



PALLIATIVE CARE AUSTRALIA

Experience internationally of the legalisation of assisted dying on the palliative care sector

FINAL REPORT

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LIST OF ABBREVIATIONS

AAHPM	American Academy of Hospice and Palliative Medicine
ACP	American College of Physicians
AMA	Australian Medical Association
AMA	American Medical Association
ANZSGM	Australian and New Zealand Society for Geriatric Medicine
ANZSPM	Australian and New Zealand Society of Palliative Medicine
APA	American Psychological Association
BVAS	Belgian Association of Doctors Syndicates
CAMAP	Canadian Association of MAiD Assessors and Providers
CFPC	College of Family Physicians of Canada
CHPCA	Canadian Hospice Palliative Care Association
CMA	Canadian Medical Association
CSHP	Canadian Society of Hospital Pharmacists
DWDA	Dying With Dignity Act
EAPC	European Association for Palliative Care
FPCF	Federation for Palliative Care Flanders
HPNA	Hospice and Palliative Nurses Association
IAHPC	International Association for Hospice and Palliative Care
MAiD	Medical Assistance in Dying
ONA	Oregon Nurses Association
PAS	Physician-Assisted Suicide
RACP	Royal Australasian College of Physicians.
RDMA	Royal Dutch Medical Association
SCEN	Support and Consultation regarding Euthanasia in the Netherlands
USA	United States of America
VAD	Voluntary Assisted Dying
WSHPCO	Washington State Hospice & Palliative Organization

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Executive summary

The review objective is to explore the international experience on the palliative care sector of the legalisation of voluntary assisted dying (VAD).

This review used the term ‘assisted dying’ as a generic term to encompass voluntary assisted dying, physician-assisted dying, physician-assisted suicide, and euthanasia.

The following jurisdictions are included within the scope of the review: Oregon (USA); Washington State (USA); the Netherlands; Belgium; Canada; and Quebec Province, Canada.

Legislative context

There are several differences between the legislative contexts for each of the in-scope jurisdictions, largely relating to access criteria including age, required diagnosis and advance requests. It is noteworthy that there have been amendments to these criteria in some jurisdictions.

Prior to accessing assisted dying legislation, all jurisdictions require that patients be informed of alternative treatment options, including palliative care.

The legislation in Canada, Quebec and Belgium actively promote the use of palliative options:

- The enactment of the Canadian *Criminal Code* provides for a parliamentary review of its provisions and of the state of palliative care in Canada to commence at the start of the fifth year (2021);
- The Quebec *Act Respecting End-of-Life Care* states that every person whose condition requires it has the right to receive end-of-life care, inclusive of palliative care and medical aid in dying; and
- Although not specified within *The Belgian Act on Euthanasia*, the integrated nature of the Belgian model of end-of-life care includes the option of eligible patients accessing euthanasia as part of the palliative course.^{1,2,3}

Delivery of palliative care services following the introduction of legislation

An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.

Where jurisdictional data is available, there are consistently high levels of patient involvement in palliative care services at the time of the death through assisted dying: 90.9% of Oregonians and 88.0% of patients in Washington State were enrolled in hospice care; and 70.9% of patients in Belgium (compared to 42.5% of those patients who died non-suddenly and who had not sought assisted dying).

1. Government of Canada (2018).
2. Government de Quebec (2018).
3. European Journal of Health Law (2008).

Health care practitioner involvement

One of the distinctions between assisted dying in the USA relative to other jurisdictions is that there tends to be a relatively low proportion of patients for whom a health care practitioner is present at the time of death. This is reflective of the legislative requirements of physician assisted suicide. Key approaches are outlined below:

- Oregon – In 2017, a prescribing physician was present at the time of death for 16% of patients, another health care practitioner for 13% of patients, with 71% of patients having no health care practitioner present at the time of death;
- Washington State – In 2017, the majority (51%) of patients had a health care practitioner other than their prescribing physician present at the time they ingested medication, whilst prescribing physicians were present in 8% of instances, no health care practitioners were present for 15% of patients, and 26% of instances were unknown;
- Canada – In 2017, 95% of medically assisted deaths in Canada involved physicians with nurse practitioners involved in 5% of cases;
- Quebec – Only registered medical practitioners (those registered with the Collège des Médecins du Québec CMQ) are permitted under the Quebec legislation to proceed with medically assisted dying and administer the injection;
- The Netherlands – GPs were involved in assisted dying in 85% of cases, with aged care specialists (3.5%), other hospital specialists (3%), and other physicians (8%) also providing assistance; and
- Belgium – Palliative care professionals provided assistance in 59.8% of instances. This is a distinctive feature of the Belgium model.

Place of death

The predominant location of death for assisted dying patients was in their own homes in all jurisdictions except Canada where most patients died in hospital. There were substantial differences between jurisdictions in the proportion of patients who died at home:

- Oregon – 90% died at home (2017);
- Washington State – 88% died at home (2017);
- Canada – 40% died at home and 42% in hospital (2017);
- Quebec – no data was available on location of death;
- The Netherlands – 80% of patients died at home (2016); and
- Belgium – 50% of patients died at home (2007).

Peak body perspectives

Different cultural and policy drivers appear to influence the approaches of peak bodies. In some jurisdictions the role of health care peak bodies, particularly medical peak bodies, has been instrumental as a driver for the implementation of assisted dying, whilst in others there has been strong resistance that has subsequently eroded with acceptance and either explicit or tacit support for the legislation. Key findings include:

- Oregon – In the years prior to the introduction of assisted dying in 1997, the issue was said to have divided the medical community. Most physicians were opposed to assisted dying. This level of opposition subsided and in the years that followed, opinion gradually shifted with a narrow majority (51%) of physicians in favour of the legislation in 2000. The Oregon Medical Association initially took a position against assisted dying.

This has shifted over time and the organisation now has a position of 'studied neutrality', essentially neither advocating nor opposing assisted dying. A similar shift in position occurred for the Oregon Hospice and Palliative Care Association.

- Washington State – As with Oregon, in Washington State the medical community was sharply polarised. In the lead-up to the legislative change, more physicians were opposed to assisted dying than in favour. The Washington State Medical Association also reflected these views, with explicit opposition to the introduction of the legislation. Subsequently, the Association has attenuated its stance – it neither condones nor opposes. It does however advocate end-of-life care planning with a focus on palliative care options. The positions of health service organisation within Washington State are inconsistent, with some allowing participation of physicians according to the individual’s ethical stance, whereas other organisations explicitly preclude the cooperation of employed physicians. The inconsistency is remarkable in that it extends to inconsistencies between health service campuses from the same parent entity.
- Canada/Quebec – The position of the Canadian Medical Association substantially evolved from strong opposition in the lead-up to the 2016 implementation of legislation on assisted dying to subsequent endorsement of the direction of policy. Indeed, the Association was involved in the development of recommendations for the practitioner process required to support legislative change and it introduced a 2017 policy on Medical Assistance in Dying which confirmed the legitimacy of physicians choosing to participate, or not, guided by their own ethical stance. It reiterated the autonomy of patients to choose and to ensure that vulnerable patients were supported with adequate safeguards. It also strongly emphasised the principle of non-abandonment. The Canadian Hospice Palliative Care Association’s focus of lobbying in the pre-implementation phase was on adequacy of resourcing of palliative care as the first order issue. In 2017, the Association developed a guidance document for health care providers involved in hospice and palliative care to support them to address patient requests for assisted dying, acknowledging that choice to pursue assisted dying ought to be upheld and respected.
- The Netherlands – The Royal Dutch Medical Association played a pivotal role in the facilitation of the introduction of assisted dying legislation. The legislation was planned against a backdrop of existing legal precedents in which exemption from prosecution for physician involvement in assisted dying was in place in advance of the legislation. The association took a lead role in the development of guidelines for its members to be fully informed on the approaches that were necessary to meet legislative and patient care objectives.
- Belgium – A steady transition in mindset occurred for the medical practitioner community and the palliative care sector in Belgium in response to moves to introduce assisted dying. Initial views were that such developments ran counter to principles of providing patients with highest quality health care, support and beneficence as the highest order priority. Over time, physicians who witnessed their palliative care patients seeking leave to access assisted dying elsewhere, began to question whether their opposition to assisted dying was compatible with serving their patients’ strong preference for autonomy in end-of-life decision-making.

Key learnings

Learnings from the implementation of assisted dying legislation in international jurisdictions reveal an increased focus on, and public policy attention towards, end-of-life care. It is noted that *the implementation of legislation may drive a stronger focus on upholding patient choice and autonomy, and there may be opportunities to introduce system improvements in palliative care, either as a direct or indirect consequence of the planned implementation of assisted dying*. In Belgium, there was an intentional drafting of parallel sets of legislation covering assisted dying and palliative care system resourcing. In other jurisdictions, there were indirect system improvements in palliative care that occurred alongside the introduction of assisted dying.

Key considerations for the palliative care sector include:

- *The integration of assisted dying as a component of end-of-life care services*. Integration may provide an opportunity for the promotion of quality of end-of-life care. In some jurisdictions there is evidence that after the introduction of assisted dying legislation, physicians have sought to improve their knowledge and understanding end-of-life care support services;

- *Access to palliative care.* Tracking of assisted dying patients indicates that a very high majority of patients have had access to palliative care. Analysis of the resourcing of the palliative care sector in the permissive Benelux countries has identified higher per capita access to palliative care relative to non-permissive European countries. Further, reviews of patient use of palliative care in advance of assisted dying found that 74% of Belgian assisted dying patients had accessed a palliative care service before end-of-life. This runs counter to the argument that assisted dying may be used by patients in circumstances where palliative care is not available;
- *Potential erosion of safeguards.* A common concern across various jurisdictions has been that access to assisted dying pathways is a 'slippery slope' whereby vulnerable people may be at risk should safeguards fail. Whilst it is noted there have been amendments to legislated eligibility criteria over time, there is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards;
- *Routinisation.* An identified risk is the lowering of thresholds by physicians to accept patient requests for assisted dying without active review of the potential for this request to mask other concerns (e.g. symptom control, uncertainty about the future and financial concerns). Whilst the trend for requests for assisted dying has increased over time in both the Netherlands and Belgium, there is no evidence this is due to reduced thresholds. Primary reasons postulated include wider acceptance by the medical community and increased rates of requests by some patient groups including those with life-limiting conditions beyond cancer;
- *Access to assisted dying pathways.* Noting the ability of practitioners and organisations to ethically oppose assisted dying, the palliative care sector will have a role in facilitating access to information or referrals to an alternative provider who is prepared to meet the patient's request;
- *Workforce capability.* The case volume of patients seen by physicians who provide assisted dying is relatively low in most jurisdictions. There tends to be a skewed distribution with a large volume of assisted dying patients receiving services from a small number of physicians. The majority of physicians with any involvement in assisted dying have very low case volumes;
- *Workforce support.* In the absence of structured support for the health care workforce, the introduction of assisted dying may have harmful effects for both the practitioners and patients involved. For practitioners, uncertainties associated with the introduction of assisted dying can be very challenging professionally and personally; and
- *Safety and quality.* It is understood that medical complications may occur relating to patients who may not initially die from lethal medication. This may have a direct impact on the palliative care sector, depending upon the setting in which assisted dying takes place.

In an environment where assisted dying has been legalised in one jurisdiction and other governments at the state/territory level are considering reform, there is a necessity for Palliative Care Australia, and other key stakeholders, to consider each of the above opportunities and risks in the formulation of key strategic directions as it relates to policy, guidelines and service development initiatives.

1. Background

1.1. CONTEXT

The *Voluntary Assisted Dying Act 2017* was passed by the Victorian Parliament on 29 November 2017. The Act has an 18-month implementation period and commences on 19 June 2019.

1.2. OBJECTIVE

This review seeks to explore the experience in international jurisdictions in which assisted dying legislation has been introduced and the influence on the palliative care sector.

The overall research question is '*What has been the experience internationally of the legalisation of assisted dying on the palliative care sector?*'.

The review has sought to address five specific areas of enquiry:

- What is the legislative context?
 - ▶ What is the practice that is allowed – euthanasia or assisted dying?
 - ▶ Does legislation also provide a right to receive palliative care?
- What has been the implication of legalising assisted dying on palliative care funding?
 - ▶ When assisted dying was legalised was an increase in palliative care promised? Was this provided?
 - ▶ How, if at all, was the experience different in those jurisdictions where legislation was introduced conferring the right to receive palliative care?
- Where is the assistance being provided and by whom?
 - ▶ Who is caring for patients as they approach their end-of-life?
 - ▶ Where are patients dying?
- What were the Position Statements of, and roles played by, relevant peak bodies prior to and following legalisation? How did these evolve over time, if at all?
- What are the opportunities and risks for the palliative care sector (and for Palliative Care Australia as a peak body) as assisted dying has been legalised in one jurisdiction and other governments at the state/territory level are considering reform?

1.3. STRUCTURE OF THE REPORT

The report is structured around addressing each of the five research questions:

- *Chapter 2* provides an outline of the underpinning legislation;
- *Chapter 3* provides an assessment of the resourcing trends;
- *Chapter 4* outlines the location and practitioner involvement in assisted dying;
- *Chapter 5* reviews the position statements of the peak bodies prior to and following legislative change; and
- *Chapter 6* provides an appraisal of the opportunities, issues and risks arising from assisted dying legislation with a focus on the implications for the palliative care sector.

Appendix 1 provides additional context by presenting an overview of recent legislative and policy developments across Australian jurisdictions.

1.4. TERMINOLOGY AND CONCEPTS

Assisted dying

Assisted dying is the term adopted by the Victorian Parliamentary Committee. Various forms of this term are used across jurisdictions, including *physician assisted dying or suicide*, *medically assisted dying* and *voluntary assisted dying* amongst others.

Voluntary Assisted Dying. The *Voluntary Assisted Dying Act 2017* defines “voluntary assisted dying” as “the administration of a voluntary assisted dying substance and includes steps reasonably related to such administration” where a “voluntary assisted dying substance” means “a poison or controlled substance or a drug of dependence specified in a voluntary assisted dying permit for the purpose of causing a person's death.”⁴

Physician Assisted Dying or Suicide is generally accepted as the voluntary termination of an individual's life by administration of a lethal substance with the direct or indirect assistance of a physician.

In some jurisdictions, such as Canada, assisted dying is referred to as Medical Assistance in Dying (MAiD).

Euthanasia. The Australian Human Rights Commission notes that the term euthanasia is often incorrectly characterised as representing one particular kind of practice when in fact it is an umbrella term for an array of practices that includes:

- *Passive voluntary euthanasia* – the withdrawal of withholding of medical treatment from a patient, at the patient's request, in order to end the patient's life;
- *Active Voluntary euthanasia* – involving medical intervention, at the patient's request, in order to end the patient's life;
- *Passive involuntary euthanasia* – involving withdrawal or withholding of medical treatment from a patient, not at the request of the patient, in order to end the patient's life; and
- *Active involuntary euthanasia* – involving medical intervention, not at the patient's request, in order to end the patient's life.⁵

In this review, the term assisted dying is used as a generic term to encompass voluntary assisted dying; physician-assisted dying or suicide; and euthanasia. Exceptions include discussions of legislative approaches that are specific to jurisdictions where the legislative terminology has been distinguished.

Palliative sedation therapy

Palliative sedation therapy is the monitored use of medications to lower a patient's awareness to provide relief of intractable symptoms that cannot be managed through usual measures, are distressing and result in considerable suffering if unrelieved.⁶

4. Voluntary Assisted Dying Act (2017).
5. Australian Human Rights Commission (2016).
6. ANZSM (2017)

End-of-life care

Palliative Care Australia describes end-of-life care as “care that combines the broad set of health and community services that care for the population at the end of their life. Quality end-of-life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community – working together to meet the needs of people requiring care”.⁷

Life-limiting illnesses

The term life-limiting illness is used to describe illnesses where it is expected that death will be a direct consequence of the specified illness. Such illnesses may include, but are not limited to cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease. The term person living with a life-limiting illness also incorporates the concept that people are actively living with such illnesses, often for long period of time, not simply dying.⁸

This term is frequently used in the paediatric palliative care setting.⁹

Life-threatening illnesses

Life-threatening illnesses are those where there is a possibility of a cure or remission, but where curative treatment may fail,¹⁰ such failure will lead to death.

Palliative care

Palliative care is “person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life”.¹¹ Palliative care involves the physical, emotional, psychosocial and spiritual care given by a multidisciplinary team to patients with life-limiting or life-threatening illnesses and their families.^{12,13} Because the term ‘life-threatening’ may imply acute situations such as trauma (for example, causing ‘life-threatening injuries’), the definition of these terms in the context of palliative care is warranted.

The term ‘palliative care’ describes an approach to care that improves the quality of life of people and their families who are facing the problems associated with a progressive illness. It does this by preventing and relieving suffering through early identification and assessment, by treating pain and other physical, psychosocial and spiritual problems and by addressing practical issues.

Palliative care is based on people’s needs rather than diagnosis or possible time to death and is delivered by a range of health and community providers. Palliative care can be provided at the same time as other treatment intended to reverse or resolve conditions.

7. Palliative Care Australia (2018a)

8. Palliative Care Australia (2018b)

9. Fraser et al. (2011).

10. The Association for Children’s Palliative Care (2009).

11. Palliative Care Australia (2018b)

12. Quest et al. (2009).

13. WHO (2018).

2. Legislative overview

This chapter provides an overview of the assisted dying and palliative care legislative contexts for each in-scope jurisdictions. There are several differences which have developed over time, largely relating to the access criteria, including age, required diagnosis and advance requests.

An overview of the Australian legislative context can be found in *Appendix 1*.

2.1. LEGISLATIVE CONTEXT

Table 2-1 summarises the legislative context of each of the six in-scope international jurisdictions. Each jurisdiction is discussed in greater detail below.

Table 2-1: Legislative context, per jurisdiction

JURISDICTION	LEGISLATIVE CONTEXT	YEAR OF INTRODUCTION	SCOPE OF PRACTICE
Oregon (USA)	The <i>Death with Dignity Act</i> permits terminally ill citizens within Oregon to end their lives through voluntary self-administration of lethal medications which have been expressly prescribed by a physician for that purpose.	1997	Assisted dying
Washington (USA)	The <i>Washington Death with Dignity Act</i> allows terminally ill adults seeking to end their life to request lethal doses of medication from medical and osteopathic physicians.	2009	Assisted dying
Netherlands	The <i>Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2002</i> imposes a set of strict conditions to be eligible for medically assisted dying.	2002	Assisted dying & Euthanasia
Belgium	Belgium legalised euthanasia through its <i>Act on Euthanasia 2002</i> which enables doctors to help patients to end their lives when they freely express a wish to die because they are suffering intractable and unbearable pain. The Belgian model of end-of-life care is termed 'integral palliative care' which embraces and embeds euthanasia as part of the palliative course.	2002	Euthanasia
Québec	The <i>Act Respecting End-of-Life Care</i> provides a framework for palliative care and medical aid in dying in the Province of Québec.	2014	Euthanasia
Canada	Medically assisted dying was made legal following amendment to its <i>Criminal Code</i> .	2016	Assisted dying & Euthanasia

2.1.1. Oregon (USA)

Introduced in 1997, the *Oregon Death with Dignity Act* (DWDA) allows Oregonians aged 18 years or older suffering from terminal disease who meet specific criteria to end their lives through the voluntary self-administration of a lethal dose of medications, expressly prescribed by a medical or osteopathic physician for that purpose.¹⁴ The Act defines terminally ill as an incurable and irreversible disease medically confirmed to produce death within six months.

2.1.2. Washington (USA)

The Washington State DWDA became law on March 5, 2009.¹⁵ The law allows terminally ill adult Washington residents, seeking to end their lives in a humane and dignified manner to request lethal doses of medication from a medical or osteopathic physician.¹⁶ Terminally ill patients requesting the medication must have an estimated six months or less to live.¹⁷

14. Oregon Health Authority (2018a).

15. Washington State Department of Health (2018).

16. Ibid.

17. Ibid.

2.1.3. Canada

In February 2015, the Supreme Court of Canada ruled in *Carter v. Canada* that changes needed to be made to parts of the Criminal Code prohibiting medical assistance in dying in order to satisfy the Canadian Charter of Rights and Freedoms.¹⁸ Amendments were made in June 2016.¹⁹ The law allows for the:

- Administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or
- The prescribing or providing by a medical practitioner or nurse practitioner of a substance to an eligible adult Canadian, at their request, so that they may self-administer the substance and in doing so cause their own death.²⁰

The Canadian law does not explicitly state that the patient needs to be a Canadian citizen. Instead it stipulates that patients must be eligible for health services funded by the federal government, or province or territory, and that generally visitors to Canada are not eligible for medical assistance in dying.²¹

The Canadian law states that the patient must be at least 18 years of age and be at a point where their natural death has become *reasonably foreseeable*, however Canadian federal law does not require a specific prognosis as to how long the patient has left to live.²² Further, patients do not need to have a fatal or terminal condition to be eligible for medical assistance in dying.²³

The legislation tasked the Minister of Health and Justice to initiate independent reviews of issues relating to requests by the following patient groups and circumstances since the enactment of the legislation:

- *Mature minors*: Whether mature minors (under the age of 18) should have access to medical assistance in dying;
- *Advance requests*: Whether access to medical assistance in dying should be available through requests made by competent individuals in advance of loss of capacity; and
- *Mental illness is the sole underlying medical condition*: Whether access to medical assistance in dying for individuals whose sole underlying medical condition is a mental illness should be more restrictive, retain the status quo, or be made more permissive and, if becoming more permissive, under what conditions to allow access.²⁴

In December 2016, the Government asked the Canadian Council of Academies (The Council) to conduct an independent review on these issues. The Council subsequently appointed an Expert Panel to conduct the review. The Expert Panel is in the process of assessing the evidence available on the three issues and will release the results of its independent review between September and November 2018. The Government is required to report back to Parliament by December 2018.²⁵

While federal legislation establishes the eligibility criteria and safeguards related to the lawful provision of medical assistance in dying in Canada, it is provincial and territorial governments that are primarily responsible for the delivery of health care services and for law enforcement across the country.²⁶

18. Government of Canada (2018).

19. Government of Canada (2016).

20. Ibid.

21. Ibid.

22. Ibid.

23. Ibid.

24. Dalhousie Health Law Institute.

25. Ibid.

26. Health Canada (2017).

2.1.4. Quebec Province

On December 10, 2015, Quebec declared itself in favour of medical aid in dying, following the Supreme Court ruling in *Carter v. Canada*. The *Quebec Act Respecting End-of-Life Care* was subsequently adopted.²⁷ The Act establishes the rights of patients who are residents of Quebec, as well as the organization of, and a framework for, end-of-life care so that everyone may have access to quality care that is appropriate to their needs, including the prevention and the relief of suffering.²⁸

The law defines end-of-life care as palliative care and medical aid in dying, where medical aid in dying is care consisting of medication or substances administered by a doctor to a person of full age at the end of their life, at their request, in order to relieve suffering by death.²⁹

Key differences between the Canadian federal and Quebec provincial legislations include:

- Federal amendments to the Criminal Code allow both the administering of a substance to a person and the prescribing or providing of a substance to a person. Quebec law only permits administering of a substance; and
- At the federal level, both physicians and nurse practitioners can administer medical aid in dying. In Quebec, the act may be performed by physicians only.³⁰

2.1.5. Netherlands

Following 30 years of public and legal discussion in the Netherlands, the *Termination of life on request and assisted suicide Act* came into force in April 2002. Both euthanasia and physician assisted suicide are covered by the Act.

Euthanasia is defined as deliberately ending a person's life at the person's request.³¹ In physician assisted suicide, the person self-administers medication that is prescribed by a physician.³² Key requirements are that the request is voluntary and well-considered and that the patient's suffering is unbearable and without prospect of improvement. The Act does not require patients to be expected to die within a specified time frame.³³

The Act allows for minors to request euthanasia or physician assisted suicide from the age of twelve with the consent of the parents or guardian. Sixteen and seventeen-year-olds do not need parental consent, however their parents or guardian must be involved in the decision-making process.³⁴

The Act also allows for patients who are no longer able to express their wishes to request euthanasia or assisted suicide in the form of an advance care directive. A physician can perform euthanasia on a patient only if such a directive exists, if statutory care is taken and if, in the physician's opinion, the patient is experiencing unbearable suffering with no prospect of improvement.³⁵ Patients suffering in the early stages of dementia can also request euthanasia or physician assisted suicide for when they reach a more advanced stage in their illness.

2.1.6. Belgium

On May 28, 2002, the Belgian House of Representatives passed *The Belgian Act on Euthanasia of May 28th, 2002*.

27. Simard (2016).

28. Government du Quebec (2018).

29. Ibid.

30. Ibid.

31. Regional Euthanasia Review Committee.

32. Ibid.

33. Buiting et al. (2009).

34. Government of the Netherlands (2016).

35. Ibid.

The legislation came into force on September 23, 2002 and defines euthanasia as the act of intentionally terminating the life of an adult or an emancipated minor by someone other than the person concerned, at the latter's request.³⁶

If the patient requesting euthanasia is not expected to die in the near future, they can still meet the criteria for euthanasia, so long as it is proven that the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident.³⁷

In cases where the patient is no longer able to express their wishes, the patient can draw up an advance care directive instructing a physician to perform euthanasia if the physician ensures that:

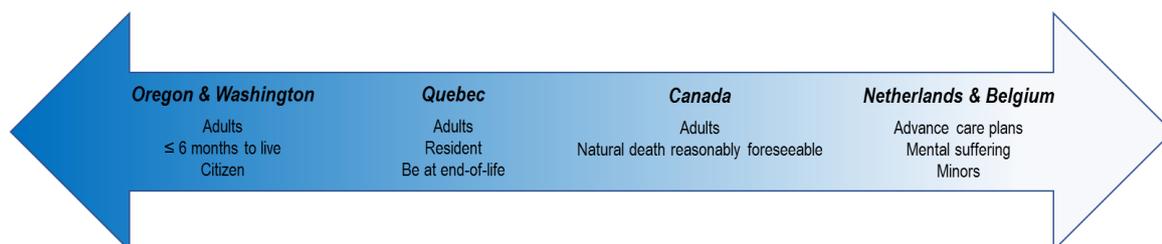
- The patient suffers from a serious and incurable disorder, caused by an illness or accident;
- The patient is no longer conscious; and
- This condition is irreversible given the current state of medical science.³⁸

In February 2014, an amendment was made to the Act allowing non-emancipated capable minors of any age to request euthanasia with the consent of their parents or guardian.³⁹

2.1.7. Summary of legislative context

Figure 2-1 places each of the in-scope jurisdictions on a spectrum of legislative requirement. The Oregon and Washington DWDAs have stricter legislative criteria for accessing assisted dying compared with the Netherlands and Belgium.

Figure 2-1: Spectrum of legislative requirement



2.2. LEGISLATIVE REQUIREMENT FOR PALLIATIVE CARE

The legislative requirements for palliative care also differ between jurisdictions.

All the studied jurisdictions require that patients be informed of alternative treatment options, including palliative care, and once these options are known may the patient meet the criteria for assisted dying.

Canada, Quebec and Belgium are unique in that their legislation and model of care promote the use of palliative treatments:

- The enactment of the Canadian *Criminal Code* provides for a parliamentary review of its provisions and of the state of palliative care in Canada to commence at the start of the fifth year (2021) following the day of the enactment;
- The Quebec *Act Respecting End-of-Life Care* is unique in that it states that every person whose condition requires it has the right to receive end-of-life care, including palliative care and medical aid in dying; and

36. European Journal of Health Law (2003).

37. Ibid.

38. Ibid.

39. Jones et al. (2017).

- Although not specified within *The Belgian Act on Euthanasia*, the integrated nature of the Belgian model of end-of-life care facilitates accessing euthanasia as an option within the palliative course.

2.2.1. Oregon & Washington (USA)

The Oregon and Washington DWDAs state that the patient must make an 'informed decision' meaning a decision by a qualified patient, to request and obtain a prescription to end his or her life in a humane and dignified manner, that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of, among other things, the feasible alternatives, including, but not limited to, comfort (palliative) care, hospice care and pain control.^{40,41}

In Oregon, legislation to improve access to palliative care through better coordination of care was enacted in 2015.⁴² There are three requirements of the Senate Bill:

- Establishment of an Advisory Council. This has subsequently occurred with the formation of the Palliative Care and Quality of Life Interdisciplinary Advisory Council within the Oregon Health Authority;
- Establishment of a website with relevant information on palliative care information. A variety of information sources is available, including on advanced care planning and how to communicate important health care decisions (e.g. Conversation Starter kit; How to choose a health care proxy and how to be a health care proxy; and How to talk to your doctor);⁴³
- Establishment of requirements for health facilities relating to palliative care.

2.2.2. Canada

Within the enactment of the Criminal Code, in establishing the eligibility criteria of medical assistance in dying, it is stipulated that a person may receive medical assistance in dying only if they meet set criteria, which includes:

'they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care'.⁴⁴

The enactment states a commitment by the Canadian government to work with provinces, territories and civil society to facilitate access to palliative and end-of-life care.⁴⁵

Further, the enactment provides for a parliamentary review of its provisions and of the state of palliative care in Canada to commence at the start of the fifth year (2021) following the day on which the Act received royal assent.⁴⁶

In response to the Supreme Court ruling in *Carter v. Canada*, the Canadian Federal government released the 2015 *Final Report of the External Panel on Options for a Legislative Response to Carter v. Canada (The Final Report)* which emphasises:

- The importance of palliative care in the context of physician-assisted dying;
- That a request for physician-assisted death cannot be truly voluntary if the option of proper palliative care is not available to alleviate a person's suffering; and
- The Parliament of Canada recognizes the importance of ensuring that all Canadians have access to high-quality palliative care, especially in the context of medical assistance in dying.

40. Oregon Health Authority.

41. Washington State Department of Health (2008).

42. Oregon Legislative Assembly (2015), Senate Bill 608

43. Oregon Health Authority, Palliative Care and Quality of Life Interdisciplinary Advisory Council. (2018) Accessed 24 October 2018, <https://www.oregon.gov/oha/HPA/DSI/Pages/Palliative-Care-Advisory-Council.aspx>

44. Government of Canada (2016).

45. Ibid.

46. Ibid.

In December 2017, in response to *The Final Report* and following amendments to the *Criminal Code*, the Canadian federal government made an amendment to *The Framework on Palliative Care in Canada Act*. This enactment provides for the development of a framework designed to support improved access for Canadians to palliative care.

The enactment states that, the Minister of Health must, in consultation with the representatives of the provincial and territorial governments responsible for health, as well as with palliative care providers, develop a framework designed to support improved access for Canadians to palliative care – provided through hospitals, home care, long-term care facilities and residential hospices – that, among other things:

- Defines palliative care;
- Identifies the palliative care training and education needs of health care providers as well as other caregivers;
- Identifies measures to support palliative care providers;
- Promotes research and the collection of data on palliative care;
- Identifies measures to facilitate a consistent access to palliative care across Canada;
- Takes into consideration existing palliative care frameworks, strategies and best practices; and
- Evaluates the advisability of re-establishing the Department of Health's Secretariat on Palliative and End-of-Life Care.⁴⁷

The Minister of Health must then prepare a report setting out the framework on palliative care.⁴⁸

2.2.3. Quebec Province

The Quebec *Respecting End-of-Life Care Act* is unique in that it covers the whole of end-of-life care, inclusive of medical aid in dying and palliative care. The Act states that:

'Every person whose condition requires it has the right to receive end-of-life care required by their state of health and to have access to quality care in accordance with their needs, particularly to prevent and relieve their suffering.'⁴⁹

Except as otherwise provided by law, a person of full age who is capable of giving consent to care may, at any time, refuse to receive life-sustaining care or withdraw consent of such care. In addition, a minor of 14 years of age or over, and in the case of a minor or a person of full age who is incapable of giving consent, the person who may give consent to care on their behalf may also make such a decision.

Every institution must adopt a policy on end-of-life care and ensure that it is provided to the persons requiring it in continuity and complementarity with any other care that is or has been provided to them. For this purpose, an institution must, among other things, establish measures to promote a multi-disciplinary approach by health and social services professionals and the collaboration of the various other resources concerned who provide services to its users.⁵⁰

2.2.4. Netherlands

Whilst a '*palliative filter*' (a compulsory prior palliative consultation) was debated, it was not adopted because of strong political pressure and the risk of passing the bill again through the senate. In order to meet the due criteria and avoid prosecution, the physician and the patient must together conclude that there is no reasonable alternative in the patient's situation. If there are alternative ways of ending or considerably reducing the patient's suffering, these must be given preference.⁵¹

47. Government of Canada (2017).

48. Ibid.

49. Government du Quebec (2016).

50. Ibid.

51. Regional Euthanasia Review Committees (2016).

2.2.5. Belgium

The Belgian Act stipulates that, without prejudice to any additional conditions imposed by the physician on his/her own action, before carrying out euthanasia he/she must in each case:

‘Inform the patient about his/her health condition and life expectancy, discuss with the patient his/her request for euthanasia and the possible therapeutic and palliative courses of action and their consequences. Together with the patient, the physician must come to the belief that there is no reasonable alternative to the patient’s situation and that the patient’s request is completely voluntary’.⁵²

The Belgian model of end-of-life care is termed ‘integral palliative care’ which embraces and embeds euthanasia as a component part.⁵³ The integral model has been available since introduction of the legislative framework in 2002. Training programs for physicians were gradually rolled out across the different regions of Belgium to adapt the content and quality of end-of-life care to the framework.⁵⁴

52. European Journal of Health Law (2003).

53. European Institute of Bioethics (2015).

54. Ibid.

3. Impact on palliative care services

The following outlines the trajectories of the palliative care sector in each of the in-scope jurisdictions following the introduction of assisted dying legislation. Comparisons to neighbouring countries and states that have not introduced the legislation have been made where data is available.

The availability and the reliability of data and literature varies across the jurisdictions. Accordingly, a consistent approach to tracking the trajectories of the palliative care sectors was not possible.

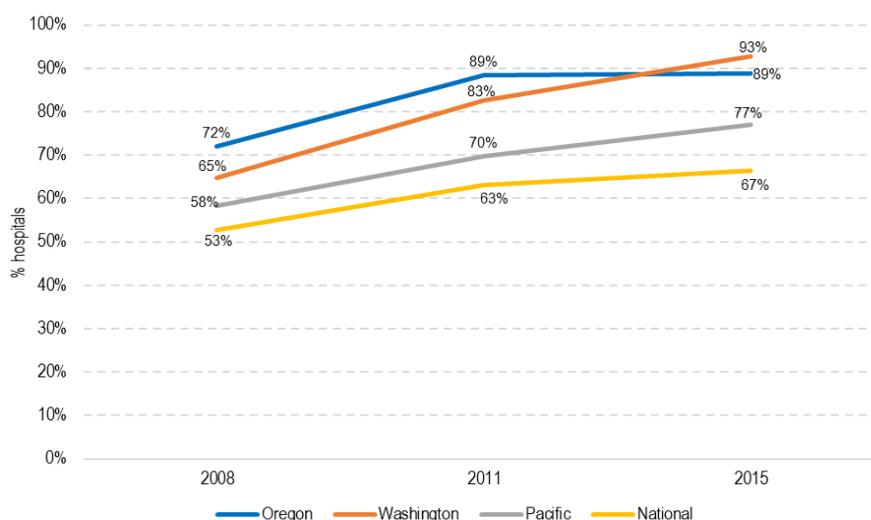
3.1.1. Oregon & Washington (USA)

Since the introduction of assisted dying legislation in 2009, Washington State saw an increase in the proportion of hospitals with a palliative care team, with an above regional and national growth rate. Conversely, since 2011, Oregon has seen a flattening in growth of the proportion of hospitals with a palliative care team, with a below regional however an above national growth rate. In 2015, both Washington State and Oregon have an above regional and national proportion of hospitals with a palliative care team.

Findings from the *2015 State-By-State Report Card on Access to Palliative Care* indicate that approximately 93% of all hospitals in Washington State and 89% of all hospitals in Oregon have a palliative care team.^{55,56} This is high compared to the wider Pacific Coast region (77%) and the nation (67%).⁵⁷

Between 2008 and 2015, Washington State saw the greatest increase in the proportion of hospitals with a palliative care team (28%), followed by the Pacific Coast (19%) and Oregon (17%) (Figure 3-1). The national increase in the proportion of palliative care teams was comparatively lower (14%).

Figure 3-1: Percentage of hospitals reporting a palliative care team, 2011 - 2015



55. Total palliative care programs divided by the total number of hospitals.

56. Morrison et al. (2015).

57. Ibid.

3.1.2. Canada & Quebec Province

Following the introduction of the legislation on assisted dying, the Canadian Federal Government committed \$6 billion over 10 years for home and palliative care, a significant increase from the funding received in financial years 2014-15 to 2015-16 (Table 3-1). No direct federal funding was allocated to the sector in the 2017-18 budget.

Table 3-1: Canadian Federal Budget Statements/Funding for Palliative Care, 2013-14–2017-18⁵⁸

FINANCIAL YEAR	STATEMENT/FUNDING
2017-2018	\$6 billion over 10 years for home and palliative care. \$184.6 million over 5 years for first-nation Canadians for home and palliative care.
June 2016	<i>Medically assisted dying was made legal following amendment to its Criminal Code.</i>
2016-2017	<i>“The Government is committed to working in partnership with provinces and territories to negotiate a new multi-year health accord that will improve health care in Canada and boost health outcomes for all Canadians. The Minister of Health has begun discussions with her provincial and territorial counterparts to enhance the affordability and accessibility of prescription drugs, improve access to home and palliative care and mental health services, and support pan-Canadian innovation in the delivery of health services.”</i>
2015-2016	<i>“The Government has heard from health stakeholders, such as the Health Charities Coalition of Canada, that the existing program parameters do not reflect the financial realities and hardships associated with caring for a dying family member. That is why the Government proposes to invest up to \$37 million annually to extend the duration of Compassionate Care Benefits from the current six weeks to six months, as of January 2016.”</i>
February 2015	<i>The Supreme Court of Canada ruled in Carter v. Canada that changes needed to be made to parts of the Criminal Code prohibiting medical assistance in dying in order to satisfy the Canadian Charter of Rights and Freedoms.</i>
2014-2015	\$1 million
2013-2014	\$1 million

This increase in funding coincides with a significant population profile shift. For the first time since the Canadian Confederation, the proportion of older people (aged ≥65 years) exceeds the proportion of youth and children (≤14 years).⁵⁹ It is projected that by 2031, approximately 23 per cent of Canadians will be aged 65 years and over.⁶⁰

Since the legislation came into force, Canadian media coverage on assisted dying and palliative care has reported anecdotal evidence that in jurisdictions where assisted dying has become legal, there has been less of an incentive to develop palliative care.⁶¹ Some coverage has gone on to report that a number of patients with limited access to palliative care feel that assisted dying is their only option.⁶² There is no evidence in the literature supporting these claims.

3.1.3. The Netherlands & Belgium

In 2002, when assisted dying was legislated in the Netherlands and Belgium, a frequently expressed concern was that its introduction could stunt the development of the palliative care sector and erode its culture of competent and compassionate care.⁶³ Evidence to support this concern has not been found in the literature.

A 2014 study found that, following the legalisation of assisted dying in 2002, Belgium’s expenditure for palliative care increased by an annual rate of 10%.

No expenditure data is currently available for the Netherlands.

58. Government of Canada (2013 – 2017)

59. Statistics Canada (2009).

60. Ibid.

61. Tibbetts (2013).

62. Stevenson (2018).

63. Bernheim et al. (2014).

In addition, the study found that in 2005, the palliative care sector in the Netherlands and Belgium was almost on a par with the United Kingdom and ahead of the other countries without the legislation including Spain, France and Germany.⁶⁴ Similar conclusions were found in a later study which focused on the seven European countries with the highest development of palliative care, which includes the three assisted dying permissive and four non-permissive countries.⁶⁵

The rate of increase in the number of structural palliative care provisions among the comparison countries was the highest in the Netherlands and Luxembourg, while Belgium stayed on a par with the United Kingdom. The Belgian government expenditure for palliative care doubled between 2002 and 2011.⁶⁶

The study compares the structural service indicators for 2005 and 2012 from successive editions of the European Atlas of Palliative Care (EAPC). As provided by the latest edition of the EAPC, shown in Figure 3-2, circled in orange, Belgium has greater than sixteen palliative care services per one million population, and the Netherlands has between twelve and sixteen services per one million population.

Figure 3-2: Proportion of palliative care service per population, 2013



The literature acknowledges that continued monitoring of the palliative care sectors in both permissive and non-permissive countries is required to evaluate longer-term effects of the legislation.⁶⁷

64. Ibid.
65. Bernheim et al (2008).
66. Ibid.
67. Ibid.

4. Assisted dying service model

This chapter details the core components of the service model relating to health practitioner involvement in assisted dying and the location of death.

4.1. HEALTH CARE PRACTITIONER INVOLVEMENT

One of the distinctions between assisted dying in the USA relative to other jurisdictions is that there tends to be a relatively low proportion of patients for whom a health care practitioner is present at the time of death. This is reflective of the legislative requirements of physician assisted suicide. Key approaches are outlined below.

4.1.1. Oregon (USA)

The reporting of data on patients who died under the Oregon DWDA includes the profile of health care practitioners who were present at both the time when medication was ingested and the time of death. *Although DWDA was implemented in 1998, data on the practitioner profile was only reported by the Oregon Health Authority's data summaries from 2001 onwards.*

For the majority (62%) of patients, there was no data reported on the health care practitioner. Of the cases where data was reported, the prescribing physician was reported to be present at the time of medication ingestion for 24 out of 143 patients in 2017; there were also 24 patients for whom another health care practitioner (other than the prescribing physician) was present.

Table 4-1: Health care practitioner present when medication was ingested by patient, 2001 to 2017, Oregon

WHEN MEDICATION WAS INGESTED	2017		2001 -2016		TOTAL	
Prescribing physician	24	17%	163	15%	187	16%
Other practitioner, prescribing physician not present	24	17%	270	25%	294	24%
No practitioner	6	4%	91	9%	97	8%
Unknown	89	62%	538	51%	627	52%
Total	143	100%	1,062	100%	1,205	100%

In 2017, for the majority (71%) of patients there was no health care practitioner present at the time of death. For 16% of patients the prescribing physician was present and for 13% of patients, another health care practitioner other than the prescribing physician was present.

Table 4-2: Health care practitioner present at time of patient's death, 2001 to 2017, Oregon

AT TIME OF DEATH	2017		2001 -2016		TOTAL	
Prescribing physician	23	16%	149	14%	172	14%
Other practitioner, prescribing physician not present	19	13%	295	28%	314	26%
No practitioner	101	71%	595	56%	696	58%
Unknown	0	0%	23	2%	23	2%
Total	143	100%	1,062	100%	1,205	100%

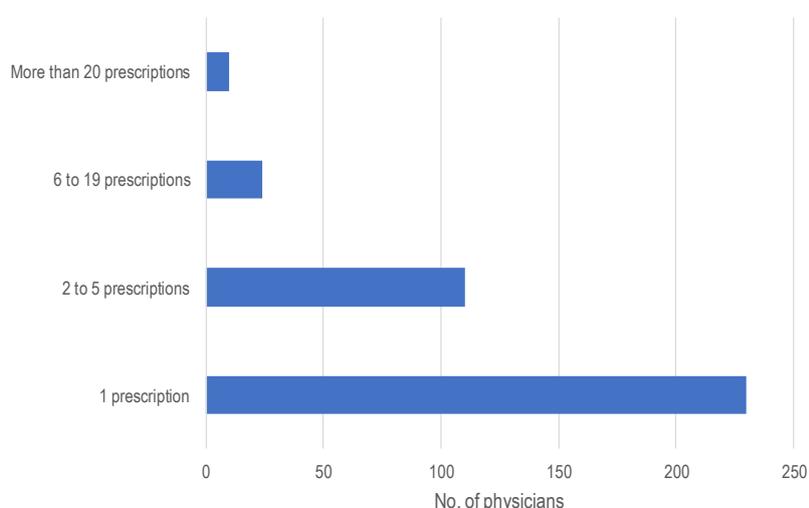
Table 4-3 summarises the numbers of DWDA prescription recipients, DWDA patient deaths and attending physicians. The per annum growth rate is lower for attending physicians (9% per annum) than the growth in number of prescription recipients (11% per annum) and patient deaths (10% per annum).

Table 4-3: Number of DWDA prescription recipients, DWDA deaths, and attending physicians, 1998-2017

YEAR	PRESCRIPTION RECIPIENTS	DWDA DEATHS	ATTENDING PHYSICIANS
1998	24	16	n/a
1999	33	27	n/a
2000	39	27	22
2001	44	21	33
2002	58	38	33
2003	68	42	42
2004	60	37	40
2005	65	38	40
2006	65	46	41
2007	85	49	46
2008	88	60	60
2009	95	59	64
2010	97	65	59
2011	114	71	62
2012	116	85	62
2013	121	73	62
2014	155	105	83
2015	218	135	106
2016	204	138	102
2017	218	143	92

Overall, the number of physicians who participate in DWDA is relatively small, with 374 physicians having written prescriptions since 2000 (*data on coding of prescribers was not available prior to 2000*). The distribution frequency shows that of the physicians involved in writing prescriptions, just under two thirds (62%) wrote only 1 prescription, where only a handful (3%) of physicians wrote more than 10 prescriptions.⁶⁸

Figure 4-1: Distribution frequency of no. of prescriptions and no. of physicians, Oregon, 2000 to 2017



The Oregon Health Authority also collects data on the median duration of the patient–physician relationship, which was just over three months (13 weeks) and ranged from 1 to 1,905 weeks.⁶⁹

68. Hedberg et al. (2017).

69. Ibid.

4.1.2. Washington (USA)

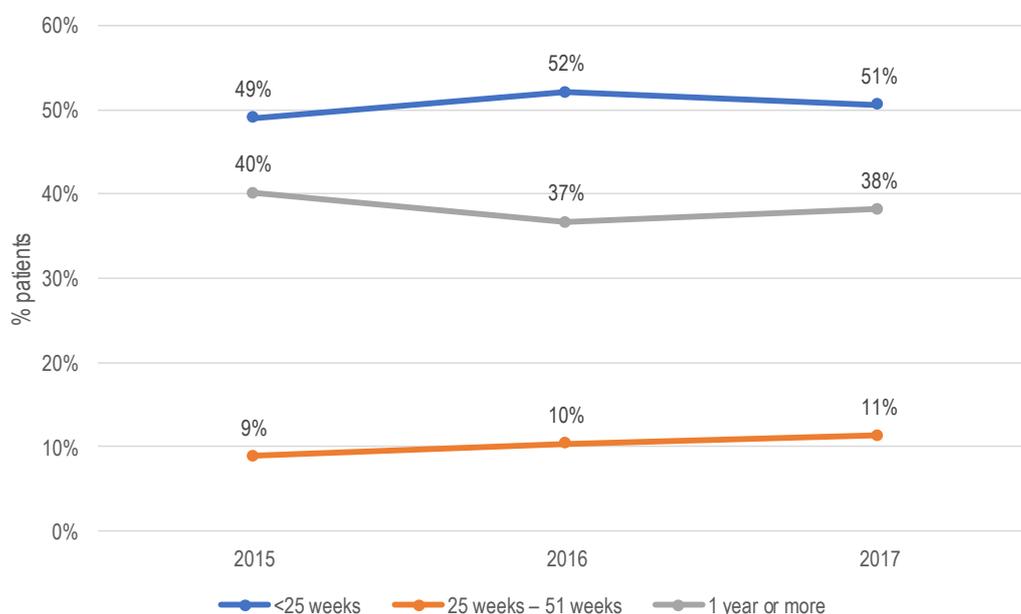
In 2017, the majority (51%) of patients had a practitioner other than their prescribing physician, present at the time they ingested medication under Washington State’s DWDA. Prescribing physicians were present in less than one in ten (8%) instances, no practitioners were present for 15% of patients and for over one quarter (26%) it was unknown whether and which type of practitioner was present.⁷⁰

Table 4-4: Health care practitioner present at time of patient’s ingestion of medicine, Washington State, 2015-2017

HEALTH CARE PROVIDER PRESENT	2017		2016		2015	
	No.	%	No.	%	No.	%
Prescribing physician	13	8%	17	9%	9	5%
Other practitioner, not prescribing physician	84	51%	99	51%	117	69%
No practitioner	24	15%	25	13%	23	14%
Unknown	43	26%	53	27%	20	12%
Total	164	100%	194	100%	169	100%

Washington State also collects data on duration of relationship between the patient and the prescribing practitioner, with the majority (51%) of patients’ relationship less than 6 months as compared to just over one third (38%) in excess of one year.⁷¹

Figure 4-2: Duration of patients' relationship with prescribing practitioner, Washington State, 2015 to 2017



70. Washington State Department of Health (2018b).

71. Ibid.

4.1.3. Canada

For the most recent period, Jul to Dec 2017, the overwhelming majority (94.9%) of medically assisted deaths in Canada involve physicians, whereas nurse practitioners were involved in 5.1% of cases.⁷²

Table 4-5: Medically assisted deaths by practitioner, Canada, Jan to Jun 2017

PROVIDER	JAN 1 TO JUN 30 2017		JUL 1 TO DEC 31 2017	
	No.	%	No.	%
Physician	837	95.7%	1,031	94.9%
Nurse Practitioner	38	4.3%	55	5.1%

Additionally, Canada Health advises that others who may help to provide medical assistance in dying include: pharmacists; family members or other people that a patient may ask to help; and health care practitioner who help physicians or nurse practitioners. It is noted that these people can assist in the process without criminal sanction.⁷³

4.1.4. Québec

Medically assisted dying has been described as an exceptional intervention requiring interdisciplinary involvement among the treating physician, the pharmacist, nurses and other members of the health care team. However, only registered medical practitioners (those registered with the Collège des Médecins du Québec CMQ) are permitted under the Quebec to proceed with medically assisted dying and administer the injection.⁷⁴ This contrasts with other provinces in Canada in which nurse practitioners may play a direct role.

A physician may refuse to proceed with a patient's request for medically assisted dying. There is an expectation under the legislation that the physician would make an appropriate referral to another physician.

4.1.5. Netherlands

In the majority of cases (84.8%), GPs act as the notifying physician in euthanasia cases in the Netherlands, with aged care specialists accounting for 3.5% and hospital-based specialists for 2.9%.⁷⁵ The 'other' category includes physicians associated with Dutch End-of-Life Clinic clinics as well as junior doctors. These physicians are often involved with more complex cases including those with a psychiatric disorder, dementia and frail elderly with multiple geriatric syndromes.

Table 4-6: Notifying physicians involved in euthanasia, The Netherlands, 2016

PROVIDER	NO.	%
General practitioner	5,167	84.8%
Elderly care specialist	216	3.5%
Specialist working in a hospital	179	2.9%
Registrar	43	0.7%
Other physician	486	8.0%
Total	6,091	100.0%

72. Health Canada (2018a).

73. Health Canada (2018b).

74. Simard (2016).

75. Regional Euthanasia Review Committees (2017).

4.1.6. Belgium

In Belgium, medical practitioners are involved in performance of euthanasia. The distinctive feature of the Belgian context is that there is a substantial role undertaken by palliative care professionals – in 59.8% of euthanasia deaths, palliative care professionals are involved in the decision-making process. In 21.1% of cases, the attending physician is part of the palliative care team.⁷⁶

4.2. LOCATION OF DEATH

The predominant location of death for assisted dying patients was in their own homes in all jurisdictions except Canada where most patients died in hospital.

4.2.1. Oregon (USA)

The overwhelming majority (90%) of DWDA patients died at home, with 9% dying in long-term, assisted living or a foster care facility in 2017. There were no patients who died in a hospital setting in 2017.⁷⁷

Table 4-7: Location of death of DWDA patients who died from ingesting a lethal dose of medication as of Jan 19 2018 by year, Oregon, 1998-2017

LOCATION	2017		1998-2016		TOTAL	
	No.	%	No.	%	No.	%
Home (patient, family of friend)	129	90%	1,052	93%	1,181	93%
Long-term care, assisted living or foster care facility	13	9%	55	5%	68	5%
Hospital	0	0%	4	0%	4	0%
Other	1	1%	15	1%	16	1%
Unknown	0	0%	6	1%	6	0%
Total	143	100%	1,132	100%	1,275	100%

The overwhelming majority (91%) of DWDA patients were reported to have been enrolled in hospice care at the time of death.⁷⁸

Table 4-8: Enrolment in hospice care, DWDA patients, 1998-2017, Oregon

ENROLMENT IN HOSPICE CARE	2017		1998-2016		TOTAL	
	No.	%	No.	%	No.	%
Enrolled	130	91%	989	90%	1,119	90%
Not enrolled	13	9%	109	10%	122	10%
Unknown	0	0%	34	-	34	0%
Total	143	100%	1,132	100%	1,275	100%

4.2.2. Washington (USA)

The predominant (88%) location of death of DWDA patients in Washington State in 2017 was home, increasing from 86% in 2015. Long-term care facilities accounted for 9%, with 3% unknown.⁷⁹

76. Dierickx (2018).

77. Oregon Health Authority (2018).

78. Ibid.

79. Washington State Department of Health (2018b).

Table 4-9: Location of death of DWDA patients, Washington State, 2015-2017

LOCATION	2017		2016		2015	
	No.	%	No.	%	No.	%
Home (patient, family, friend)	144	88%	169	87%	146	86%
Long-term care, assisted living or foster care facility	15	9%	14	7%	17	10%
Hospital	0	0%	0	0%	0	0%
Other	0	0%	3	2%	1	1%
Unknown	5	3%	8	4%	5	3%

The large majority (88%) of patients who participated in DWDA were enrolled in hospice care, 6% were not enrolled and for 5% enrolment status was unknown.⁸⁰

Table 4-10: Enrolment in hospice care, DWDA patients, Washington State, 2015-2017

ENROLMENT	2017		2016		2015	
	No.	%	No.	%	No.	%
Enrolled	145	88%	150	77%	138	82%
Not enrolled	10	6%	27	14%	19	11%
Unknown	9	5%	17	9%	12	7%

4.2.3. Canada

The predominant location of death for Canadian patients who sought assistance in dying was in hospital. In the most recent six-month period ending 31 December 2017, 43% of patients sought assisted dying in their own home, an increase from 40% in the preceding six months. The next most frequent location was hospital, with 41% in the most recent period, followed by long term care facilities/nursing homes (5%), hospice (3%) and other (8%).⁸¹

Table 4-11: Location of death for cases in which assistance in dying occurred, Canada, 2017⁸²

LOCATION	JAN TO JUN 2017		JUL TO DEC 2017	
	No.	%	No.	%
In hospital	368	42%	440	41%
Home	350	40%	470	43%
Long Term Care Facility or Nursing Home	78	9%	58	5%
Hospice	-	-	32	3%
Other: clinician office; facility; undisclosed	79	9%	86	8%
Total	875	100%	1,086	100.00%

4.2.4. Québec

Data was not available on location of death for patients seeking medical assistance in dying in Québec.

80. Ibid.

81. Health Canada (2017).

82. Excludes data from Quebec, Yukon, Northwest Territories, and Nunavut provinces.

4.2.5. Netherlands

Four out of five (80%) cases of termination of life on request involved patients who died at home.⁸³ Other categories were relatively low, with as few as 3% dying in a hospital setting.

Table 4-12: Location of death, termination of life on request and cases of assisted suicide, The Netherlands, 2016

LOCATION	NO.	%
Home	4,904	80%
Hospice	367	6%
Care home	300	5%
Nursing home	233	4%
Hospital	199	3%
Elsewhere ⁸⁴	99	2%
Total	6,102	100%

4.2.6. Belgium

A 2013 Belgian population-based survey was undertaken into the practices of euthanasia and assisted suicide.⁸⁵ The review team undertook a retrospective audit of death certificates in June to November 2007 and surveyed a stratified sample of 6,927 death certificates of people who died 'non-suddenly' in Flanders. A questionnaire was sent to attending physicians to review end-of-life decisions as well as palliative care involvement and patient characteristics. A response rate of 60.6% was obtained, yielding 3,751 deaths for review. Place of death was one of the patient-level characteristics obtained from the analysis of death certificates.

For physician-assisted deaths, the main location for place of death was a person's home (50%) followed by hospitals (42%). For a small proportion of people, a physician-assisted death occurred in a care home (4%) with 'other' locations accounting for 4%.

Table 4-13: Place of death, physician assisted deaths, Belgium

PLACE OF DEATH	%
At home	50%
Hospital	42%
Care home	4%
Other	4%
Total	100.0

Another important finding of the study was that palliative care services were involved in the end-of-life care of 71% of those who requested euthanasia as compared to less than half (43%) of those who died non-suddenly and who had not sought or requested euthanasia.⁸⁶

83. Regional Euthanasia Review Committees (2017).

84. 'Other/unknown' denotes retirement homes; assisted or supportive living; ambulatory setting; day program space; clinician's office; funeral home; hotel/motel; hospices (for Jan to Jun 2017); or, undisclosed.

85. Dierickx et al. (2018).

86. Ibid.

5. Peak body perspectives

This chapter considers the position of peak bodies in the lead up to the introduction of the legislation and how these positions evolved over time.

5.1.1. Oregon (USA)

The introduction of the DWDA in Oregon was not without controversy and at the time, in 1994, its passage was said to have divided the medical community.⁸⁷ In the ensuing five years, only modest attitudinal shift had occurred, with four out of five physicians reporting that they had *not* changed their views between 1994 and 1999.

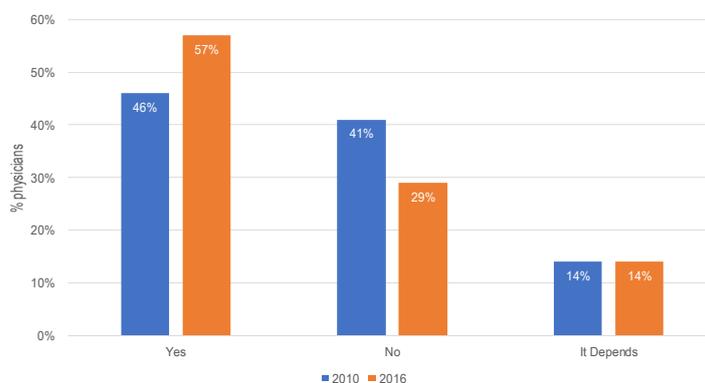
The survey of practising Oregon physicians by Ganzini et al. found that in 2000, just over one half (51%) of physicians supported the *Dying with Dignity Act*, around one third (32%) opposed it and 17% neither supported nor opposed the law. It found that 14% of physicians had become more willing to prescribe a medication for assisted suicide to a dying patient and that 8% had become less willing. One third of physicians reported that they would be prepared to prescribe a lethal medication, 20% were uncertain and just under one half (46%) were unwilling.⁸⁸

Irrespective of physicians' support or opposition to the *Dying with Dignity Act*, there was common support for the importance of improving care of the dying in Oregon:

- Just under one third (30%) of physicians stated that they had increased hospice referrals since 1994;
- One third perceived that hospice service availability for their patients had increased; and
- Over three quarters (76%) said they had endeavoured to improve their knowledge of management of pain medication in the treatment of patients with terminal illnesses.⁸⁹

More recent US-wide surveys of physicians' views of assisted dying have shown an increase in support since 2000. A 2016 survey of 7,500 US physicians by Medscape (a clinical news and training provider) reported 57% in favour of assisted dying, an increase from 46% in 2010, with opposition declining from 41% to 29% over the period.⁹⁰

Figure 5-1: Should physician assisted suicide or physician assisted dying be allowed for terminally ill patients?



This relatively high level of physician support was also found in another survey by MedPageToday which reported 61% of 604 physicians in favour.⁹¹

87. Ganzini (2001).

88. Ibid.

89. Ibid.

90. Reese (2016).

91. Roehr (2018).

Despite the apparent majority support for assisted dying amongst individual physicians, there has been resolute opposition from the main US provider organisations including the American Medical Association (AMA), the American College of Physicians (ACP) and the American Academy of Family Physicians.

The AMA Code of Medical Ethics Opinion 5.7 states:

Physician-assisted suicide occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide).

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in assisted suicide would ultimately cause more harm than good.

Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.

Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end-of-life. Physicians:

(a) Should not abandon a patient once it is determined that cure is impossible.

(b) Must respect patient autonomy.

(c) Must provide good communication and emotional support.

(d) Must provide appropriate comfort care and adequate pain control.⁹²

The most recent 2017 ACP Position Statement states:

The ACP affirms a professional responsibility to improve the care of dying patients and their families. The ACP does not support the legalization of physician-assisted suicide, the practice of which raises ethical, clinical, and other concerns. The ACP and its members, including those who might lawfully participate in the practice, should ensure that all patients can rely on high-quality care through to the end-of-life, with prevention or relief of suffering insofar as possible, a commitment to human dignity and management of pain and other symptoms, and support for families. Physicians and patients must continue to search together for answers to the challenges posed by living with serious illness before death.⁹³

At its 2018 annual meeting, the AMA maintained its staunch opposition to medically assisted dying, although delegates voted for the organisation to continue reviewing its guidance on the issue.⁹⁴

A number of US state-based medical societies have changed stance from active opposition to neutral, including the California Medical Association, the Colorado Medical Society, the Medical Society of the District of Columbia and the Maryland Medical Society.⁹⁵

Other organisations have reversed previous opposing positions and instead opted for a position of '**studied neutrality**'. This neutral position reflects a position that seeks to "recognise the diversity of views and foster discussion".⁹⁶

92. AMA (2018).

93. Sulmasy et al. (2017).

94. Bever (2018).

95. Span (2017).

96. Frye et al. (2016).

Peak organisations with a ‘studied neutrality’ position include:

- American Academy of Hospice and Palliative Medicine;
- American Medical Students Association;
- American Pharmaceutical Association;
- California Medical Association;
- Oncology Nursing Society;
- Oregon Health & Science University;
- Oregon Hospice and Palliative Care Association;
- Oregon Medical Association; and
- Task Force to Improve the Care of Terminally Ill Oregonians.^{97,98}

As a case in point, the approach taken by Taskforce to Improve the Care of Terminally Ill Oregonians was to strive to improve the access to palliative care for Oregonians and to ensure that providers were in a position to be informed about how to respond to patient requests for assisted dying and to concurrently ensure that patients’ palliative care needs were appropriately assessed and their physical, emotional and spiritual support needs addressed.⁹⁹

“These providers were challenged not only to ensure that palliative care was being fully implemented but also to learn how to evaluate such requests, to use them as opportunities to understand and respond to other dimensions of suffering, and to develop a way of working with such patients regardless of whether a particular physician supported or was opposed to physician-assisted suicide.”¹⁰⁰

The Oregon Hospice and Palliative Care Association has a neutral position on assisted dying:

“The Oregon Hospice and Palliative Care Association supports the rights of Oregonians to choose or not to choose any and all legal end-of-life options, and supports hospice and palliative care programs in development of their own policies around the *Oregon Death With Dignity Act* and *Physician-Assisted Death*.”¹⁰¹

The Association essentially presents the perspective that the policy position on assisted dying has been enacted through legislation and that the issue for its members is how to ensure that patients are supported in receiving optimal palliative care. It also seeks to ensure that patients who seek assisted dying are supported and not disadvantaged in accessing palliative care.

“It no longer matters whether physician-assisted dying should or should not be permitted. It is a legal option in Oregon. Oregonians need not choose *between* hospice and physician-aid in dying. Dying Oregonians can choose *both* from among the options on the end-of-life continuum of care.”

“A prescription for life-ending medication should not be the option of first choice for relieving fears or pain or symptoms of a terminal illness. A hospice should never deny a person its services because he or she has asked a doctor for a prescription, even when the hospice intends to exercise its right to not be involved.”

“Hospices are uniquely qualified to address the needs of the dying and the Oregon Hospice & Palliative Care Association strongly recommends that a person be enrolled in hospice for comfort care during the required waiting period, if they are not already a hospice patient.”¹⁰²

97. Quill et al. (2003).

98. Frye et al. (2016).

99. Quill et al. (2003).

100. Ibid.

101. Oregon Hospice & Palliative Care Association (2017).

102. Ibid.

Notwithstanding the apparent neutral position of the Oregon Hospice Association, Campbell and Cox argue that in practice, there are impediments that operate to limit hospice patients' participation in assisted dying.

“The vast majority of Oregon hospice programs set programmatic, professional, and moral boundaries to their involvement in physician-assisted deaths, and many of them do not participate in most or all features of implementing physician-assisted death under the Oregon law. Indeed, most Oregon hospice programs treat deaths attributable to physician-prescribed medications differently than other deaths that they attend.”¹⁰³

Frye and Stuart argue that while ‘studied neutrality’ may resolve the tendentious issue for organisations of political alignment, it may not offer practical support to health providers.¹⁰⁴ In the wake of the introduction of Oregon’s DWDA legislation, there is some evidence that for individual physicians they perceived a lack of professional and personal support and guidance.¹⁰⁵

The 2016 position of the American Academy of Hospice and Palliative Medicine (AAHPM) is one of pragmatic acknowledgement that assisted dying has become a reality in many states across the US, with one sixth of the US population residing in the states where assisted dying is legal. It concedes that its members hold varied and conflicting ethical positions on assisted dying. Rather than prescribing that its members abide with a singular policy position of the Academy, AAHPM considers that its members need to follow their own ethical stance, but still advocates that in any request for assisted dying its members should review the underlying source of the request. It emphasises that high quality palliative care can alleviate many sources of suffering but in spite of this, acknowledges that some patients may still seek to end their own life with the assistance of a physician. Palliative care is still held to be quite distinct from assisted dying.

Whilst AAHPM promotes a ‘studied neutrality’ position, it also gravitates to a conservative position on assisted dying, outlining policy reservations about the potential unintended consequences that may arise for the physician-patient relationship and professional integrity.

“Such a change [to assisted dying] risks unintended long-range consequences that may not yet be discernable, including effects on the relationship between medicine and society, the patient and physician, and the perceived or actual integrity of the medical profession.”¹⁰⁶

To meet the information needs of AAHPM members, an advisory brief sets out to describe the context and steps that physicians should consider taking to respond to patient requests for assisted dying. The advisory brief advocates the pursuit of palliative care as far as is feasible to alleviate a patient’s situation whilst also providing information and advice, in states where assisted dying is legal for physicians, to respond to an assisted dying request where this is the option of last resort.

“The emphasis of this guidance statement is to entreat those medical providers who care for patients with terminal disease to understand the complexity of the request for assisted death, to provide an educated systematic response, and to use the best practices of palliative care to alleviate the suffering of patients that triggers a desire to pursue PAD. A primary goal of the American Academy of Hospice and Palliative Medicine (AAHPM) is to promote the development, use, and availability of palliative care to relieve patient suffering and to enhance quality of life while upholding respect for patients' and families' values and goals.”¹⁰⁷

103. Campbell et al. (2010).

104. Frye et al. (2016).

105. Dobscha et al. (2004).

106. American Academy of Hospice and Palliative Medicine (2016) Statement on Physician-Assisted Dying, <http://aahpm.org/positions/pad> accessed 14 October 2018

107. American Academy of Hospice and Palliative Medicine (2018)

5.1.2. Washington (USA)

In the preceding years before the introduction of the DWDA in 2009, physicians' attitudes towards physician-assisted suicide in Washington State were divided. In a 1994 survey of 1,355 randomly selected physicians (with a 69% response rate), almost one half (48%) of physicians agreed with the statement that euthanasia is never ethically justified and fewer (42%) disagreed. Nonetheless, over one half (54%) of physicians considered that euthanasia should be legal in some situations, with only one third willing to actively enable physician-assisted dying.¹⁰⁸

Cohen et al. concluded from this survey that physicians' attitudes towards assisted suicide and euthanasia were 'sharply polarised' and that the wide public interest in the issue clearly indicated a need for improved care of terminally ill patients: "Whether assisted suicide and euthanasia have a role in the care of such patients remains an issue for further debate".¹⁰⁹

In the lead-up to the 2009 legislation, the Washington State Medical Association was opposed to the legislation enabling physician-assisted suicide.¹¹⁰ Subsequently, there appears to have been a shift in position. Although there is no explicit position statement in support of physician-assisted dying or even neutrality, it is apparent that there is no longer explicit opposition. The Association includes end-of-life care resources on its website including the End-of-life Coalition which states as its vision "a community where people are empowered to make knowledgeable choices regarding their end-of-life that are known, respected and honoured."¹¹¹

In terms of health organisations' positions on assisted dying, there are differences within Washington State. One health care provider, *Provider Health and Services*, is a case in point. Its physicians in one part of the state are not allowed to participate with assisted dying in any way whereas elsewhere, the Providence-affiliated hospital in Seattle allows such participation at the physician's discretion.¹¹²

5.1.3. Canada

The position of the Canadian Medical Association in the early 2000s was one of categorical opposition towards euthanasia. Its 2007 CMA policy on euthanasia and assisted suicide states: "Canadian physicians should not participate in euthanasia or assisted suicide".¹¹³ A May 2014 editorial in the Canadian Medical Association Journal considered that the direction of public policy was putting the 'cart before the horse' by proceeding with policies on assisted dying in advance of assuring adequacy of funding for palliative care. The Canadian Medical Association (CMA) in 2014 took a more accommodating stance in its updated policy on euthanasia and assisted death. This policy position recognised physicians' right to freedom of conscience not to provide euthanasia and also acknowledged that physicians were free to provide assistance in dying given de facto legislative protections.¹¹⁴

A similar evolution occurred for the College of Family Physicians of Canada. In its April 2011 position statement, the College outlined a clear expectation that all patients with a life limiting illness should have access to palliative care.¹¹⁵ It explicitly stated that euthanasia and physician assisted suicide were practices that were not legally supported by Canadian legislation at the time and were inconsistent with the WHO definition of palliative care. It also highlighted the expectation for physicians to ensure adequate assessment, symptom management and consideration of referral to palliative care services, noting that requests for "hastened death are often calls for the family physician's urgent attention".

108. Cohen JS et al. (1994)

109. Cohen JS et al. (1994), p.94

110. Steinbrook R (2008)

111. Washington State Medical Association (2018).

112. Wohlfel (2018).

113. Canadian Medical Association (2007).

114. Canadian Medical Association (2014).

115. The College of Family Physicians of Canada (2011).

The College followed suit in 2015, putting forward a more inclusive focus of the diverse ethical perspectives of both physicians and patients. In the 2015 statement *A Guide for Reflection on Ethical Issues Concerning Assisted Suicide and Voluntary Euthanasia*, the College recognised that physicians may or may not choose to participate in medical assistance in dying on ethical grounds. It emphasised that family physicians' play a fundamental role in supporting patients and their families in end-of-life care, "recognizing that those who have serious illness or disabilities and those who are dying are among their most vulnerable patients, family physicians can be health advocates on behalf of such patients".¹¹⁶

Recognising the foundational principle of patient autonomy, the College concluded:

"And, if your wish is for physician-assisted suicide or euthanasia, we will listen without judgment, abide by our conscience, and ensure that you will be cared for with respect and dignity until the very end, within the accepted legal framework."¹¹⁷

It also reiterated the distinction between access to palliative care and euthanasia: "Canadians should have access to quality palliative care in their communities. This access is an issue of social justice. Permitting physician-assisted suicide and voluntary euthanasia should not undermine efforts to improve comprehensive medical, mental health, and palliative care. Rather, these efforts should be intensified."¹¹⁸

In June 2016, CMA endorsed the introduction of the 2016 legislation on medical assistance in dying.

"The CMA was pleased that historic federal legislation on medical assistance in dying was passed by Parliament, which closely followed the recommendations developed in consultation with its membership."¹¹⁹

CMA's position evolved further in its 2017 policy on Medical Assistance in Dying, which followed the introduction of Canada's 2016 legislation. This further confirmed the legitimacy of physicians' choosing to participate, or not, in medical assistance in dying, guided by their own ethical stance. It reiterated the autonomy of patients to choose and to ensure that vulnerable patients were supported with adequate safeguards. It also strongly emphasised the principle of non-abandonment. That is, that in a situation where a physician could not ethically support a patient's decision to choose euthanasia, the physician would support the patient to be referred to another physician able to provide medical assistance in dying.¹²⁰

A strong emphasis in the policy is the importance for the physician-patient relationship to be upheld and that respecting patients' right to choose medical assistance in dying is not inimical to exploring with patients clinical and emotional issues that may have a bearing on their decision. The CMA policy explicitly delineates medical assistance in dying as separate and distinct from palliative care. The statement recognised that in consultation with patients, withholding or withdrawal of medical interventions may be ethically acceptable and legally permissible in certain circumstances, if the interventions are considered to create unreasonable burdens for patients and are unlikely to be of benefit.¹²¹

Exploring the reasons for the CMA's "overwhelming change" on assisted death over the last decade, Martin interviewed a number of physicians who had taken public positions on the issue. She spoke to Dr James Downar, one of the authors of the CMAJ's 2014 editorial advocating against euthanasia, who reflected that he and his colleagues had become increasingly aware of the changing context. He commented that "a multitude of jurisdictions have shown that palliative care can survive and thrive in an environment where assisted death is legal." In turn, "many of the members of CMA have changed their opinions".¹²²

116. The College of Family Physicians of Canada (2015).

117. Ibid.

118. Ibid.

119. Canadian Medical Association (2016).

120. Canadian Medical Association (2017).

121. Ibid.

122. Martin (2018).

Part of the input into the revised CMA policy came from town hall style consultations with patients and consultation sessions with its own members in 2014. According to the then CMA president, Simpson, the underlying rationale for the consultation process was not so much to achieve consensus but rather to establish a basis on which to “support physicians and patients if the law changes”.¹²³ This culminated in October 2014 in the change to the CMA’s previous policy of opposition to physician participation in euthanasia to an accommodative stance. In June 2015, this sea-change in the CMA’s position is evident from the release of its draft *Principles-based Recommendations for a Canadian Approach to Assisted Dying*.¹²⁴

As with the CMA, the Canadian Society of Palliative Care Physicians’ (CSPCP’s) initial stance was one of resolute opposition to assisted dying, as reflected in its 2010 position statement:

“the Canadian Society of Palliative Care Physicians strongly opposes the legalization of euthanasia and assisted suicide”.¹²⁵

CSPCP sought to partner with the CMA and the Canadian Hospice Palliative Care Association (CHPCA) in 2014 to advocate for a clear demarcation between palliative care and the practice of euthanasia.¹²⁶ CPSP’s intensified its lobbying in 2016 with the release of the report “How to improve palliative care in Canada: A call to action for federal, provincial, territorial, regional and local decision-makers”.¹²⁷ Its rationale for the “urgent need” for improved quality and access to palliative care was argued on a number of grounds including:

- *Low access to palliative care* – “Only 30% of Canadians have access to specialized palliative care, and with current funding and workforce shortages, specialist palliative care services in all jurisdictions are facing pressures from changing needs and expectations”; and
- *Response to assisted dying legislation* – “The legalization of Medical Assistance in Dying (MAiD) has reinforced the imperative for all Canadians to have access to palliative care, which is currently not the case.”¹²⁸

Surveys of CSPCP members have shown a gradual attenuation to opposition to assisted dying over the last eight years:

- In 2010, in a survey of just under one half (46%) of CSPCP members: 88% were opposed to the legalisation of euthanasia; 80% were opposed to assisted suicide; 90% were not willing to participate in euthanasia; and 83% were not willing to participate in physician assisted death;¹²⁹
- In a follow-up survey in 2015, with a 74% response rate, opposition had abated somewhat, with just under three quarters (73%) opposed to legalisation of euthanasia and 69% opposed to physician-assisted suicide. The large majority (74%) of physicians responded that if legalised, they did not consider that assisted dying should not be facilitated or provided by palliative care physicians or palliative care services;¹³⁰
- By 2017, there was a turnaround in palliative care physicians’ views on assisted dying. The survey had a 54% response rate:
 - ▶ Well over one half (57%) responded that “advance requests for MAiD should be granted after necessary safeguards to reduce harm are in place”, with 35% responding that such requests should “never be granted” and 8% responding ‘other’;
 - ▶ 22% of physicians conduct MAiD assessments and 8% provide the MAiD procedure;
 - ▶ A very low minority (3%) of physicians who receive a MAiD request reported that they transfer all care to another physician whereas nearly three quarters (74%) provide information about MAiD, over one half (53%) refer patients for an assessment for MAiD, around one in five (21%) act as a MAiD assessor for patients under their care and one in ten (11%) act as MAiD assessors for patients referred to them;

123. Ibid.

124. Canadian Medical Association (2015)

125. Canadian Society of Palliative Care Physicians (2010)

126. Canadian Society of Palliative Care Physicians (2014)

127. Canadian Society of Palliative Care Physicians (2016)

128. Ibid, p.8

129. Canadian Society of Palliative Care Physicians (2010)

130. Canadian Society of Palliative Care Physicians (2015)

- ▶ In response to the question, “How has palliative care access or delivery been impacted by MAiD in your area?”, 40% of respondents considered it had ‘no impact’, 17% responded ‘some positive impacts’, just over one third (35%) responded that it had had ‘some negative impacts’ and 22% responded that they were ‘unsure’.¹³¹

The qualitative analyses of respondents with a positive view of MAiD indicated that: “the prevailing positive impact MAiD has had in communities is that it has opened up communication between patients and providers as well amongst providers and in the community. This has improved awareness, not only for MAiD as an option, but also for palliative care options that patients may not have previously considered.”

Of those respondents with a negative view, the qualitative feedback indicated the general theme that “MAiD has negatively impacted access or delivery of palliative care in their community noted primarily a lack of understanding, mostly referring to the patients understanding of what palliative care is and their full range of options”.

Since the introduction of legislation in 2016 there has been an increasing focus in provision of support and training to health professionals across several Canadian jurisdictions. Ontario is a case in point. It backed the implementation of an Advanced Course on Medical Assistance in Dying, with on-line and in-person training sessions delivered by a training organisation (Joule) linked to the Canadian Medical Association.

The Canadian Nurses Association has followed suit with an online education module Medical Assistance in Dying: What Nurses Need to Know.¹³²

In its response the legal developments in assisted dying in Canada, the Canadian Hospice Palliative Care Association sought to focus the policy debate on the necessity to adequately resource palliative care as a first order issue. Accordingly, in 2010, it released its campaign ‘Let’s Talk about Hospice Palliative Care Instead’. This policy clearly differentiated assisted dying from palliative care:

“Euthanasia, physician assisted dying or assisted suicide are not considered a part of the practice of hospice palliative care.”¹³³

The campaign aimed to squarely rebut the need for assisted dying by advocating instead for hospice palliative care as an alternative.

“Hospice palliative care providers have observed – and these observations are confirmed by research evidence, that the desire for euthanasia or physician-assisted suicide usually stems from one or more of the following factors: a desire not to be a burden on others; the individual’s need for control over the illness and his or her body/life, his/her autonomy; depression and psychological distress often associated with illness; fear of pain and suffering that may accompany terminal illnesses. Comprehensive hospice palliative care can help alleviate many of the factors that may cause people to consider physician assisted suicide, particularly the burden on loved ones, depression and pain and symptom management.”¹³⁴

A somewhat more accommodating statement was subsequently released that conceded that there may be a minority of patients for whom palliative care could not totally alleviate unbearable pain and suffering. It took the view that the CHPCA ought not to promulgate a single, overarching position, given the contrasting and conflicted ethical beliefs of its members. It further took the view that for a small number of patients for whom palliative care was not able to relieve suffering, their choice to pursue assisted dying ought to be upheld and respected.

131. Canadian Society of Palliative Care Physicians (2018)

132. Health Canada (2018a).

133. Canadian Hospice Palliative Care Association (2010a)

134. Ibid.

“For the vast majority of people, high quality hospice palliative care will be a better option than euthanasia or assisted suicide. However, despite access to high quality end-of-life care, a small number of Canadians may still choose to have control over their own death. As hospice palliative care providers, we will respect their right to choose and will not abandon them.”¹³⁵

This campaign was further bolstered in 2012 with the intent of shifting the policy focus away from the “negative views of death” preoccupying the end-of-life care debates around assisted dying towards a more positive focus on “high quality hospice palliative care and living until the end.”¹³⁶

In the lead-up to the passage of the assisted dying legislation in June 2016, CHPCA continued its focus on lobbying the federal government towards enhanced resourcing of the palliative care sector and that this be addressed as a distinctively separate focus from the implementation of assisted dying. Its members were advised by the Executive President of the apparent success of this lobbying:

“Hospice Palliative Care continues to be recognized as a parallel issue that is separate from Medical Assistance in Dying and the government has indicated that as a part of a multi-year health accord, it will commit to providing \$3 billion over four years to improve home care, which will include palliative care.”¹³⁷

The Canadian Association of MAiD Assessors and Providers (CAMAP) was established in 2017 with the aim of providing a community of interest with peer support, research and advocacy for professionals involved in medical assistance in dying. CAMAP’s remit extends to support for patients and families.¹³⁸

In 2017, the Canadian Hospice Palliative Care Association developed a guidance document for health care providers involved in hospice and palliative care to support them to address patient requests for MAiD.¹³⁹ The guide provides a series of prompts and follow-up questions for health care practitioners to seek to understand the underlying reason or precipitating issues leading to a MAiD request as well information about MAiD and a list of resources for referral to MAiD.

135. Canadian Hospice Palliative Care Association (2010b).

136. Baxter (2012).

137. Ibid.

138. Health Canada (2018a).

139. Canadian Hospice Palliative Care Association (2017).

6. International learnings

This section presents findings from international experience on the opportunities and issues and risks for the palliative care sector arising from the implementation of assisted dying.

6.1. THE CHANGING LANDSCAPE

The extent to which the health system incorporates assisted dying as a component of end-of-life care services is vexed. At one end of the spectrum, in Belgium, an integral model of end-of-life care encapsulates assisted dying as one component of end-of-life care services, with palliative care another component. Palliative care physicians in the integral model are able to offer continuity to patients who elect to seek assisted dying. Reviews of patient use of palliative care in advance of assisted dying found that 74% of Belgium assisted dying patients had accessed a palliative care service before end-of-life. A positive association between use of palliative care and assisted dying was also found in The Netherlands.

The following section presents an outline of changing ideologies and the integration of assisted dying into end-of-life care and mainstream health care in relevant jurisdictions.

6.1.1. Netherlands

The introduction of legislation in 2002 in the Netherlands to allow euthanasia and physician-assisted suicide – technically, to create an exemption to prosecution – was the culmination of many years of case law development in that direction.¹⁴⁰ For this reason, it has been argued that its introduction did not usher in significant changes to physicians' approaches to assisted dying, so much as formalising approaches that had progressively emerged and become accepted. Notably, the Netherlands is considered remarkable insofar as it is a case study of how the country's medical association, the Royal Dutch Medical Association (RDMA), had been prepared to articulate and advocate for the legislation.¹⁴¹ It introduced a vision for how physicians should approach patient requests for assisted dying with due care in 1984.¹⁴²

The preceding case law had established a basis upon which physicians who had acted out of concern for reducing unreasonable suffering would be largely exempt from prosecution under the crimes act. Further clarification of the procedural requirements expected to be followed by physicians to demonstrate conformance to appropriate and prudent end-of-life care planning was a feature of the decade leading up to the 2002 legislation.

Indeed, the RDMA played a lead role in articulating the 1984 guidelines that underpinned appropriate processes for end-of-life care steps. Partly, this was undertaken to reduce the potential risks that physicians would be prosecuted. Transparency of reporting was an important element of the approach advocated, with physicians required to report cases of assisted dying and the steps that were taken.¹⁴³

Surveys of the general acceptance of assisted dying reveal that the majority of the population (85%) and to a lesser extent, the general physician community (64%), were in favour of assisted dying.¹⁴⁴ In a separate survey, it was found that the majority of physicians considered that the *Euthanasia Act* has both improved legal certainty as well enhancing the care with which assisted dying is provided.

140. Legemaate (2004).

141. Griffiths et al. (1998)

142. Central Board of the Royal Dutch Medical Association (1984).

143. Rietjens et al. (2009).

144. Ibid.

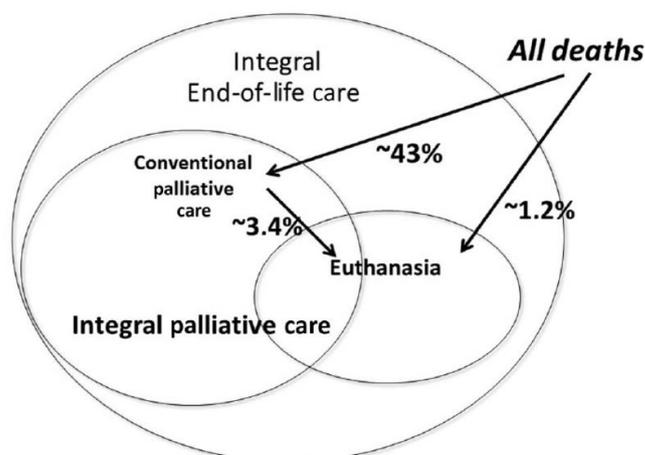
Since the introduction of the *Euthanasia Act*, a substantial focus for RDMA has been on the quality of medical decision-making. Supported financially by the Dutch Ministry of Health, the RDMA initiated the SCEN-project (Support and Consultation regarding Euthanasia in The Netherlands). The aim of the SCEN-project has been to establish regional groups of trained physicians who can act as independent consultants as required in the legislation. Additionally, these physicians are able to provide advice and information to practising doctors in relation to patient-initiated requests for physician-assisted deaths.¹⁴⁵

6.1.2. Belgium

The Federation for Palliative Care Flanders (FPCF) in 2003 gave support to the inclusion of assisted dying as an option within the provision of palliative care services. "Palliative care and euthanasia are neither alternatives nor antagonistic [...] Euthanasia may [...] be part of palliative care [...]. Caregivers are fully entitled to ethical limitations, but they must be expected to state these limitations candidly, clearly and above all in due time".¹⁴⁶

The FPCF further reiterated its position of support for 'integral' provision of palliative care and assisted dying in 2013.¹⁴⁷ In the 2017 review by Bernheim and Raus, the FPCF is regarded as the only professional palliative care organisation worldwide that supports the embedding of assisted dying within an integrated palliative care service.¹⁴⁸ The model of integral end-of-life care is shown schematically in Figure 6-1.

Figure 6-1: Integral end-of-life care, Belgium



One of the contextual issues identified in the lead up to the Belgium legislative change in 2002 was the issue of 'informal euthanasia'. Several studies undertaken in Belgium identified that an appreciable proportion of deaths were associated with informal euthanasia: one study identified 5% of all deaths in general practice occurred as a consequence of drugs administered with the explicit intention of shortening life¹⁴⁹ and another study identified the rate of administration of lethal drugs to patients without their explicit request at 3%.¹⁵⁰

The chair of the Belgian Association of Doctors Syndicates (BVAS), Dr Marc Moens, argued that the legalisation of assisted dying would not prevent abuses associated with end-of-life care and could jeopardise care. Legalisation of assisted dying it was argued would make the "exception the rule. Euthanasia is the exception. Caring for life should continue to be the rule."¹⁵¹

145. Legemaate (2004).
146. Bernheim et al. (2017).
147. Vanden Berghe et al. (2013).
148. Bernheim et al. (2017).
149. Bilsen et al. (2004).
150. Deliens et al. (2000).
151. Cohen-Almagor (2009).

More broadly, Cohen-Almagor considers that prior to legalisation of assisted dying in Belgium, medical practitioners were opposed on the grounds that it 'opened the door' to ending life. Doctors expressed concerns that end-of-life choices would be taken by patients with incurable diseases who yet had years to live.¹⁵²

In the years following the legalisation of assisted dying, Vanden Berghe et al. consider that there has been a gradual accommodation across the palliative care sector to the concept of assisted dying as one component of overall end-of-life caring practice.

"The caring practice of 'euthanasia accompaniment' is part of the daily work of palliative care professionals, who support the treating doctor and team in all aspects of the patient's request, while only very occasionally carrying out euthanasia themselves".¹⁵³

A number of reasons are given for this shift in perspective from the palliative care sector which was originally described as "very reticent" to align palliative care services with assisted dying. Factors put forward include the perspectives gained by palliative care staff who witnessed patients seeking assisted dying from alternative medical practitioners outside their familiar palliative care setting. This displacement effect was considered less than optimal. For others, assisted dying was identified as consistent with genuinely good care for patients who had exhausted palliative possibilities.

"Since the key reasons for euthanasia requests appeared to be a desire to be in control, fear of dependency and existential despair, euthanasia no longer seemed a failure of, or antagonistic to, palliative care, but something that could be served by it."¹⁵⁴

Vanden Berghe concludes that "it is the experience of many of us that the developments seen in the last ten years have resulted in more professional end-of-life care that better responds to patients' wishes".¹⁵⁵

Evidence that there has been a gradual shift towards acceptance of the accommodation between palliative care and assisted dying is that the three Belgian palliative care federations (the FPCF, the Fédération Wallonne des Soins Palliatifs and the Fédération Pluraliste Bruxelloise de Soins Palliatifs et Continus) have agreed in a common position paper to 'respect the choice of patients who want euthanasia' and 'place them in the centre of the process'.¹⁵⁶ Bernheim et al. also consider that the Belgian model of integral end-of-life care, in which assisted dying is an available option that may occur at the end of a palliative care pathway, has gained broad acceptance. They venture that this is now "the majority view" held by health professionals, including palliative care professionals, and the broader public.¹⁵⁷

Underpinning the Belgian experience has been the interdependent and reciprocal development of policy with a pragmatic flavour within a pluralistic society. Common ground between advocates of assisted dying and palliative care were the shared concerns for centrality of the patient and compassion. Differences in emphasis were reflected in the emphasis on *patient autonomy* for the assisted dying proponents and for *exemplary care for the patient* in the case of palliative care providers.

"The common ground between those who sought better palliative care and those who were campaigning for the legalisation of euthanasia, together with the influence of the core group of those who supported both, gradually created a climate of public and professional opinion that was open to the possibility of euthanasia legislation."¹⁵⁸

152. Cohen-Almagor (2009).

153. Vanden Berghe et al. (2013).

154. Ibid.

155. Ibid.

156. Ibid.

157. Bernheim et al. (2014).

158. Bernheim et al. (2014).

In contrast to Belgium's stance on integral end-of-life care, the European Association for Palliative Care is not supportive – it rejects the notion that assisted dying be included in palliative care practice.¹⁵⁹ More broadly, the European Association for Palliative Care has not condoned the provision of assisted dying and explicitly states that euthanasia is not a part of palliative care.¹⁶⁰

A similar position is taken by the *International Association for Hospice and Palliative Care* (IAHPC).¹⁶¹ The IAHPC considers that palliative care units should not have any direct involvement in assisted dying “as doing so would place the professionals, their staff and, in some cases, their patients and families, in an untenable position.”

6.2. OPPORTUNITIES

The implementation of assisted dying legislation presents several opportunities. These are considered from the perspective of: patients; the palliative care sector; and the health care workforce.

6.2.1. Patient autonomy

Proponents of assisted dying consider that there is a far stronger focus on upholding patient choice and autonomy under assisted dying. They contrast the situation in jurisdictions without assisted dying where there is less transparency about end-of-life decision-making. In the US, the illegal use of physician-assisted suicide outside of Oregon was estimated at 5% in 2003.¹⁶² A Belgian study identified that prior to legalisation of assisted dying, the proportion of deaths involving euthanasia without patient consent was estimated at 3.2% of deaths; this declined to 1.7% deaths following the implementation of legalisation of assisted dying.¹⁶³ A similar reduction was identified in the Netherlands with pre-legislation death rates involving lethal drug administration without explicit patient consent estimated at 0.8%, falling to 0.2% in the post-legislation context in 2010.¹⁶⁴

Opponents consider that patient autonomy is not a sufficient justification for assisted dying and that physicians' ethical duties are bound to acting with beneficence and nonmaleficence, consistent with their roles as healers and comforters.^{165,166} Moreover, the European Association for Palliative Care white paper considers *patient autonomy* to be one of the hallmarks of palliative care.¹⁶⁷

6.2.2. Enhancing palliative care

There may be opportunities to introduce system improvements in palliative care, either as a direct or indirect consequence of the planned implementation of assisted dying.

Belgium provides a case in point of a direct link. There was an intentional drafting of parallel sets of legislation covering a) decriminalisation of euthanasia; b) legal right to palliative care for all; and c) broader patient rights.¹⁶⁸ Similarly, in Canada, the assisted dying legislation requires that to be eligible for assisted dying, patients must be first advised of available service options to reduce suffering, inclusive of palliative care.¹⁶⁹

159. Radbruch et al. (2015).

160. Radbruch et al. (2015).

161. The board of directors of IAHPC comprises 15 individuals from palliative care providers from different professions (nursing, oncology, palliative medicine, pharmacy, psychiatry, and psychology) from 10 different countries (Argentina, Australia, Germany, India, Kenya, Panama, Uganda, United Kingdom, United States, and Vietnam).

162. Quill et al. (2003).

163. Chamberlain et al. (2015).

164. Onwuteaka-Philipsen et al. (2012).

165. Sulmasy et al. (2017).

166. Radbruch et al. (2015).

167. Ibid.

168. Berghe PV et al. (2013)

169. Canadian Institute for Health Information (2018) p. 21

In other jurisdictions, there were indirect system improvements in palliative care that occurred alongside the introduction of assisted dying. This reflected the focus that was placed upon end-of-life care as a whole and the increased focus and public policy attention directed to the sector.

It reflected debate around the importance placed upon assisted dying as a *complement* to palliative care and not as an *alternative* to palliative care.

Notwithstanding the general opposition expressed by the European Association for Palliative Care to assisted dying, the recent 2015 white paper conceded that one potential positive contribution for jurisdictions that have legalised assisted dying has been the greater transparency given to end-of-life care debate and policy deliberation.

“Even with critical reflection on the experiences in Belgium, the Netherlands and Oregon, it has to be acknowledged that there may be more transparency and open discussion around end-of-life than in most other countries, where similar procedures may happen in a more covert way.”¹⁷⁰

Not only has this resulted in additional palliative care resources¹⁷¹ but a strengthening of capability as seen by improved medical workforce training, communication of patients’ wishes in relation to end-of-life care decisions on treatment and settings of care, symptom management.^{172,173}

In Washington State, the Washington State Medical Association does not condone assisted dying. However, its website does include a range of resources on end-of-life care resources including: Palliative care; Advance Care Planning; and Physician Orders for Life-Sustaining Treatment.¹⁷⁴

In Oregon State, surveys of physicians identified an increased awareness by physicians of options for palliative care and perceptions that access to palliative care had increased since the introduction of the *Dying with Dignity Act*.¹⁷⁵ Other system-level indicators reported in Oregon that reflect a strong focus on palliative care since the Act’s introduction include: increased hospice referral rates; high per capita morphine prescription rates relative to other US states; low rates (31%) of in-hospital death rates; high rates (91%) of do-not-resuscitate orders in nursing home residents; high levels of advance-directive completion and high rates of physician attendances at palliative care case conferences.¹⁷⁶

6.2.3. Health care workforce

In the absence of structured support for the health care workforce, the introduction of assisted dying can have harmful effects for both the practitioners and patients involved. For practitioners, uncertainties associated with the introduction of assisted dying can be very challenging professionally and personally.¹⁷⁷ The professional isolation experienced by physicians in Oregon at the time of the introduction of assisted dying was exacerbated by the lack of preparedness to communicate with their professional peers.¹⁷⁸ In other jurisdictions, support for the health care workforce was explicitly marshalled through professional colleges such as the Royal Dutch Medical Association’s proactive leadership on training to the Canadian Medical Association facilitation of clinical guidelines and physician support.¹⁷⁹

In place of direct opposition to assisted dying, some professional organisations have taken a ‘studied neutrality’ approach to assisted dying. This is an explicable response by organisations to avoid a perception of involvement of their organisations in difficult and vexatious ‘political’ and ‘ethical’ decisions.

170. Radbruch et al. (2015).

171. Chambaere et al. (2015).

172. Quill et al. (2007).

173. Steinbrook et al. (2008).

174. Washington State Medical Association (2018).

175. Ganzini L et al. (2001).

176. Quill et al. (2003).

177. Quinn et al. (2017).

178. Dobscha et al. (2004).

179. Canadian Medical Association (2016).

However, it is argued that this can lead to health practitioners lacking assistance and guidance in navigation of assisted dying and lacking support in how they may respond to requests from patients for assisted dying.¹⁸⁰

In contrast to ‘studied neutrality’ other professional organisations have opted for ‘engaged neutrality’. For example, the American Psychological Association’s position of engaged neutrality involves no political stance, rather proactive responses to the implementation of assisted dying. Steinbrook argues that “the imperative to provide for the real needs of patients and the community justifies taking a position beyond rigid or hands-off neutrality”.¹⁸¹

6.3. ISSUES AND RISKS

There are several issues and risks relevant to the palliative care sector that have been often been at the centre of debates on assisted dying.

6.3.1. Access to palliative care

A frequent risk identified is that people may seek recourse to assisted dying if there are resource or access constraints to palliative care. This issue has been strongly argued in many jurisdictions by opponents of assisted dying.^{182,183,184}

In the debate about this in Belgium, consideration was given to a ‘palliative care filter’ process. Essentially, the intent was to ensure that prior to a patient opting for assisted dying pathway there would need to have been consideration given to the patient’s assessment by a palliative care team. This option was not upheld in Belgium. It was argued that such an approach would impinge upon patient autonomy to exercise freedom of choice.¹⁸⁵

Analysis of the resourcing of the palliative care sector in the ‘permissive’ Benelux countries – that is, Belgium, the Netherlands and Luxembourg where assisted dying has been introduced – has identified higher per capita access to palliative care relative to non-permissive European countries.¹⁸⁶ This is not to say that there are not challenges in meeting demand for palliative care in countries such as Belgium, where it is noted that an increase in public awareness of end-of-life choices has been associated with increased demand for community-based care and additional pressure on the existing palliative care workforce and resources.¹⁸⁷

Other concerns have been that patients who are socio-economically disadvantaged may not have the resources to access palliative care and may disproportionately seek assisted dying in its place. In jurisdictions that have introduced public reporting of key statistics on assisted dying, analysis of the socio-economic profile of assisted dying patients indicate that typically patients using assisted dying are more affluent and more educated.^{188,189,190}

Tracking of assisted dying patients indicates that a very high majority of patients have had access to palliative care.¹⁹¹

180. Frye et al. (2016)

181. Steinbrook (2016).

182. Sulmasy and Mueller (2017)

183. Quill and Cassell (2003)

184. Radbruch et al. (2015)

185. Vanden Berghe P (2013)

186. Chambaere K and Bernheim JL (2015)

187. Bernheim et al. (2014)

188. Ezekiel et al. (2016).

189. Battin et al. (2007).

190. Hedberg et al. (2017).

191. Dierickx S et al. (2018)

Recent analysis of the Canadian experience confirms that a majority (70%) of patients who opted for assisted dying, and who had been hospitalised, had been identified as palliative during the hospitalisation and 35% had been hospitalised primarily for palliative care.¹⁹² and has received palliative care. This runs counter to the argument that assisted dying may be used by patients in circumstances where palliative care is not available.

A further finding is that for only a minority of patients who provide reasons for terminating their life through assisted dying cite uncontrollable pain as a contributing factor. For a majority of patients, the reasons cited include loss of autonomy and dignity and being less able to enjoy life's activities.¹⁹³

6.3.2. Potential erosion of safeguards

The concern of some stakeholders is that access to assisted dying pathways is a 'slippery slope' whereby vulnerable people may be at risk should safeguards fail. This issue may have implications for the palliative care sector given that there is a concern that assisted dying pathways may substitute for palliative care through erosion of safeguards.

A number of strategies have been implemented to seek to mitigate this risk:

- Compliance with safeguards – there is a requirement across jurisdictions for physicians involved in assisted dying to undertake compliance reporting to a designated public authority. The intent is to ensure that processes and eligibility criteria are being observed by physicians who enable assisted dying access for patients. Only a small number of cases have resulted in reporting to the public prosecutor across jurisdictions: 75 cases in the Netherlands (but no prosecutions resulted); one case in Belgium; one case in Orgeon.¹⁹⁴
- Second physician review – most jurisdictions have a requirement for a second, independent physician review to ensure strict adherence to eligibility criteria. Some commentators are concerned that there are ways and means of selecting 'independent' physicians to review criteria but that in practice there may be a degree of tacit inter-dependence between physicians involved in assisted dying assessments.¹⁹⁵
- Competency – there is a requirement for competency of decision-making for patients to be eligible for assisted dying. This raises the issue of the reliability of clinical assessments of patient competency. Typically patients who are diagnosed with dementia are not eligible. Some cases have involved challenges to clinicians' assessment as to patient competency;¹⁹⁶
- Scope – Scope of patients eligible for assisted dying are explicitly defined in legislation and compliance with criteria is monitored through public reporting.
 - ▶ One risk identified is that the scope of eligibility criteria may be broadened over time following the initial introduction of legislation. To date, proponents argue the scope of eligibility criteria in the legislation has been stable. Opponents point to changes in scope over time such as the recent 2007 extension of assisted dying in the Netherlands to severely malformed newborns; and in Belgium to all ages from 2014, as long as there is confirmation that the patient is capable of discernment.¹⁹⁷
 - ▶ Critics argue that there are areas of grey in some criteria and that strict adherence to the criteria may not be assured in all cases from the information reported publicly.¹⁹⁸
 - ▶ An Oregon study found that screening for eligibility may not have effectively screened patients for depression with the potential that some potentially ineligible patients may have accessed assisted dying.¹⁹⁹

192. Canadian Institute for Health Information (2018) p. 21

193. Ezekiel et al. (2016).

194. Ibid.

195. Cohen-Almagor R (2009)

196. De Jong A and van Dijk G

197. Ibid.

198. Ganzini et al. L (2001)

199. Ganzini et al. (2008)

- Monitoring of trends – monitoring utilisation trends over time is one key means of identifying uptake of assisted dying by patient profile (age and socio-demographic, disease type etc.). More powerful analyses involve a review of death certificates. This provides a basis on which to analyse per capita uptake of assisted dying for non-sudden deaths.²⁰⁰
- Studies of use of assisted dying have not shown a disproportionate risk of uptake by vulnerable populations.²⁰¹

6.3.3. Routinisation

A more diffuse argument is that the practice of assisted dying may over time become routinised and that as a result, there may be a lowering of thresholds by physicians to accept patient requests for assisted dying without active review of the potential for this request to mask other concerns patients may have. Being alert to the risks of routinisation of assisted dying is critical to ensure that this option is not chosen simply because it is easier than providing patients “with the kind of care that would make them want to keep living”.²⁰² Opponents argue that requests for assisted dying may be masking other concerns patients may have about symptom control, uncertainty about the future and financial concerns.²⁰³

There is also the risk of routinisation associated with patients perceiving that they have become a burden to family and society. The College of Family Physicians of Canada identifies that physicians have a role in challenging stereotypes such as the ‘grey tsunami’ that may contribute to a society-wide lessening of respect for the worth of human life. The College notes that physicians need to be attuned to the concept of ‘attributed dignity’ – that is, the perception that patients may have about their relative worth and potential sense of being a burden on their families and carers at the end-of-life. Addressing this proactively requires that physicians have the skills to engage in conversations to address patients’ concerns about losing self-worth, to actively listen and understand what lies behind concerns patients may have about ‘losing dignity’, to enable access to support services that will buttress wellbeing through appropriate environments and support including psychosocial and spiritual support.²⁰⁴

Measurement of routinisation is inherently difficult. One crude indicator is simply the trend in the number of explicit requests for assisted dying, irrespective of whether the request was granted. In both the Netherlands and Belgium, this trend has increased over time.^{205,206,207} Reasons for the increase in the Belgian rate of assisted dying are postulated to include: a wider acceptance within the medical practitioner community; integration of assisted dying within the palliative care continuum; increased rates of requests by some patient groups including those life-limiting conditions beyond cancer; and wider acceptance among health care organisations which had previously been reluctant.²⁰⁸

6.3.4. Right of practitioner refusal

Access to assisted dying is dependent on the availability of physicians who are prepared to be involved in assisted dying. Typically, legislation allows for health care practitioners to exercise their right to be ethically opposed to assisted dying and of not being compelled to agree to a patient’s request for assisted dying. There is however a general expectation that practitioners will provide information or facilitate access to a referral to an alternative practitioner who is prepared to meet the patient’s request.²⁰⁹

200. Ezekiel E et al. (2016)

201. Battin MP et al. (2007)

202. Steinbrook (2008).

203. Sulmasy LS and Mueller PS (2017)

204. College of Family Physicians of Canada (2015), p.7

205. Onwuteaka-Philipsen et al. (2012).

206. Chambaere et al. (2015).

207. Dierckx et al. (2015).

208. Ibid.

209. Stahl et al. (2017).

The College of Family Physicians of Canada emphasised the centrality of recognising the need for patient support and facilitation of access to other referral options in circumstances where physicians decline on ethical grounds a patient's request for assisted dying.

“The CFPC opposes in principle any action that would abandon a patient, without any options or direction.”²¹⁰

6.3.5. Right of organisation refusal

In Oregon, there are diverse practices that reflect differences in organisational philosophy of end-of-life care services, with some explicitly precluding it, some explicitly allowing it, and others adopting a neutral stance, allowing for the discretion of individual physicians. Proponents of integration consider that some organisations which are publicly stated to be neutral, may nonetheless raise obstacles in practice to meeting patients request to access assisted dying.²¹¹

Under Oregon's *Dying With Dignity Act*, there is provision under the legislation for health care organisations to proscribe writing lethal prescriptions under the Act on their premises or by physicians they employ. As many as 18% of physicians surveyed for their views and practices in relation to DWDA worked in health care systems that had policies forbidding assisted dying.²¹²

6.3.6. Practitioner support and capability

The issue of provider support and capability is identified as a core requirement for effective implementation of assisted dying. This issue is relevant for the palliative care sector as there are likely to be some physicians who provide palliative care and who may also provide assisted dying.

Experiences vary widely across jurisdictions. There are important technical and information requirements that physicians need as well as professional support and training. Guidelines have been developed in the Netherlands and Belgium for physicians and pharmacists.^{213,214} Oregon has an online guidebook for health care practitioners.²¹⁵

An additional challenge is the emotional burden for health care practitioners associated with assisted dying.^{216,217,218,219} This has been identified as taking a significant toll on practitioners. In a physician survey in the Netherlands, there was a very high rate (86%) of physicians reporting assisted dying as presenting a high emotional burden.²²⁰ Conversely, a qualitative survey of physicians who participated in assisted dying in Oregon found that in spite of the significant emotional investment required in assisted dying, most physicians did not regret their involvement in assisted dying and reported that it had extended them professionally and that they were more confident and proactive in raising end-of-life care issues.²²¹ This survey also found that these physicians sought to discuss their concerns around emotional support with their spouses rather than with their professional colleagues, indicating a continuing stigma and lack of trust to broach these issues for discussion in a professional context.²²²

210. College of Family Physicians of Canada (2015), p.4

211. Campbell CS and Cox JC (2010)

212. Ganzini et al. (2001).

213. Order of Physicians (2005).

214. Schaus (2015).

215. Task Force to Improve the Care of Terminally-Ill Oregonians (2007).

216. Dobscha et al. (2004).

217. Ganzini et al. (2001).

218. Stevens (2006).

219. Dobscha et al. (2004).

220. Van der Heide et al. (2012).

221. Dobscha et al. (2004)

222. Ibid.

Other factors that are disincentives for practitioner participation in assisted dying include the substantial paper work and the perception that remuneration for these cases can be relatively low.^{223,224}

The case volume of patients seen by physicians who provide assisted dying is relatively low in most jurisdictions. For example, in Oregon, the proportion of licensed physicians who are involved in assisted dying increased from 0.2% in 2000 to 0.6% in 2016.²²⁵ There tends to be a skewed, uni-modal distribution with a large volume of assisted dying patients receiving services from a small number of physicians. The majority of physicians with any involvement in assisted dying have very low case volumes.²²⁶

In Oregon, a survey of physicians' approaches to assisted dying in the context of the *Dying with Dignity Act* identified that many considered that they had sought to improve their knowledge and understanding end-of-life care support services. Those physicians who received patient requests for assisted dying self-reported that they had sought to improve their knowledge and understanding of pain management approaches than those physicians without assisted dying requests. Notwithstanding this positive finding, there were concerns that some physicians who were involved in assisted dying requests were not necessarily aligned with the expectations under the Act for ensuring compliance with patient eligibility screening practices, information sources used in relation to lethal medications were not consistent with recommended channels and one in six were unsure how to establish 6 month life expectancy, an expectation of the Act.²²⁷

6.3.7. Access to assisted dying pathways

With assisted dying available in limited Australian States/Territories, there is the potential for people to move away from their local place of residence to access a jurisdiction within which they can be assisted to die (noting legislative requirements regarding period of residence).

Dying estranged from a person's every-day living context is likely to run counter to person-centred principles espoused in end-of-life care policies. Other jurisdictions have typically limited this eventuality by stipulating that patient place of residence within the jurisdiction as one of the key eligibility criteria for assisted dying.

6.3.8. Problems and complications

The issue of problems and complications is raised as an issue for further research given that there is a minority of patients who may not initially die from lethal medication. This may have a direct impact on the palliative care sector, depending upon the setting in which assisted dying takes place.

In the US state of Oregon, over the period 1998 to 2015, there were complications reported for 2.4% of cases involving regurgitation of medication. A further 0.7% of patients regained consciousness after ingesting lethal medications. A small number of patients are reported to have a lapse in time between ingestion and death with the median time between ingestion of lethal medication and death 25 minutes but the range extending to more than four days.²²⁸ In Washington State, 67% died within 90 minutes with a range extending to 30 hours.²²⁹

Complications arising in the context of assisted dying for PAS reported from a 2000 study undertaken in the Netherlands included difficulty swallowing for 10.6% of cases, and complications including vomiting or seizures for 8.8% of cases.²³⁰

223. Roehr (2018).

224. Martin (2018).

225. Hedberg et al. (2017).

226. Steinbrook (2008).

227. Ganzini et al. (2001).

228. Ezekiel et al. (2016).

229. Ibid.

230. Groenewoud et al. (2000).

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A1. Australian context

Within the Australian context, assisted dying has emerged as a key topic for policy makers. Over the past two decades, several bills to legislate assisted dying have been introduced to state parliaments, however only the Northern Territory *Rights of the Terminally Ill Bill 1995* (later repealed) and the Victorian *Voluntary Assisted Dying Act 2017* have been enacted. The approaches to this issue across Australian jurisdictions are summarised below.

A.1.1. ASSISTED DYING LEGISLATIVE CONTEXT

A1.1.1. New South Wales

The Voluntary Assisted Dying Bill was introduced into the New South Wales (NSW) Parliament on 21 September 2017.²³¹ The upper house debated the bill throughout several sittings in November 2017, and on 16 November the bill was voted down 20 votes to 19.²³²

A1.1.2. Northern Territory & Australian Capital Territory

The Rights of the Terminally Ill Bill was passed by the Northern Territory's Legislative Assembly on 25 May 1995.²³³

The following year, the law was voided by the *Euthanasia Laws Act 1997*, a statute of the Australian Parliament which amended the *Northern Territory (Self-Government) Act 1978*, the *Australian Capital Territory (Self-Government) Act 1988*, and the *Norfolk Island Act 1979*, which saw the removal of the power of each of those territories to legalise euthanasia, and repealed the Northern Territories *Rights of the Terminally Ill Act 1995*.^{234,235,236}

In August 2018, an attempt was made to repeal the *Euthanasia Laws Act 1997* with the introduction of the *Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015*. The bill was subsequently rejected by the Senate by 36 votes to 34.²³⁷

A1.1.3. Queensland

In September 2018, Queensland's Premier ordered an inquiry into end-of-life care, including the issue of euthanasia.²³⁸

A1.1.4. South Australia:

In November 2016, the *South Australian Death with Dignity Bill 2016* was rejected in the House of Assembly. The bill passed to a second reading stage however was rejected during the clauses debate.²³⁹

231. Parliament of New South Wales (2017).

232. SBS (2017).

233. Legislative Assembly of the Northern Territory (2018).

234. Australian Government (1997).

235. Australian Government (1978).

236. Australian Government (1988).

237. Parliament of Australia (2018).

238. ABC (2018).

239. Government of South Australia (2016).

A1.1.5. Tasmania

In November 2013, Tasmania's *Voluntary Assisted Dying Bill 2013* was narrowly defeated by a vote of 13-12.²⁴⁰

A1.1.6. Victoria

Discussions surrounding the consistency of Victorian laws relating to the provision of assisted dying and the need for laws to allow citizens to make informed decisions regarding their own end-of-life, prompted the 2015 Parliamentary Committee *Inquiry into End-of-life Choices* in Victoria.

Following the Inquiry, the Parliamentary Committee made 49 recommendations, 48 of which related to palliative care and advance care planning. The 49th recommendation outlined their proposal for legalising voluntary assisted dying in Victoria:

*Recommendation 49: That the Victorian Government introduce a legal framework providing for assisted dying, by enacting legislation based on the assisted dying framework.*²⁴¹

Based on this recommendation, the Voluntary Assisted Dying Ministerial Advisory Panel (the Panel) was given the responsibility of developing the voluntary assisted dying framework for Victoria.

The Panel recommended that the Victorian Department of Health and Human Services establish an Implementation Taskforce to advise on the development of the legislation and to coordinate, oversee and facilitate the implementation of the recommendations made by the Panel.²⁴²

Informed by the recommendations made by the Panel, The *Voluntary Assisted Dying Act 2017*, was passed by the Victorian Parliament on 29 November 2017 with an 18-month implementation period.

As stipulated by the Act, the key eligibility criteria for accessing voluntary assisted dying in Victoria includes:

- The person must be aged 18 years or more;
- The person must:
 - ▶ Be an Australian citizen or permanent resident;
 - ▶ Be ordinarily resident in Victoria; and
 - ▶ At the time of making a first request, have been ordinarily resident in Victoria for at least 12 months.
- The person must have decision-making capacity in relation to voluntary assisted dying;
- The person must be diagnosed with a disease, illness or medical condition that:
 - ▶ Is incurable;
 - ▶ Is advanced, progressive and will cause death;
 - ▶ Is expected to cause death within weeks or months, not exceeding 6 months; and
 - ▶ Is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.
- A person is not eligible for access to voluntary assisted dying only because the person is diagnosed with a mental illness, within the meaning of the *Mental Health Act 2014*;
- A person is not eligible for access to voluntary assisted dying only because the person has a disability, within the meaning of section 3(1) of the *Disability Act 2006*;

240. Smiley (2013).

241. Parliament of Victoria (2016).

242. DHHS (2017).

- If the person is diagnosed with a disease, illness or medical condition that is neurodegenerative, that disease, illness or medical condition must be expected to cause death within weeks or months, not exceeding 12 months;
- A person may make a request to a registered medical practitioner for access to voluntary assisted dying. Minimum requirements for the consulting medical practitioner (who accepts the patients first request) and for the co-ordinating medical practitioner (who accepts a transfer of the role medical practitioner) are:
 - ▶ Each consulting and co-ordinating practitioner must - hold a fellowship with a specialist medical college; or
 - ▶ Be a vocationally registered general practitioner.²⁴³

As of October 2018, the Implementation Taskforce is working with the community, health and legal sectors to implement voluntary assisted dying in Victoria.²⁴⁴

During the implementation period, a Voluntary Assisted Dying Review Board will be established to oversee the operation of the Act.

From 19 June 2019, Victorians who meet the eligibility criteria will be able to request access to voluntary assisted dying.

A1.1.7. Western Australia

In August 2018, a cross-party parliamentary committee recommended legalising of voluntary euthanasia for patients suffering from a terminal illness, saying it will limit "unnecessary suffering at end-of-life".²⁴⁵

A.1.2. PALLIATIVE CARE LEGISLATIVE CONTEXT

In addition to assisted dying policy and legislation, there are a number of palliative care specific policy drivers at the national, state and territory levels as summarised below.

A1.2.1. National

The *Australian National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End-of-life* represents the combined commitments of the Australian, state and territory governments, palliative care service providers and community-based organisations to develop and implement palliative care policies, strategies and services that are consistent across Australia.²⁴⁶

The Strategy has four goal areas:

- *Awareness and Understanding.* To significantly improve the appreciation of dying and death as a normal part of the life continuum and to enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services;
- *Appropriateness and Effectiveness.* Appropriate and effective palliative care is available to all Australians based on need;
- *Leadership and Governance.* To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches; and
- *Capacity and Capability.* To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.²⁴⁷

243. Voluntary Assisted Dying Act (2017).

244. DHHS (2018).

245. Kagi (2018).

246. Commonwealth of Australia (2010).

247. Ibid

The Australian Government provides financial support to state and territory governments to operate palliative care services. In addition, the Australian Government funds a range of National Palliative Care Projects focussing on education, training, quality improvement and advance care planning.

Recent federal government funding of the palliative care sector has included:

- *Greater Choice for At Home Palliative Care.* As part of the 2017-18 Federal Budget, \$8.3 million over three years to 2019-20 was provided for the *Greater Choice for At Home Palliative Care* measure which will improve palliative care coordination through Primary Health Networks (PHNs);
- *National Palliative Care Projects.* The Australian Government funds a range of national palliative care projects primarily focused on education, training, quality improvement and advance care planning; and
- *Specialist Palliative Care and Advance Care Planning Advisory.* The Australian Government funds specialist palliative care and advance care planning advisory services nationally to aged care providers and general practitioners providing health care for recipients of aged care services. A consortium led by the Queensland University of Technology will undertake this activity commencing in 2017-18. The specific objectives of the Advisory Services are to:
 - ▶ Provide specialist palliative care and advance care planning advice to aged care providers and GPs providing health care for recipients of aged care services;
 - ▶ Improve linkages between aged care services and palliative care services;
 - ▶ Improve the palliative care skills and advance care planning expertise of aged care service staff and GPs providing health care for recipients of aged care services; and
 - ▶ Improve the quality of care for aged care recipients, prevent unnecessary hospital admissions and shorten hospital stays.²⁴⁸

A1.2.2. New South Wales

The NSW Government plan to increase access to palliative care 2012-2016 sets out the NSW Government's policy to ensure access to quality palliative care regardless of individuals economic or social circumstances, geographical location or medical condition. The Plan seeks to enhance existing palliative care services and to draw upon and expand the skills of the multi-disciplinary teams who provide such care.²⁴⁹

In 2016, The NSW Government committed \$35 million over four years to improve access and support to care for people who are dying, their families and their careers.²⁵⁰

The key action areas identified within the plan are:

- Expand community-based palliative care services, especially in rural areas and for special needs populations;
- Integrate primary care, aged care and specialist palliative care services across the state;
- Expand support for families and carers; and
- Extend the capacity of palliative care services in NSW.²⁵¹

A1.2.3. Northern Territory

A priority objective of the *Northern Territory Health Strategic Plan 2018 – 2022* is to enable patient choice in end-of-life care.²⁵² However, the Northern Territory does not have a current strategic plan or specifically for end-of-life care or palliative care.

248. Ibid.

249. New South Wales Ministry of Health (2012).

250. Ibid.

251. Ibid.

252. Northern Territory Health (2018).

The most recent palliative care strategy for the Northern Territory is the *Northern Territory Palliative Care Strategy 2005-2009*.

The vision of The Strategy is to ensure that all Territorians have long and healthy lives and have a health and community services system that is responsive, accountable and effective.²⁵³

The Strategy proposes initiatives in six priority areas:

- Territorians have improved access to palliative care services on the basis of identified care needs and informed choices;
- People with a life-limiting illness, their families and carers access a flexible service model to ensure a holistic continuum of care;
- The needs of people in rural and remote areas are reflected in palliative care and support services;
- A skilled and competent workforce that is committed to palliative care is developed and nurtured;
- Territorians have an improved awareness and understanding of palliative care through a health promoting framework that incorporates education, advice and support; and
- A sound data, continuous evaluation and evidence base is developed to inform service delivery and development.²⁵⁴

A1.2.4. Queensland

Queensland's *State-wide strategy for end-of-life care 2015* is intended to integrate end-of-life care as a core element of health services in Queensland.

The Strategy asserts that end-of-life care should be delivered based on an assessment of need considering but not limited by diagnosis, prognosis, setting of care or anticipated illness trajectory. The strategy describes the components of end-of-life care across the full range of levels of care from a palliative approach through to general and specialist palliative care. It identifies key service directions to guide planning and service development to meet future demand.²⁵⁵

The four overarching key service directions are:

- Knowledge of end-of-life care throughout public health organisations is expanded and includes a comprehensive awareness of the benefits of the planning and delivery of end-of-life care and availability of supporting services/resources within and between health services;
- Earliest possible identification of patients who will or are anticipated to have shortened life expectancy as a result of known health conditions is routinely achieved, together with timely Advance Care Planning and the initiation of co-ordinated planning of end-of-life care;
- End-of-life-care delivered in Queensland public services consistently responds to the needs of patients throughout their illnesses and meets established clinical safety and quality standards; and
- The strategic capability and configuration of end-of-life care services in Queensland is strengthened to maximise system health service delivery and performance so as to provide access to appropriate services for the projected population, while making the most effective use of available resources.²⁵⁶

A1.2.5. South Australia

The vision of *South Australia's End-of-Life Care Strategy* is for all South Australians to experience quality care at the end of their life.

253. Northern Territory Health (2005).

254. Ibid.

255. Queensland Health (2015).

256. Ibid.

To achieve this vision, and guide the development and implementation of the strategy, the following key goals have been identified:

- Care is supported by increased community awareness that dying is part of life;
- Care is always guided by a person's values and wishes, and involves them, or their Substitute Decision Maker, Persons Responsible or loved ones, as active participants in decisions about their care (person centred);
- People, and their family or carer(s), are well informed about care treatment options, and can provide feedback, including complaints, about their experience of care;
- People, and their family and carer(s), record their values and wishes for care at the end-of-life, and this information is readily available to health professionals across care settings to guide care;
- Health professionals have the skills and knowledge to recognise and sensitively communicate that a person is approaching the end of their life, assess their care needs and provide appropriate care;
- Health professionals understand their professional and legal responsibilities in providing care to people at the end-of-life;
- Service provision is interdisciplinary, coordinated and responsive, and supports high quality care over time (not episodic) and seamless transitions between care settings;
- People, and their family and carer(s), have access to services and a contact person for reassurance, advice and support, 24 hours a day, 7 days a week;
- Decisions about the design of services and allocation of resources are informed by consumer, family and carer feedback, data evaluation, and optimise equity of access; and
- SA Health services and commissioned services have processes in place to monitor and improve the safety and quality of end-of-life care services.²⁵⁷

A1.2.6. Tasmania

The Tasmanian Governments *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017-21* provides a framework for how Tasmania will achieve its vision for palliative care. Tasmania's vision is for a compassionate community that works together to ensure all Tasmanians have access to high quality, coordinated, respectful and responsive palliative care that is person-focussed and supports families and carers.

The key priorities areas for achieving this vision are as follows:

- Providing inclusive palliative care that is community and person focused by:
 - ▶ Developing a Tasmanian Palliative Care Community Charter by the end of June 2017.
- Strengthening communities of care by:
 - ▶ Finalising a state and sector wide strategy, *Strengthening Communities of Care: A strategy to build the capacity and capability of all Tasmanians in palliative care 2017–20*.
- Enhancing end-of-life care by:
 - ▶ Developing *End-of-life care: Supporting Tasmanians to live well at the end-of-life*, a consistent approach across Tasmania to delivering end-of-life care by the end of June 2017.
- Enhancing bereavement care by:
 - ▶ Implementing the recommendations of *Bereavement Care in Tasmania: Current Status and Future Directions for Palliative Care over the duration of Compassionate Communities*; and
 - ▶ Establishing Bereavement Care Networks by December 2017.

257. South Australian Health (2018).

- Delivering contemporary, accountable and sustainable specialist palliative care services by:
 - ▶ Commencing development of a model of care for specialist palliative care services by June 2017; and
 - ▶ Developing a plan by December 2017 to agree and implement an associated reporting and performance framework.
- Providing leadership, coordination, monitoring and evaluation by:
 - ▶ Developing processes to support ongoing development, leadership and coordination of the palliative care system, in partnership with key sector representatives by December 2017; and
 - ▶ Providing an annual progress report to the Minister for Health.²⁵⁸

A1.2.7. Victoria

In 2016, the Victorian Government released *Victoria's end-of-life and palliative care framework: A guide for high-quality end-of-life care for all Victorians*. The vision of the framework is for all Victorians and their families to receive the best possible end-of-life care that places them at the centre where preferences, values, dignity and comfort are respected, and quality of life matters most.²⁵⁹

To achieve this vision, the government has developed the following goals in consultation with community and expert representatives:

- People experience optimal end-of-life care;
- People's pain and symptoms are managed using quality interventions;
- People's preferences and values are recognised and respected in their end-of-life care;
- Carers are better supported;
- People are cared for in their place of choice; and
- Where possible, people can choose to die in their place of choice.²⁶⁰

Victorian Government will work with communities and services to deliver optimal care by:

- Focusing on people and outcomes;
- Enabling local solutions;
- Equipping the service system to deliver earlier and more connected support;
- Ensuring safety, quality assurance and innovation; and
- Using data and evidence for service development and monitoring.²⁶¹

A1.2.8. Western Australia

The aim of the *Western Australian End-of-Life and Palliative Care Strategy 2018-2028* is to provide strategic state-wide policy direction and outline the vision, values and priorities for end-of-life and palliative care in Western Australia (WA) to 2028.

This Strategy affirms that palliative care is a human right and is fundamental to improving the quality of life, wellbeing and dignity of all individuals. It outlines the care values and supporting factors that are at the foundation of end-of-life and palliative care.²⁶² Priority areas aim to guide and inspire public, private, community and non-government health sectors to partner for the provision of best-practice end-of-life and palliative care. This includes the delivery of specialist and non-specialist teams providing end-of-Life and palliative care.

258. Tasmanian Government Department of Health and Human Services (2017).

259. DHHS (2016).

260. Ibid.

261. Ibid.

262. Government of Western Australia Department of Health (2018).

The identified priority areas are:

- Care is accessible to everyone, everywhere.
- Care is person-centred;
- Care is coordinated;
- Families and carers are supported;
- All staff are prepared to care; and
- The community is aware and able to care.²⁶³

A1.2.9. Other

Table A1-1 summaries other key government documents on palliative care.

Table A1-1: Palliative care policy summary

POLICY
The Australian Commission on Safety and Quality in Health Care 2015 <i>National Consensus Statement</i> ²⁶⁴
The <i>National Palliative Care Standards</i> ²⁶⁵
The <i>Palliative Care Service Development Guidelines</i> ²⁶⁶ communicate the expectations of Palliative Care Australia (PCA)
The <i>Aboriginal and Torres Strait Islander peoples Palliative Care Resource Kit</i> ²⁶⁷

A.1.3. PLACE OF DEATH

Surveys consistently show that between 60% and 70% of Australians would prefer to die at home, and that residential care facilities are their least preferred option.²⁶⁸ In addition, the cost of dying at home is considerably lower than the cost of dying in hospital or at an aged care facility (Table A1-2).

Table A1-2: Place and costs of death for older people, Australia, 2011²⁶⁹

PLACE OF DEATH	NO. OF DEATHS	% DEATHS	COSTS (\$M)	% COSTS	COST PER DEATH
Acute inpatient	51,759	35%	2,440	48%	\$47,142
Residential care	50,866	35%	2,330	46%	\$45,807
Sub-acute	21,470	15%	221	4%	\$10,293
Community care	4,655	3%	77	2%	\$16,541

However, only around 14% of people die at home in Australia, 54% die in hospitals and 32% in residential care.²⁷⁰ Home and other non-institutional deaths are about half as prevalent in Australia as they are in New Zealand, the United States, Ireland and France.²⁷¹

The likelihood and timing of death is now more predictable and there is more opportunity and time to prepare for death because people are now much more likely to die from chronic disease in old age.²⁷² With this development, the personal preference of terminally ill patients, and the reduced cost per death, allowing more Australians to die at home could be better facilitated.

263. Ibid.
 264. Commonwealth of Australia (2015).
 265. Palliative Care Australia (2018a).
 266. Palliative Care Australia (2018b).
 267. The National Palliative Care Program (2007).
 268. Duckett et al (2015).
 269. Duckett et al (2015).
 270. Ibid.
 271. Broad Et al (2013).
 272. Ibid.

A.1.4. PEAK BODY POSITIONS REGARDING ASSISTED DYING

There are varying degrees of support for assisted dying by peak bodies across Australia.

Peak bodies and their positions are as follows:

- The *Australian Medical Association (AMA)* does not support interventions whereby a doctor has as their primary intention to end a person's life. It recommends doctors involvement in open conversations around, and development of, assisted dying legislation (2018).
- The *Australian and New Zealand Society of Palliative Medicine (ANZSPM)* does not support the legalisation of assisted dying but recognises that ultimately these are matters for government to decide having regard to the will of the community and, critically, informed by appropriate research and consultation with the medical community, including palliative medicine practitioners. ANZSPM endorses international guidelines reaffirming that assisted dying is not part of best practice palliative care. ANZSPM will continue to advocate for and, through its members, deliver good quality care for the dying, and this does not include the practice of assisted dying (2017).
- The *Australian and New Zealand Society for Geriatric Medicine (ANZSGM)* supports the views of the ANZSPM, the AMA, the WMA and the RACP (NZ) on the issues of assisted dying - it opposes legislation which would allow euthanasia or PAS (2010).
- The *Royal Australasian College of Physicians (RACP)* respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is very important. The existence of divergent views constrains the RACP position on medical assistance in dying. Having considered the large number of thoughtful and nuanced consultation responses from members, the College has decided that a neutral position is most appropriate (2018).
- The *Palliative Care Nurses Australia (PCNA)* believe that: palliative care does not include the practice of euthanasia or assisted suicide; and that the intent of palliative care is to neither hasten or postpone death (2017).
- The *Australian Nursing & Midwifery Federation (ANMF)* support legislative reform so that persons who have an incurable physical illness that creates unrelieved, unbearable and profound suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes (2016).