macron annonce pour avril un projet de loi prévoyant une 'aide à mourir' sous 'conditions strictes'", *Le Monde*, 10 March. https://www.lemonde.fr/societe/article/2024/03/10/fin-de-vie-emmanuel-macron-annonce-pour-avril-un-projet-de-loi-prevoyant-une-aide-a-mourir-sous-conditions-strictes 6221208 3224.html.
- Lewy, Guenter (2011). "Assisted Suicide in Switzerland", Chapter 4 in Assisted Death in Europe and America: Four regimes and their lessons, Oxford University Press.

Smer 2024:4 References

Lundy, Sharon (2015). "Judge rejects Lecretia Seales' right-to-die plea", Radio New Zealand, 5 June, https://www.rnz.co.nz/news/national/275512/judge-rejects-lecretia-seales'-right-to-die-plea.

- Mercopress (2022). "Uruguay's Lower House passes Euthanasia Bill", 7 October.
  - https://en.mercopress.com/2022/10/07/uruguay-s-lower-house-passes-assisted dying-bill.
- Ministerio de la Presidencia, Justicia y Relaciones con las Cortes (2021). Ley Orgánica 3/2021, de 24 de marzo, de regulación de la euthanasia,
  - https://www.boe.es/boe/dias/2021/03/25/pdfs/BOE-A-2021-4628.pdf.
- Ministerio de salud y proteccion social (2018). Resolucion numero 00000825 de 2018 Por medio de la cual se reglamenta el procedimiento para hacer efectivo el derecho a morir con dignidad de los niños, niñas y adolescentes, https://www.alcaldiabogota.gov.co/sisjur/normas/Norma1.jsp? dt=S&i=75844.
- Ministerio de Sanidad (2021). *Manual de buenas prácticas en eutanasia*, Ministerio de Sanidad, Madrid, https://www.sanidad.gob.es/eutanasia/docs/Manual\_BBPP\_eutanasia.pdf.
- Ministerio de Sanidad (2022). *Informe anual 2021 de la prestación de ayuda para morir*, https://www.sanidad.gob.es/eutanasia/docs/InformeAnualEutanasia 2021.pdf.
- Ministerio de Sanidad (2023). *Informe de evaluación anual* 2022 sobre la prestación de ayuda para morir, https://www.sanidad.gob.es/eutanasia/docs/InformeAnualEutanasia\_2022.pdf.
- Ministre de la Santé et de la Sécurité sociale (2023). Commission nationale de contrôle et d'évaluation de l'application de la loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide 2023: septième rapport à l'attention de la Chambre des Députés (années 2021 et 2022). https://sante.public.lu/fr/publications/r/rapporteuthanasie-2021-2022.html.

References Smer 2024:4

Ministry of Health (2022). Assisted dying service – Ngā Ratonga Mate Whakaahuru: Annual Report to the Minister of Health. https://www.health.govt.nz/system/files/documents/publications/registrar-assisted-dying-annual-report-jun22.pdf.

- Ministry of Health (2023). Assisted Dying Service Ngā Ratonga Mate Whakaahuru: Annual Report to the Minister of Health. https://www.health.govt.nz/publication/registrar-assisted-dying-annual-report-june-2023.
- Montagna, G. et al. (2023). "Long-term development of assisted suicide in Switzerland: Analysis of a 20-year experience (1999–2018)", Swiss Medical Weekly, Vol. 153, No. 3.
- Nelson, Mark & Acosta, Frank (2023). "Cuba quietly authorizes euthanasia", Reuters 22 December. https://www.reuters.com/world/americas/cuba-quietly-authorizes-assisted dying-2023-12-22.
- New Zealand Parliament (2020). "What is the End of Life Choice Act Referendum about?", https://www.parliament.nz/en/get-involved/features/what-is-the-end-of-life-choice-act-referendum-about.
- Nguyen, HQ et al. (2018). "Characterizing Kaiser Permanente Southern California's experience with the California End of Life Option Act in the first year of implementation", pp. 417–21 i *JAMA Internal Medicine*, Vol. 178, No. 3.
- Nuffield Bioethics Council (2023). "Exploring Public Views on Assisted Dying".

  https://www.nuffieldbioethics.org/publications/assisted-dying-project.
- Oregon Health Authority (2023). Oregon Death with Dignity Act: 2022 Data Summary, Public Health Division, Center for Health Statistics.

  https://www.oregon.gov/oha/PH/PROVIDERPARTNERRES OURCES/EVALUATIONRESEARCH/DEATHWITHDIG NITYACT/Documents/year25.pdf.

Smer 2024:4 References

Parliament of Canada (2023). Medical Assistance in Dying in Canada: Choices for Canadians. Report of the Special Joint Committee on Medical Assistance in Dying. https://www.parl.ca/Content/Committee/441/AMAD/Reports/RP12234766/amadrp02/amadrp02-e.pdf.

- Parliament of Victoria (2016). *Inquiry into End of Life Choices:* Final Report, 9 June 2016 (often referred to as the 'Victorian Committee Report').
- Preiss, Benjamin & Towell, Noel (2017). "Historic euthanasia laws pass Victoria's lower house after marathon sitting", *The Age*, 20 October.
  - https://www.theage.com.au/national/victoria/historic-euthanasia-laws-pass-victorias-lower-house-after-marathon-sitting-20171020-gz4q3u.html.
- Premier of Victoria (2017). "Voluntary assisted dying model established ahead of vote in Parliament". https://www.premier.vic.gov.au/voluntary-assisted-dying-model-established-ahead-vote-parliament.
- Ramírez Coronel, Maribel (2023). "7 de cada 10 mexicanos apoyan la eutanasia o muerte asistida", *El economista*, 1 June. https://www.eleconomista.com.mx/arteseideas/7-de-cada-10-mexicanos-apoyan-la-eutanasia-o-muerte-asistida-20230601-0058.html.
- Ramos-Pozón, S. et al. (2023). "Persons with mental disorders and assisted dying practices in Spain: An overview", pp. 1–6 in *International Journal of Law and Psychiatry*, Vol. 87. https://www.sciencedirect.com/science/article/pii/S0160252723 000146.
- Redelmeir, Donald A. (2021). "Association of socioeconomic status with medical assistance in dying: a case–control analysis", pp. 1–10 in *BMJ Open*, Vol. 11, No. 5. https://bmjopen.bmj.com/content/bmjopen/11/5/e043547.full. pdfA.
- Reilly, Catherine (2023). "Assisted dying: where does Irish medicine stand?", *The Medical Independent* 27 August. https://www.medicalindependent.ie/in-the-news/news-features/assisted-dying-where-does-irish-medicine-stand.

References Smer 2024:4

République française (2024). *Projet de loi relatif à l'accompagnement des malades et de la fin de vie*. https://www.legifrance.gouv.fr/dossierlegislatif/JORFDOLE00 0049401821.

- Rijksoverheid (2023). "Kabinet werkt aan regeling levensbeëindiging voor kinderen tot 12 jaar die ondraaglijk en uitzichtloos lijden".

  www.rijksoverheid.nl/actueel/nieuws/2023/04/14/kabinet-werkt-aan-regeling-levensbeeindiging-voor-kinderen-tot-12-jaar-die-ondraaglijk-en-uitzichtloos-lijden.
- RTE (2023). Regional Euthanasia Review Committees: Annual Report 2022. https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports.
- Safer Care Victoria (2019). Report of Operations 2018–19, Voluntary Dying Review Board. https://www.safercare.vic.gov.au/best-practice-improvement/publications/VADRB-2018-19.
- Scottish Parliament (2024). "Assisted Dying for Terminally Ill Adults (Scotland) Bill", 27 March. https://www.parliament.scot/bills-and-laws/bills/assisted-dying-for-terminally-ill-adults-scotland-bill/overview.
- Smer (Statens medicinsk-etiska råd, Swedish National Council on Medical Ethics) (2017). *Dödshjälp. En kunskapssammanställning*, Wolters Kluwer. https://smer.se/wp-content/uploads/2017/11/Smer-2017.2-D%C3%B6dshj%C3%A4lp-En-kunskapssammanst%C3%A4llning.pdf.

Smer 2024:4 References

Sosiaali- ja terveysministeriö (2021). Selvitys sääntelytarpeista jatyöryhmän näkemyksiälainsäädännön muuttamisesta: elämän loppuvaiheen hoitoa, itsemääräämisoikeutta,saattohoitoa ja eutanasiaa koskevanlainsäädäntötarpeen asiantuntijatyöryhmän loppuraportti, Helsinki. The document in Finnish: https://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/163 380/STM\_2021\_23\_R.pdf?sequence=1&isAllowed=y Press release in English: https://valtioneuvosto.fi/-/1271139/elamanloppuvaiheen-asiantuntijaryhma-esittaa-muutoksia-palliatiivisen-hoitoon-eutanasian-laillistamisesta-ei-loydettyyhteista-nakemysta?languageId=en US.

- State of Victoria, Department of Health and Human Services (2017). Ministerial Advisory Panel on Voluntary Assisted Dying: Final Report, 21 July (often referred to as the 'Victorian panel report').
- Statista 2024: "Total number of deaths in Luxembourg from 2008 to 2022", https://www.statista.com/statistics/594113/number-of-deaths-in-luxembourg.
- Statistics Netherlands (2019). "Vast majority do not fundamentally reject euthanasia", 19 November, www.cbs.nl/en-gb/news/2019/47/vast-majority-do-not-fundamentally-reject-euthanasia.
- Supreme Court of Canada (2015). *Carter v. Canada*. Supreme Court Judgment in Case 35591, 2015-02-06. https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do.
- Swissinfo.ch (2022). "Swiss doctors adopt tighter assisted suicide guidelines", www.swissinfo.ch/eng/swiss-doctors-adopt-tighter-assisted-suicide-guidelines/47610372.
- UK Parliament (2022). Assisted dying, POSTbrief 47. https://researchbriefings.files.parliament.uk/documents/POST-PB-0047/POST-PB-0047.pdf.
- Voluntary Assisted Dying Board Western Australia (2023). *Annual Report 2022–23*, Government of Western Australia, Department of Health.
  - https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2022-23.pdf.

References Smer 2024:4

Voluntary Assisted Dying Commission Tasmania (2023). The Voluntary Assisted Dying Commission Annual Report 2022–23, Tasmanian Government Department of Health. https://www.health.tas.gov.au/sites/default/files/2023-11/voluntary\_assisted\_dying\_commission\_annual\_report\_2022-23.pdf.

- Voluntary Assisted Dying Review Board Queensland (2023).

  Annual Report 2022–2023, Queensland Government,
  Queensland Health.
  https://www.health.qld.gov.au/\_\_data/assets/pdf\_file/0024/126
  1185/vad-annual-report-2022-23.pdf.
- Voluntary Assisted Dying Review Board South Australia (2023). Annual Report 2022–23, Government of South Australia, SA Health. https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/resources/voluntary+assisted+dying+annual+report.
- Voluntary Assisted Dying Review Board Victoria (2023). *Annual Report July 2022 to June 2023*, Safer Care Victoria. https://www.safercare.vic.gov.au/sites/default/files/2023-08/VADRB%20Annual%20Report%202022-23.pdf.
- Waller, Katherine et al. (2023). "Voluntary assisted dying in Australia: A comparative and critical analysis of state laws", pp. 1–45 i *University of New South Wales law journal*, Vol. 46, No. 4.
- Willmott, Lindy m.fl. (2016). "(Failed) voluntary euthanasia law reform in Australia: two decades of trends, models and politics", *University of New South Wales law journal*, Vol. 39, No. 1.
- ZonMw (2023). Vierde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding. https://open.overheid.nl/documenten/c59d186d-36c8-47e9-ab2e-762fef4f92d7/file.

## Consulted experts

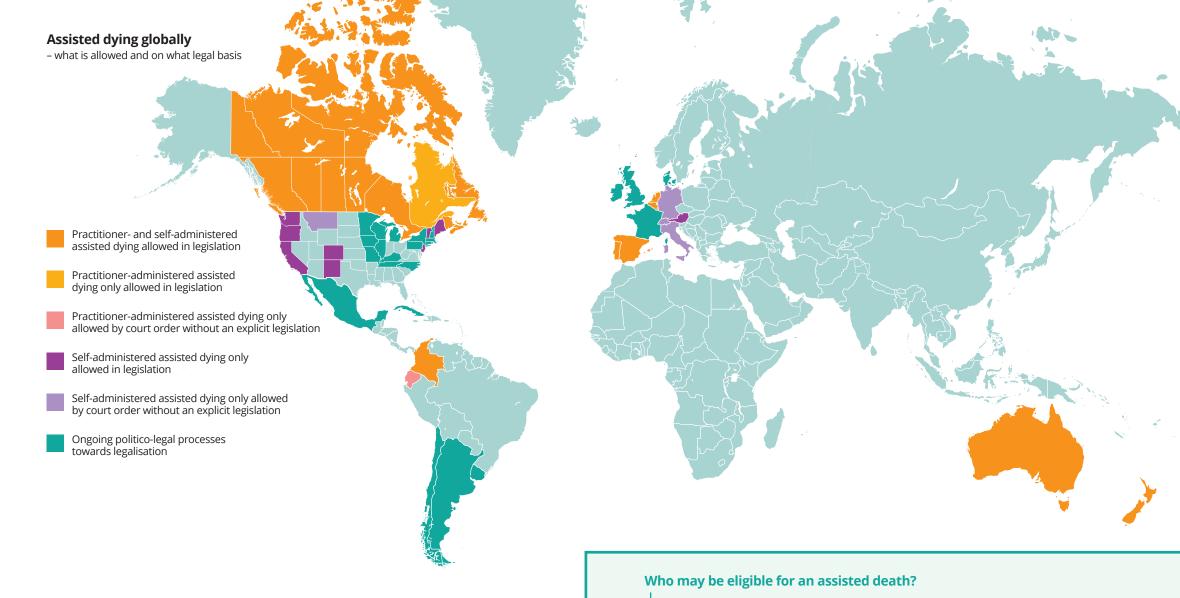
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## What form of assisted dying is allowed?



Patients choose between practitioner-administered and self-administered assisted dying

Belgium

Colombia

Canada 1

Cariaua

Luxembourg

Netherlands

New Zealand

Spain

Presumption in favour of self-administration with practitioner-administration conditional

Australia<sup>2</sup> Portugal Self-administered assisted dying only

Austria Germany

Jennai

Italy

Switzerland

US states

1 The province of Quebec only allows practitioner-administration.

2 The strength of the presumption varies with Victoria and South Australia being the most strict and New South Wales leaving the choice to the patient.

#### $oldsymbol{\perp}$

Patients with terminal illness

Australia

New Zealand

US states

As above plus patients with non-terminal somatic conditions causing them intolerable suffering that cannot be alleviated

Canada

Colombia

Ecuador

Italy

Portugal

As above plus patients with a mental illness causing them intolerable suffering that cannot be alleviated

Belgium

Netherlands

Switzerland

Luxembourg

(allowed in principle but is not practiced)

Spain

(allowed in principle but is not practiced)

Cormany

(allowed in principle, praxis unknown)

Nustria

(allowed in principle, praxis unknown)