



Parliament of  
South Australia

---

**REPORT**

**OF THE**

**JOINT COMMITTEE**

**ON END OF LIFE CHOICES**

---

*Laid on the Table of the Legislative Council and ordered to be printed on 13 October 2020*

---

**Second Session, Fifty-Fourth Parliament 2020**



# CONTENTS

<b>1. The Joint Committee</b>	
1.1 Appointment	3
1.2 Membership	3
1.3 Meetings	3
Committee Statement	5
<b>2. Findings</b>	5
<b>3. Overview of evidence</b>	7
<b>4. Background</b>	8
<b>5. The Inquiry</b>	9
5.1 Term of reference (a)	9
5.2 Term of reference (b)	20
5.3 Term of reference (c)	35
5.4 Term of reference (d)	43
<b>6. Acknowledgements</b>	44
<b>Appendix 1: List of witnesses</b>	45
<b>Appendix 2: List of submissions</b>	46



# 1. Joint Committee on End of Life Choices

## 1.1 Appointment

A Joint Committee of the South Australian Parliament has been established to inquire into and report on:

- (a) The practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;
- (b) The current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian and Western Australian Parliamentary Inquiries into end-of-life choices, Victoria's *Voluntary Assisted Dying Act (2017)* and implementation of the associated reforms;
- (c) What legislative changes may be required, including consideration of:
  - i. The appropriateness of the Parliament of South Australia enacting a Bill in similar terms to Victoria's *Voluntary Assisted Dying Act (2017)*;
  - ii. An examination of any federal laws that may impact such legislation;
- (d) Any other related matter.

## 1.2 Membership

The Hon. K. J. Maher, MLC (Chairperson)

The Hon. D.K.B. Basham, MP

Mr. S. J. Duluk, MP (*until 4 February 2020*)

The Hon. D.G.E. Hood, MLC

The Hon. M.C. Parnell, MLC

The Hon. A. Piccolo, MP

Mr. S. P. Murray, MP (*from 6 February 2020*)

### *Secretary*

Ms. L. Guy, Clerk Assistant

Mr. A. Beasley, Parliamentary Officer

### *Research officer*

Dr. M. Robinson

## 1.3 Meetings

The Select Committee advertised for interested persons to provide written submissions or to register an interest in appearing before it. The Committee met on 11 occasions, on 5 occasions to hear evidence. A list of people who appeared before the Committee are listed in Appendix 1. The Committee received 126 written submissions related to the Terms of Reference, and a significant number of other submissions. The submissions the Committee resolved to publish are listed in Appendix 2.



## Committee Statement

Recognising that the Terms of Reference placed considerable import on Voluntary Assisted Dying, the Committee wished it noted that Members of the Committee held divergent views on the issue, with some being supportive of legislative change, while others were not.

## 2. Findings

The Committee's first two Terms of Reference dealt with a number of existing matters:

- Current medical practices that assist people to exercise their preferences with regard to managing their end of life - specifically in the context of chronic and terminal illness and including palliative care;
- Current legal frameworks in South Australia and other jurisdictions;
- Relevant reports and materials from around the world including the work of Parliamentary Committees such as those in Western Australia and Victoria; and
- The implementation of reforms associated with Victoria's *Voluntary Assisted Dying Act (2017)*

In undertaking work on these terms of reference, a number of consistent themes emerged:

1. Palliative Care is a critical part of our health and wellbeing system although it requires a greater level of funding to ensure that it provides more consistent and equitable access.
2. Any improvements to the Palliative Care system should design services that are appropriate and accessible for people in regional areas, Aboriginal people and those for whom English is not a primary language.
3. A key focus of Palliative Care should be on the dignity of people who are approaching the end of life.
4. There is a general need to improve data collection and reporting on palliative care – including the experiences of patients, their families and loved ones, clinicians and carers.
5. Advanced Care Directives provide a critical tool for people to express their wishes and ensure that these are respected and enacted within boundaries.
6. There is a need for greater awareness amongst the broader population about the existence, operation and limits of Advanced Care Directives
7. There is a need for greater education amongst clinicians, care workers and emergency services about the operation of Advanced Care Directives and their importance to the dignity and wellbeing of those who have chosen to prepare them.
8. Whilst South Australia was viewed as an international leader in Advanced Care Directives, the legislation and its associated policies may benefit from review and updating in light of changes in health care and community attitudes.
9. Similar to palliative care, there is a need to improve data collection and reporting on Advanced Care Directives – including the experiences patients, their families and loved ones, clinicians and carers. Improved reporting will assist in addressing other findings related to awareness and education.

10. There are different systems for Advanced Care Directives or their equivalents in Australian jurisdictions and this presents a barrier to people who are not in their home jurisdiction when elements of the Directive may be triggered. South Australia should liaise with the Commonwealth and all states and territories about the appropriateness of federal legislation, or a harmonised approach, or legislative mutual recognition of these instruments.

A further Term of Reference focused on potential new legislative measures in South Australia. With regard to this matter, it is recognised that:

1. There are sincere, genuine and deeply held divergent views, reflected in previous attempts at legislative reform and in witness testimony, on the merits and specifics of law changes.
2. Over time, jurisdictions around the world and some in Australia have adopted a range of legislative approaches to voluntary assisted dying;
3. Based on the evidence received by the Committee, the most relevant approach with the highest levels of safeguards, checks and balances while allowing this end of life choice appears to be Victoria;
4. The Victorian approach, that has now operated for more than a year, has attracted divergent observations that it may present barriers to people as a result of the level and type of conditions that apply and calls to relax them are seen by some as potentially increasing the risk of misuse of the scheme.
5. Western Australia has introduced a system for voluntary assisted dying that provides greater flexibility for people in regional and remote areas noting that South Australia is more affected by geographic dispersion of population than Victoria but less than Western Australia.
6. South Australia should monitor and review the outcomes of the systems in Victoria and Western Australia and should the Parliament at some future date decide to legislate for a Voluntary Assisted Dying scheme it should have regard of how the different schemes could be integrated to prevent any further hardship or trauma.

The Committee's Terms of Reference also allowed it to investigate and report on any other related matter. A number of issues arose that do not necessarily fit into one of the areas referred to above but which warrant recognition. These are:

1. The benefits to individuals and the health system from a connected, well-funded and coordinated end of life approach that reduces avoidable hospital admissions and provides people with greater capacity to die in a location of their choosing;
2. The significant, traumatic and enduring impacts on those closest to a person at the end of life who is not able to exercise choices and preferences and who experiences prolonged distress because the lack of appropriate resources; and
3. The work of, and impacts on, emergency services workers including police and ambulance officers who are called upon to manage situations immediately before and after end of life.



### 3. Overview of Evidence

Evidence before the Committee revealed deeply held values and beliefs around death, dying and end of life decision-making, resulting in strongly divergent views and entrenched but conflicting ideological perspectives. These opposing stances generated emotive arguments either for law reform or for the retention of the practices currently being utilised in South Australia. The Committee was urged, implored, pleaded with, as the decision-makers, and prayed for, given the incredibly difficult challenge vested in its role.

From the perspective of those seeking change, the Committee was entreated to advocate for law reform that would relieve the suffering of those at the end of their life. Conversely, the stance of those opposed to change was for the Committee to hold fast to the existing laws and principles against killing and, thus, to sustain life. Individuals, health professionals and their associations, hospitals and care providers, legal academics, former politicians, research institutes, advocacy groups, and representatives from the church hierarchy and laity petitioned the Committee. With opinion polarised across the spectrum, their voices came from both sides of the divide.

Evidence on current practices for managing end of life assistance revealed strong support for palliative care but also the shortcomings in the system stemming from lack of funding, resources and coordination across the several settings that provide that care. The call was for an accessible, fully resourced palliative care service to meet increasing demand. While the legal underpinnings of end of life care were deemed innovative and balanced, deficiencies were exposed in the lack of knowledge of the legal requirements around consent and the role and import of Advance Care Directives (ACDs) among both the general public and clinicians.

From personal experience, family members and health professionals revealed the intractable suffering of some patients and the limited options to afford them relief. While a few may have access to illegal assistance in their request to die, others endured protracted deaths from the paucity of choices available to them: terminal sedation or their refusal of treatment, food and hydration. Details of the only other option for those seeking early release from their suffering, suicide, revealed its often brutal impact on family, police and paramedics.

In considering other jurisdictions that have legalised voluntary assisted dying (VAD), the Committee heard strong opposition from Christian organisations, individuals and advocacy groups that detailed the multiple failings in those systems. They condemned the likelihood of the “slippery slope” that would inevitably lead to involuntary euthanasia, the coercion of vulnerable patients, including the mentally ill, the elderly and patients with a disability, of wrongful deaths, and safeguards being breached. Many clinicians insisted that palliative care could provide the necessary care and relief of suffering. Even so, evidence from reformers refuted these claims.

With regard to South Australia enacting similar legislation to that of Victoria, opinions again diverged, but in this instance they were not so equally divided. Although there was a degree of praise for Victoria’s unhurried, consultative development and implementation of the Act, and a few were broadly supportive, many were critical of its excessive caution and multiple safeguards that presented dying patients with too many barriers to surmount. Given the extent of the criticism, the overall assessment was that South Australia should not “mirror” the complexity of the Victorian Act but devise legislation that is more efficient and responsive to the patient’s needs. The Committee travelled to Victoria to better inform the Inquiry.

## 4. Background

In Australia, commonwealth, state and territory governments have attempted to reform laws relating to voluntary assisted dying (VAD) for more than three decades. The Northern Territory was the first jurisdiction in the world to legalise VAD with the *Rights of the Terminally Ill Act 1995*. It was overturned by the Commonwealth Government under its constitutional powers by way of the *Euthanasia Laws Act 1997* that still prohibits territories from passing laws relating to VAD.

Oregon enacted the *Death With Dignity Act* in 1997, the first in the United States. In time, another 9 jurisdictions would follow suit. In Europe, VAD is legal in the Netherlands (2002), Belgium (2002) and Luxembourg (2009). Switzerland's unique legal structure has been in place since 1942. VAD is also lawful in Quebec (2015), Canada (2016) and, by Resolution, Colombia (2015).

There have been a notable number of failed legislative attempts in Australia. By 2015, 51 bills relating to VAD had been introduced at the commonwealth, state and territory level, 39 specifically aimed at legalising VAD. A further seven bills were tabled from the beginning of 2016. Amid international trends to permit VAD and emergent social science evidence about the practice, more recently many of these bills have come close to passing. The *status quo* was overturned in Victoria when the *Voluntary Assisted Dying Act 2017* was passed in November 2017. The law came into effect on 19 June 2019. The Western Australian Parliament passed the *Voluntary Assisted Dying Act 2019* in December 2019.

In South Australia there have been a significant number of Private Members' Bills tabled in the Parliament, more than in any other Australian jurisdiction.<sup>1</sup> The first was in 1995. The last, the Death with Dignity Bill, was defeated in the House of Assembly on 17 November 2016 by one vote, the casting vote of the Speaker, after prolonged debate.

On 20 March 2019, the Hon. Kyam Maher, Leader of the Opposition in the Legislative Council, moved a motion that a joint committee be appointed to inquire into end of life choices. He noted that Victoria had "done the legwork" via a parliamentary committee and passed legislation with numerous safeguards. At that time, Western Australia was also near to introducing legislation as a result of its own parliamentary committee. Essentially, VAD has widespread community support that has increased over time. He went on to describe the suffering and cruel death of his mother and a political colleague. Their pain and loss of dignity gave impetus to his commitment to ensure people have control at the end of their lives.

On 3 April 2019, the Hon. Stephen Wade, Minister for Health and Wellbeing, amended the motion by revising Term of Reference (c), deeming the existing version too open-ended. Asking the Committee to consider instead "the appropriateness of the Parliament of South Australia enacting a Bill in similar terms to Victoria's *Voluntary Assisted Dying Act (2017)*" would provide a focus and starting point. As such, a rational, respectful and productive discussion would be more likely ensue.

---

<sup>1</sup> In its submission, the South Australian Voluntary Euthanasia Society (SAVES) cited 15 Bills aimed at legalising VAD between 1995-2016. (Sub 95, p 18). They referenced SAVES FACTSHEET 33: Timeline for voluntary euthanasia bills in the South Australian Parliament that provides details of each Bill, elements of the debate, the Bill's progress and voting numbers: <https://988c9073-ec7c-40b2-8b6c> South Australian Parliament Research Library, *Assisted Dying*, June 2019 details the timeline of euthanasia-related legislation introduced in the Upper and Lower houses of the of the South Australian Parliament between 1995-2016, with links to the Bills and votes, 2005–2019, pp. 7-9.

The motion and the amendment were supported. The Joint Select Committee on End of Life Choices was established on 4 April 2019.

## 5. The Inquiry

### 5.1 Term of reference (a)

*The practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;*

The current practices in South Australia’s end-of-life care are underpinned by:

- the *Consent to Medical Treatment and Palliative Care Act 1995* (the Consent Act);
- the *Advance Care Directives Act 2013* (the ACD Act) that succeeded and consolidated both the Consent Act and the *Guardianship and Administration Act 1993*; (Evidence, p 13, 14, 24)
- the *Advance Care Directives Variation Regulations 2019*, following a review of the *Advanced Care Directives Act 2013* by Professor Wendy Lacey in 2019; (Sub 110, p 6; Evidence, p 35)
- SA Health’s *Resuscitation Planning - 7 Step Pathway* for standardised clinical care, including patients’ preferences for treatment and limitations placed on resuscitation and other life-sustaining treatments. (Sub 111, p11)

Tensions and divisions were exposed in the interpretation of the legislation.

The Committee heard that South Australia has been a “pioneer in end-of-life legislation”, with the Consent Act being the first time in the world that “palliative care” had appeared in an act of parliament. It was judged to be “excellent consent legislation”, providing a framework for end-of-life care. (Evidence, p 24) The ACD Act, too, is among the most advanced in the world, promoting an Advanced Care Directive (ACD) to provide a “legally binding ‘voice’” for those who have lost decision-making capacity, along with the appointment of substitute decision makers to act on the person’s behalf. (Sub 110, p 3)

Dr Chris Moy, President, Australian Medical Association (South Australia) (AMA SA), affirmed that the State “currently has the most complete framework of legislation”, with the ACD Act and the amendments to the Consent Act promoting self-determination, while also protecting doctors. (Evidence, p 35) Effectively, the current legislation offers an “elegant balance” in good end-of-life care by clarifying consent ages, while focussing on individual autonomy and an individual’s values and wishes, particularly relevant refusals of treatment, even if they have lost decision-making capacity. As such, a doctor must withdraw even life-sustaining measures if directed by the patient or their representative. Equally, doctors are not required to offer or continue futile treatment of no medical benefit to a dying patient, with protection when they are providing adequate treatment to ensure comfort and dignity. (Sub 105, p 9; 110, p 4; Evidence, p 14, 15)

Dr Roger Hunt, Senior Consultant, Central Adelaide Palliative Care Service, (CAPCS) explained that the Consent Act, deemed progressive in 1995 and “the envy of other states of Australia and the world”, was designed to protect clinicians, clarifying much about “what was legal, what was not legal and who had what rights around end-of-life care”. Under the Act,

there is “no civil or criminal liability by administering treatment with the intention of relieving pain or distress ... even though an incidental effect of the treatment is to hasten the death of the patient”. (Evidence, p 14, 16) Accordingly, it affords protection to persons who administer palliative care at the end of life where medication may also accelerate the patient’s death, effectively codifying the Doctrine of Double Effect, i.e. the doctor’s intention when administering the medication. (Sub 6, p 2; Sub 66A, p 1)

Despite that assessment, Professor Ben White and Professor Lindy Willmott<sup>2</sup>, who have researched extensively in health law and end of life decision-making, judged protection for doctors under the Consent Act to be less than what was previously available at common law. Those providing the medication are required to adhere to a higher standard of medical practice: doctors must work in accordance with proper professional standards of palliative care and without negligence, with the intention of relieving pain or distress. Moreover, the person to whom the medication is administered must be in the terminal phase of a terminal illness. (Sub 66A, p 1, 6, 7; Sub 67, p5)

Although the Consent Act may shield clinicians, in Dr Hunt’s view it lacks safeguards for patients. Under the current regime, there are “no two doctors involved, ... no witnessed written statements, ...no documentation”, nor protection from abuse and coercion. (Evidence, p 14, 15, 16) Concomitant with that, the AMA (SA) and others advised of “significant caution” in relation to the *Advance Care Directives Variation Regulations 2019*, arising from the review of the ACD Act. The Regulation disallows any ACD purporting to refuse specific medical treatment if the doctor suspects the person has attempted suicide. As such, the Regulation removes South Australians’ right to have their wishes respected, altering that “fine balance” between protecting individuals and safeguarding autonomy, thus undermining the central principle of the Act, which is to support self-determination. (Sub 107, p 4, 5; 110, p 8; Evidence, p 35)

Notwithstanding the capacity of an ACD to ensure that a person’s end of life wishes are recognised, the take-up rate has been limited. Professor Gregory Crawford, Professor of Palliative Medicine, University of Adelaide, acknowledged that there is “clearly no ongoing support in any material way” regarding the ACD “rollout, legislation and its use” in local health networks, much less in the whole community, as further evidenced by limited attendance at Palliative Care South Australia (PCSA) open education sessions. He identified the need for ongoing education and support for the general public around death literacy and health literacy, suggesting that the current use of ACDs “is very white middle-class, higher socio-economic status stuff, that high basic literacy”. (Sub 105, p 9; Evidence, p 24)

Sandra Bradley, RN, PhD and an ACD Consultant, argued that there is still “a long way to go to educate the public on how to complete an ACD, when to complete it and why”. In her view, vested interest groups are determined that the document fail and “do their best” to ensure this occurs. She referred to healthcare professionals who “don’t believe in the form or refuse to accept the instructions” and lawyers/solicitors who change the wording of the forms or challenge their legality. Additionally, family members are “constantly bombarded with messages in the media and elsewhere”, including from healthcare professionals, that there are “cures” and “more that can be done” when, in fact, treatments are only delaying the inevitable. (Sub 2, p 1)

---

<sup>2</sup> Professor Lindy Willmott and Professor Ben White are employed at the Queensland University of Technology.

Further to that, the AMA (SA) emphasised the stark misalignment of inadequate funding to educate and train health practitioners about their obligations to respect patient ACDs and their wishes when compared to the exponentially increasing cost of life-saving technologies for serious conditions approaching end of life. Particularly in cancer and intensive care cases, these technologies are sometimes used to treat patients at odds with their wishes, as well as good medical practice. (Sub 110, p 5)

Moreover, the fact that vulnerable groups in the community present significant barriers to discussing death and dying has not been adequately considered. Professor Crawford advised, “Australian Aborigines are really fearful of talking about death”. To engage in such end of life discussions requires considerable “relationship building”. Similarly, culturally and linguistically diverse (CALD) people frequently do not have the “same self-autonomous view about decision-making”. While most Australians might assert that it is their body and, thus, their right to decide, it is not so in all communities, especially among the vulnerable who may require different practices from the current “one size fits all” attitude. (Evidence, p 24)

A further challenge to the generic approach to death and dying came from disability advocacy group for VAD, *My Body My Choice*. While they asserted their autonomy and their right to decide, they raised concerns based on consistent experience with medical authorities. People with disabilities, especially those that stem from a damaged brain, are commonly accorded less status and respect than other patients. They are given less credibility and, should there be any difficulty in hearing or understanding the person due to their disability, their views are frequently discounted or ignored completely. As such, should a person with a disability later acquire an illness meeting the criteria for VAD, the concern is that they could be refused access to VAD because of their disability, effectively encountering discrimination. (Sub 89, p 2, 3)

Additional impediments exist in within the “actively involved general practice population” where there are misunderstandings about current consent, the consent legislation and the safety and provisions it provides. (Sub 105, p 9) Professor White and Professor Willmott researched the knowledge of doctors who practise medicine at the end of life. Their findings indicate that doctors have poor understanding of the law about withholding and withdrawing of treatment at the end of life from adults who lack decision-making capacity. In their view, this needs to be considered when drafting and implementing laws at the end of life. (Sub 66, p 7)

Despite these reservations regarding the existing legal framework, there was strong advocacy for the essential role of palliative care in managing end of life preferences. As PCSA explained, “death and dying are not just a medical or health event”. Rather it is a “human experience”, where care is “person centred”. That philosophy is amplified in Palliative Care Australia’s (PCA’s) definition:

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. (Sub 105, p 5)

PCSA insisted that the delivery of quality palliative care at the optimum level to all South Australians, irrespective of geographic location or socio-economic status, must precede the implementation of any VAD scheme. They rejected the introduction of any such scheme due to “gaps in systems reform” and funding in palliative care, while also acknowledging the current inequitable access across the State. As such, there is a wide discrepancy between

palliative care services available in the metropolitan area and those accessible in rural and remote regions. Without significant changes to funding and delivery, these inequities will only continue to increase. (Sub 105, Covering letter, p 1, 2; Sub p 5)

The Australian & New Zealand Society of Palliative Medicine (ANZSPM) reiterated the inadequacies in the current systems in both countries that deny universal access to quality end of life care which may extend over the last days, weeks and years of a person's life. (Sub 121, p 2, 3) ANZSPM proposed that good palliative care supports the person, carers and health professionals, ensuring that the person is informed about their condition, is involved in shared decision-making, and in communicating preferences for their care; proactive clinical care for physical, psychological and emotional needs is fundamental. Support for informal caregivers is also critical, including in the bereavement period. Despite these stated goals, the society maintained that the health care system is failing to manage adequately the complexity of the needs and burdens of people at the end of life, including access to services, quality of care, health professional competencies, and responsiveness to preferences and choices. (Sub 121, p 5, 6)

Palliative care is delivered by a range of health providers in different settings, including community services in the home, residential aged care, and in specialist palliative care facilities. Acknowledging that care in South Australia is patchy and inadequate, Professor Crawford explained that with a referral to a specialist palliative care service, a person is likely to access "good to excellent symptom control" and be more likely to be cared for and potentially die in their preferred place. (Sub 105, p 12; Evidence, p 25) The latter is relevant, given that 70 per cent of people would prefer to die at home but only 14 per cent do; most die in hospital or residential care. (Sub 67, p 7) Even so, quality of palliative care and access are dependent on referral pathways, geography, socio-economic status, and personal resources. While there are specialist palliative care beds in some public and private hospitals, these services are limited in number and tend to care principally for patients with terminal cancer. (Sub 67, p 4; Sub 105, p, 5 10) In Sandra Bradley's view, if palliative care cannot be resourced to provide care to everyone, then it is a resource for the wealthy and elite and should be paid for privately. (Sub 2, p 2)

PCSA clarified that the manner in which community services are delivered in this State add layers of complexity and disparity in outcomes. There are differences in how local health networks disperse funds to community and inpatient services, along with inconsistencies in the metrics of outpatient programs and home visiting programs. (Sub 105, p 10) Dr Moy explained that the deficiencies arise from inadequate resourcing and poor coordination of palliative care and end of life care, particularly in the community where responsibility of care is fragmented across several silos: general practice, specialist palliative care, private health services and non-governmental organisations (NGOs). The Apostolic Administrator of the Adelaide Archdiocese and Bishop of Port Pirie, Greg O'Kelly, advised that in Australia Catholic hospitals provide approximately 13 per cent of all palliative care and in South Australia the Catholic Church is the largest provider of private palliative care beds. (Evidence, p 37; 126)

Effectively, the "fee for service" business model for general practitioner (GP) remuneration throws up another barrier to community based end of life care. In Australia, GPs are not remunerated appropriately for the time or cost of visiting a person at home, unlike the United Kingdom where GPs are salaried through the National Health Service (NHS). This enables home visiting without financial disadvantage and provides systems support for GPs, such as an End of Life Register that identifies a patient in the last year of life. (Sub 105, p 10, 11; Evidence,

p 25, 26) While agreeing that home visits are not paid adequately, Dr Carolyn Lawlor-Smith, Doctors for Assisted Dying Choice, also maintained that the new generation of GPs, many of them overseas trained, are not accustomed to after-hours work. They “want to work part-time; they don’t want to do any after-hours”. (Evidence, p 10)

While palliative care in aged care homes is dependent on the availability of experienced GPs who are willing to do home visits and in and out of hours calls, many of these facilities are managed by after-hours, under-qualified (GP Registrar) locum doctors. Due to reduced staffing ratios and fewer trained staff (often only one registered nurse for 80 residents overnight), anyone who might deteriorate after hours is generally sent by ambulance to an acute care hospital. This has resulted in increasing numbers of patients dying in ambulances and emergency departments. (Sub 67, p 4) Statistics from the Australian Institute of Health and Welfare (AIHW) in 2018 revealed that South Australia had the highest rate of palliative care-related hospitalisations in all hospitals at 38.5 per 10,000 population. For private hospitals, the State recorded the highest overnight average length of stay (ALOS) at 15.9 days; for public hospitals it was 10 days. (Sub 105, p 6, 7) In light of that, residential care facilities have been identified as requiring more attention and support. They have become the “slow-stream hospices” of the health system where, increasingly, people are dying in environments with large disparities in staffing levels, the knowledge base, access to medications and good medical advice both during the day and after hours. (Sub 105, p 11; Evidence, p 26)

State and Commonwealth Government jurisdictions add further to the complications around community support and lead to a diversion of resources, with federal My Aged Care services being used in an attempt to provide community packages of palliative care. In addition, some SA Health programs will assist the acutely dying or relatively short-term dying but nurses coordinating the process must determine prognoses and try to accommodate people into programs. If the person is under 65, however, it is more difficult to access services, equipment and other essential support as there are barriers to referral, some due to health literacy and funding. Equally, people with non-cancer conditions miss out, with a ratio of 80 per cent cancer patients to 20 per cent non-cancer patients in most palliative care services. (Sub 105, p 10, 11)

Essentially, the State needs a properly constructed, fully resourced palliative care service that is easy to access, along with more accurate data on the people who receive palliative care, the quality of that care, and how much and where money is spent. South Australia’s Health Performance Council (HPC) data does not reveal details about the care palliative medicine physicians and their teams provide in the State’s specialist hospices and palliative care units. (Evidence, p 27) Clinicians are further hampered in their ability to “facilitate a good death” by the limited uptake of ACDs, as noted above, and the greater emphasis on “active treatment to the end” in many acute hospitals, with some specialist physicians and surgeons resisting a referral to palliative care services; further indication that discussions about death and end of life matters are still “taboo” for many in this State. (Sub 67, p 4)

The HCP’s *Revisit Review of South Australia’s Palliative Care Services Plan 2009-16* in November 2018 summed up:

Despite the early impetus to establish ... a centrally coordinated model of end-of-life care, progress ... has stalled. The four objectives identified in the plan – improved health and wellbeing outcomes, person-centred care, more care in the community, and consistent service delivery – have been achieved only in part. The lack of progress is

due to factors such as contested resources, service variability between local health networks, and the absence of central coordination and governance. (Sub 105, p 7)

In light of that, PCSA applauded the State Government's commitment to invest an additional \$16 million over the next four years to build capacity and ensure equitable access to palliative care services. This will go part of the way to:

- building 24/7 community palliative care capacity to support people at home in their final stage of life, with the help of their GP and experienced palliative care community nurses;
- integrating palliative care across the acute care setting which would relieve pressure on the acute system and reduce the number of terminally ill people in hospital beds, including intensive care, and fewer emergency department presentations.

Even so, there is still greater need to increase targeted funding to ensure the increased demand for palliative care and services is met. (Sub 105, p 8)

Helen Chalmers, Executive Director, Health Services, Programs and Funding, SA Health, provided further details regarding the \$16 million being invested from 2018-19 to 2020-21. The four aims are to:

- expand community outreach palliative care services from the current predominantly weekday service to that of 24/7;
- undertake a statewide assessment of palliative care needs;
- establish a statewide clinical network for palliative care; and
- co-design and deliver a new palliative care services plan.

She also advised of the Palliative Care in Aged Care agreement with the Commonwealth Government. The total funding of \$7.65 million is focused on improving access to palliative care in residential aged-care facilities, building stronger partnerships with the primary care sector, and increasing the education and training of the residential aged-care workforce. (Evidence, p 80)

The Bishop of Port Pirie, Greg O'Kelly, provided further data from a recent PCA and KPMG report<sup>3</sup> that an annual investment of \$365 million would see Australia's palliative care system operating efficiently. The funding would end the "underfunded at-home care and the token services administered too late" that result in people being taken "in and out of hospital in their late stages" in an ambulance because "there is not a proper palliative care set-up". The report proposed that \$240 million would provide timely access to at-home palliative care, \$75 million would fund specialist palliative services at aged-care facilities, and \$50 million would expand the end of life services. (Evidence, 126, 127)

Reflecting existing conditions, however, the Committee received many disturbing personal submissions recounting the end of life experiences of family members and friends. While one woman described the doctors and nurses providing palliative care as "beyond angelic", her father still died a "disgusting" death, "in a cancer toxin ridden body, starved/dehydrated to death in a palliative care coma". For her, his death "will be forever traumatically etched" in his family's memory. Seeing "how inhumane it was", she begged for a "swifter, kinder, pain free passing". (Sub 39, p 1) Another woman also acknowledged that palliative care staff were "wonderful, there just were enough of them", adding that the "sad truth" is that understaffed

---

<sup>3</sup> *Investing to Save: The economics of increased investment in palliative care in Australia*, Palliative Care Australia and KPMG, May 2020: <https://apo.org.au/sites/default/files/resource-files/2020-05/apo-nid305285.pdf>



palliative care units cannot properly monitor patients “to make them comfortable so it’s up to the loved ones to sit with them and watch them die slowly and ask for more pain relief”. (Sub 9, p 1) A man reported that his wife endured two years of pain and suffering during which she had the best of care, “including supposedly palliative care” which was “totally inadequate”, partly because they lived in the country but also because “the routine didn’t fit the circumstances” with three weekly trips to Adelaide, five hours travel each way. He is still traumatised. “No-one should have to suffer as she did” and no family should have to watch their loved one suffer so. (Sub 11, p 1) Many more referred having nightmares when recalling a traumatic death, of cruelty, of patients being tortured, with them begging to die, begging for mercy, even the convoluted process of accessing care that caused more suffering. Another writer said that her husband would have chosen a gentler end to his life, avoiding much of the mental and physical suffering he was forced to endure; moreover, she would not be tormented by the traumatic memories. (Sub 13, p 6; Sub 18; Sub 38, p 1, 4; Sub 41, p 1; Sub 43, p 1, 2)

Medical professionals also advised of being haunted by the sadness of having “grievously let someone down”; of wrestling with a “lifelong series of ethical quandaries” since even a subtle adjustment of dosage or the prescription of multiple drugs to relieve suffering could have been justified, despite the risk of hastening death. One doctor described leaving the room with the patient and family members in tears and she, herself, “not ashamed to admit” to entering “the nurses station in tears at my inability to provide the solace and care that the patient and their family so richly deserve”. She also recalled a man with advanced Chronic Obstructive Lung Disease “who was grabbing at everyone and everything he could reach as he experienced drowning on dry land” before being heavily medicated to manage his distress. In her view he should never have been allowed to get to that state, as earlier he had expressed the wish to be relieved of his suffering. “We can do so much more better than this for our friends and families”. (Sub 10, p1, 2; Sub 36, p 3;)

Indeed, regardless of the State’s legislative and medical infrastructure and palliative care sector where “death is generally well managed”, with pain and symptoms adequately controlled, Dr Hunt (CAPCS) counselled that some terminally ill patients “continue to suffer ... because dying is a very unpleasant business. Palliative care does not have all the answers to suffering”. (Sub 66, p 479; Evidence, p 14) In contrast, Dr Moy (AMA SA) argued that under current legislation and double effect, a doctor can continue to give enough medication to relieve distress even if the secondary effect may be to hasten death. “And that is palliative care. There is always something more” the doctor can give. (Evidence, p 37) Then again, Marshall Perron, former Chief Minister of the Northern Territory, asserted it is false to claim that comprehensive, well-funded palliative care would ensure that no one need die a “bad death”, since even the best-resourced service cannot relieve the extreme suffering some endure. (Sub 6, p 2;) Despite such dissension, the trauma for a small cohort of people results in some five to ten per cent of patients of palliative care services requesting a hastened death, asking their doctor “Can you speed it up?” Lee Thomas, Australian Nursing and Midwifery Federation (SA Branch) (ANMF SA) told of “how hard it is to die for some people, and they are imploring ‘Please help me’”. Although death is part of the “everyday work” of health professionals, such appeals have a significant impact on staff whose “hands are tied”. (Evidence, p 17, 52)

While those patients suffering in palliative care may say they have “had enough” and ask for death to be hurried, under the existing regime their appeal, being illegal, would be refused. Even so, Dr John Willoughby, Professor Emeritus, Flinders University, offered insight into individual instances of illegal assisted dying. He clarified that people who wish to die on their own terms avoid palliative care, as assisted dying is illegal and generally opposed by palliative

care physicians. In rare situations in this State, however, where the person requesting assistance to die has the support of their family and where the request is judged appropriate by the immediate medical carers, assisted dying has been provided illegally within a “conspiracy of silence”. A group committed to such a conspiracy can be easily organised if all agree with the request. (Sub 15, p 1; Sub 13, p 4; Evidence, p 17)

While it is not known to what extent VAD is practised illegally in Australia, a few studies offer some data. Kuhse *et al* concluded that in 1995-1996, 1.8 per cent of all deaths in Australia resulted from voluntary euthanasia, and 0.1 per cent from physician-assisted suicide.<sup>4</sup> In 1995, as part of a campaign to legalise assisted suicide, seven Melbourne doctors wrote an open letter to the Victorian Premier, published on the front page of *The Age*, in which they admitted to having performed euthanasia.<sup>5</sup> (Sub 67, p 6, 7)

In response to the Hon. Mark Parnell’s question regarding the “every day” incidence of concealed unlawful VAD, Dr Roger Hunt (CAPCS) provided details of an anonymous survey of Australian surgeons from the *Medical Journal of Australia* that concluded:

More than a third of surgeons surveyed reported giving drugs with an intention to hasten death, often in the absence of an explicit request. However, in many instances, this may involve the use of an infusion of analgesics or sedatives, and such actions may be difficult to distinguish from accepted palliative care, except on the basis of the doctor’s self-reported intention.<sup>6</sup>

Dr Hunt deemed the survey supported the Hon. Mark Parnell’s supposition that patients are having their deaths intentionally hastened; it is happening “every day” and the practice lacks safeguards and oversight. Moreover, if the surgeons were open and honest about this practice, and if the law was enforced, more than one third of Australian surgeons would face prosecution for homicide. (Dr Hunt, Additional Information)

Although it does occur, Dr Willoughby pointed out that should anyone disagree with the individual’s request to hasten death, the conspiracy is thwarted. The risk of the illegality being exposed deprives the person of the opportunity to obtain assisted dying. Not being equally available to suffering persons, the current practice is inequitable. (Sub 15, p 2) The South Australian Voluntary Euthanasia Society (SAVES), too, was critical that health equity is not commonly raised in relation to law reform to allow VAD. In their opinion, the “current two-tier system – a chosen death and an end to pain outside the law for those with connections, and strong refusals for most other people – is one of the greatest scandals of contemporary practice”. (Sub 95, p 13) From personal experience, Shayne Higson argued it should not be a lottery where a small number of clinicians are willing to break the law and risk prosecution for allowing their patients to die peacefully at a time of their choosing, when others endure “horrendous suffering”. (Sub 38, p 4)

Being denied access to a chosen, albeit illegal, death, the remaining legal options for a person suffering beyond medical help, who is seeking to hasten dying, are “three hard roads”: terminal

---

<sup>4</sup> Helga Kuhse, Peter Singer, Peter Baume, Malcolm Clark and Maurice Rickard, “End-of life decision-making in Australian medical practice”, *Medical Journal of Australia*, 1997; 166 (4): 195-196.

<sup>5</sup> R Syme, D Russell, P Scrivener, N Roth, A Buchanan, D Bernshaw, S Benwell, “An Open Letter to the State Premier of Victoria”, *The Age*, 24 March 1995.

<sup>6</sup> Douglas CD, Kerridge IH, Rainbird KJ, McPhee JR *et al*, “The intention to hasten death: a survey of attitudes and practices of surgeons in Australia”, *Medical Journal of Australia*, Nov 19, 2001; 175 (10) 51-5.

sedation; refusing all medical treatment, food and water; or self-managed suicide. (Sub 15, p 2; Sub 120, p 17)

Within such an environment, the palliative care response to untreatable pain or refractory suffering that is difficult to control, is palliative or terminal sedation, as allowed under the Consent Act. It is a medically controlled process utilised close to the end of life, commonly without the explicit consent of the patient. Clinicians use opioids like morphine and sedatives, commonly midazolam, a sedative/relaxant like diazepam. The medication is placed in a syringe under the skin attached to a pump that slowly depresses the plunger, ensuring a constant infusion of the medication. The delivery is slowly titrated upwards, meaning that control of pain and suffering may take days to achieve. Marshall Perron maintained that once commenced, the death of the patient is intended and certain; sedation is usually continued until the patient dies. (Sub 6, p 3; Sub 64, p 2; Evidence, p 16)

Under the Doctrine of Double Effect, the intent cannot be to cause death but rather to induce unconsciousness to manage pain. In Dr Hunt's view, however, the "clinician's intention is a subjective thing, and it may be ambiguous". (Evidence, p 15) Similarly, Doctors for Assisted Dying Choice argued, a "doctor's intent cannot be quantified, perhaps even by the doctor". Death may occur with terminal sedation, when the patient slowly dehydrates and starves to death, but may take up to seven days or more, causing severe distress to patients and families. Effectively, it is a measure of last resort, with the primary intention of reducing suffering by reducing consciousness, even if the general effect is to hasten dying. (Sub 6, p 3; Sub 38, p 1; Sub 67, p 5, 7; Evidence, p 16)

Doctors for Assisted Dying Choice advised that it can be very difficult to keep a patient sedated with opioids, as well as comfortable over many days: ensuring their position is changed every two hours to prevent pressure areas; keeping them clean and dry; managing bodily secretions to maintain their dignity. Patients become increasingly tolerant to opioids, with doctors having to increase the dose. As opioid effectiveness declines, patients may be in and out of consciousness, with restlessness, distressed crying, hallucinations and sometimes aggression over many days before they die. (Sub 67, p 5)

Findings from the Victorian Legislative Council's Legal and Social Issues Committee Inquiry noted that, although widely practised, terminal sedation is "not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it". (Sub 120, p 16) Professor Lindy Willmott and Professor Ben White reported that in Australia little is known about the extent of palliative sedation at the end of life, with only limited exploration of the legal and ethical implications as to:

- whether the patient or the patient's family is involved in the decision-making process, particularly whether consent is obtained before sedation is provided;
- the circumstances when it does occur – whether to relieve physical symptoms or to relieve psychological or existential suffering;
- whether artificial nutrition and hydration is provided or withdrawn during the period of sedation leading to the patient's death. (Sub 66A, p 6)

Despite claims that there is no evidence that terminal sedation does hasten dying, (Evidence, p 44) in Dr Hunt's view, based on global parliamentary and legal reports, the "general effect is to hasten dying". The person is bed bound, their cough is suppressed, they are unable to communicate, unable to eat and drink and, usually, there is no provision for artificial hydration or nutrition, all of which contribute to hasten dying. But the duration of dying is uncertain,

from minutes to weeks, “where the person is in a pharmacological oblivion ... lying there, fading away, becoming skeletal, perhaps rattling with their breathing”. Some refer to it as “slow euthanasia ... a slow hastening of death”; it is not uncommon, occurring in 10 to 50 per cent of deaths in palliative care. (Evidence, p 16) Even with ordinary palliative care, it can take up to three weeks or so for a person to die. It is very stressful for the person and also for carers, often resulting in horrible post-traumatic stress. (Evidence, p 2)

Attendant to that, every adult who has “capacity” or is “competent” has the right to refuse medical treatment. The withdrawal or withholding of treatment, even life-sustaining treatment, can often involve very difficult and emotional decisions enmeshed in ethical, cultural, religious and moral considerations, as well as concerns about the legal implications. (Sub 67, p 4; Sub 120, p 17) Voluntary palliated starvation, or the voluntarily ceasing of food and fluids, is judged to be occurring more frequently, given the lack of options. (Sub 66, p 6) Although some patients will choose specifically not to receive artificial nutrition or hydration, and may so direct in an ACD, in other instances some family members may insist on parenteral fluids or a feeding tube. But fluids given subcutaneously can cause swelling and increase difficulty in breathing and, thus, suffering. Dying of dehydration can take up to 10 days and is distressing for the patient, family and carers. (Sub 67, p 4)

Submissions to the Inquiry portrayed the personal experience of patients who adopted the only legal avenue available to them – death by starvation and dehydration – and the inevitable suffering that accompanied “this slow and otherwise painful death”. During the three weeks it took one patient to die, part of the process was to refresh her mouth with swabs, along with her being bed-toileted and bathed, and turned every two hours, day and night. Low-level sedation and a level of pain relief subject to review was initiated but, so that there could be no question of hastening death, occasionally the “top up” pain relief was reactive rather than proactive. Phil Browne, an experienced palliative care nurse, advised while the belief may be that people will die a peaceful death within a few days of stopping food and fluid, many experience prolonged drawn-out suffering, sometimes for more than 10 days. During that time, patients have fluctuating levels of consciousness, drifting between confusion and lucidity and periods of agitation and distress. (Sub 3, p 2, 3; Sub 8, p 1, 2; Sub 13, p 5)

In light of this, people who are chronically or terminally ill and experiencing an “irreversible decline in physical health” have elected to commit suicide rather than endure what palliative care has to offer. (Sub 67, p 6) The State Coroner, David Whittle, advised that amid the increase in the number of deaths reported to the coroner each financial year, approximately 200 deaths - in 2018-19 there were 210 – are categorised in the courts as resulting from suicide. Mr Whittle explained that, due to budget and accommodation constraints, the Coroners Court has not yet established a suicide register or a coronial prevention unit as exists in some other states that would offer the fine statistical analyses of suicide data provided to the Inquiry in Victoria. With funding now having been made available through the Chief Psychiatrist, however, he is liaising with the Victorian Coroners Prevention Unit and the AIHW with a view to establishing a similar database (Evidence, p 66, 68, 72)

Even so, he identified a number of deaths by suicide, seemingly in response to people suffering “a deteriorating quality of life” from a disease likely to result in death. Although some of the cases did not involve a terminal illness and most did not include a prognosis of an estimated life expectancy of six or 12 months, or less or more, the person’s quality of life had “become so degraded” they had taken their own life in response. The Deputy Coroner, Anthony Schapel, concluded that people will continue to take their own lives, not necessarily due to a terminal

illness but because of the “degeneration of their quality of life” and the “hopelessness of their situation”. (Evidence, p 66, 68, 69, 71, 72) The Coroners Court of Victoria’s submission to the State Inquiry into End of Life Choices offered confirmation, reporting that there were 240 suicides of people experiencing “irreversible decline in physical health”. (Sub 67, p 6)

The Assistant Commissioner of Police, Scott Duval, provided further data from SAPOL’s holdings, showing the number of deaths attributed to suicide over the last four financial years:

- in 2016-2017 205
- in 2017-2018 203
- in 2018-2019 238
- 2019-2020 90 until 22 November 2019 (the date of SAPOL’s submission)

From 1 January until 22 November 2019, ten people had taken their lives as a result of terminal illness, equating to approximately 11 per cent of all suicides during that period. The age of those persons ranged from 63 to 88 years. A further seven people aged between 71 and 91 years took their own life; the reason was identified only as “age”. It is not uncommon for a combination of loneliness and health conditions related to age, rather than terminal illness, to lead to suicide. In some instances, the deceased person had viewed pro-euthanasia websites for methods that might be used. (Sub 123, p 1, 2)

The Assistant Commissioner advised that SAPOL respond to and investigate every death by suicide. Most deaths in such circumstances are undignified and violent. Some may be “botched”, possibly with a degree of pain, depending on the method and the person’s level of expertise when taking their life. Dr Lawlor-Smith advised there are some “very horrible ways of committing suicide. It is quite difficult to commit suicide”. People often fail many times, but they are desperate. Evidence before the Committee revealed deaths through plastic bag and helium asphyxia, carbon monoxide poisoning, self-inflicted gunshot wounds, by stockpiling medications, and hanging; as well as people travelling to Switzerland to access the resources of Dignitas, to Mexico to obtain Nembutal, and risking prosecution by importing lethal tablets from China. (Sub 13, p 1; Sub 36, p 3; Sub 67, p 7; Sub 120, p 23; Sub 123, p 1; Evidence, p 3)

Under the *Criminal Law Consolidation Act 1935*, it is not an offence to commit or attempt to commit suicide in South Australia. It is, however, an offence to assist in a suicide or a suicide attempt. In light of that, the “vast majority” of suicides are committed in isolation, when the person is alone “without their family to comfort them”. (Sub 13, p 3) As a result, the death may not be known for some time but, too frequently, a family member finds the deceased person. Mr Schapel reasoned, “human experience must dictate” that family members are badly distressed. (Evidence, p 77) Dr Lawlor-Smith provided information on the impact on carers. Apart from the added stress of dealing with the police and the coroner, “suicide survivors” often experience grief that is especially complex and dramatic, with increased susceptibility to shame, abandonment and post-traumatic stress disorder (PTSD). Feelings of isolation and the stigma of suicide can see them reluctant to confide in others, with the risk of depression and/or alcohol or substance abuse. In contrast, the bereaved families of cancer patients who chose a medically assisted death had significantly less post-traumatic stress reactions and complicated grief symptoms than those of comparable cancer patients who died a natural death. (Dr Carolyn Lawlor-Smith, Further Information, 20 July 2019, p 1, 2)

Although police and ambulance officers may be familiar with such circumstances, it does not mean that they are not affected by horrific scenes of suicide. An Advanced Care Paramedic

told of the “utter devastation and sheer horror” that continues to trouble him following attendance at two particularly brutal suicides. He still cannot imagine how the men’s families coped – one family was sobbing and absolutely inconsolable at the time – knowing “how desperate and alone their loved one was when he pulled the trigger”. Others expressed concern that the suicide was committed “needlessly early”, while the person was still well, out of fear of leaving it too late, when their physical deterioration would prevent them taking their own life. (Sub 13, p 3; Sub 30, p 3; Sub 53, p 6; Sub 73, p 2; Sub 79, p 14; Sub 123, p 1, 2; Evidence, p 66, 74, 77)

## **5.2 Term of reference (b)**

*The current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian and Western Australian Parliamentary Inquiries into end-of-life choices, Victoria’s Voluntary Assisted Dying Act (2017) and implementation of the associated reforms;*

The Northern Territory was the first jurisdiction in the world to legalise VAD with the *Rights of the Terminally Ill Act 1995* (NT). It was overturned by the Commonwealth Government under its constitutional powers by way of the *Euthanasia Laws Act 1997* that still prohibits territories from passing laws relating to VAD. (Sub 7, p B; Sub 66, attachment *Assisted Dying in Australia*, p 483)

There are multiple jurisdictions around the world – in Europe, North America, South America and, from 19 June 2019, Victoria– where VAD is legal. On 10 December 2019, the Western Australian Parliament passed the Voluntary Assisted Dying Bill 2019, with an 18-month implementation period. (Sub 95, p 15; Sub 7, p B) Details of the legal framework in each jurisdiction are outlined below.

## **INTERNATIONAL ASSISTED DYING REGIMES**

### **EUROPE**

There are four jurisdictions in Europe where assisted dying is lawful: the Netherlands and Belgium, which have been in operation longest, Luxembourg that is similar to Belgium, and Switzerland where legislation has not been passed to make either euthanasia or assisting a suicide lawful in specific circumstances. (Sub 66, p 484)

#### **The Netherlands**

In the Netherlands, euthanasia and assisted suicide were effectively legalised through the use of the defence of necessity in prosecutions of, primarily, doctors. The defence is available when the doctor is faced with a conflict between the duty to preserve life and to relieve suffering. Over some 30 years, the courts developed this duty-based defence of necessity in euthanasia cases, placing conditions on the defence, including: an express and earnest request; unbearable and hopeless suffering; consultation; careful termination of life; record-keeping; and reporting. These conditions, known as requirements of due care or careful practice, were eventually codified in legislation in 2002. The judicially developed necessity defence is still applied to cases involving incompetent persons, particularly neonates. (Sub 73, attachment, “Assisted Dying Regimes”, Professor Penney Lewis, Kings College London, p 1)

Both voluntary euthanasia and physician-assisted suicide are permitted for physiological and psychological suffering in the Netherlands. Under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002*, doctors are protected from criminal charges if they adhere to the stipulated requirements for assisting patients to die. In each request for VAD, doctors must consider the due care criteria and know the patient sufficiently well to assess whether the criteria have been met. Accordingly, before proceeding doctors must:

- be satisfied that the patient has made a voluntary and carefully considered request;
- be satisfied that the patient's suffering is unbearable and that there is no prospect of improvement;
- have informed the patient of his or her situation and further prognosis;
- have come to the conclusion, together with the patient, that there is no other reasonable alternative;
- consult at least one other independent physician, who must see the patient and give a written opinion on whether the due care criteria set out above have been fulfilled;
- have exercised due medical care and attention in terminating the patient's life or assisting in the self administration.

The law applies to adults and to patients under the age of majority. If the patient is between 16 and 18 years old, with a reasonable understanding of their interests, the parent(s) or guardian must be involved in the decision process, although there is no requirement for them to agree with their child's request. If the patient is between 12 and 16 and passes the same test of capacity, the consent of the parent(s) or guardian is required. If a patient aged 16 years or older, who is no longer capable of expressing their wishes, had earlier made a written declaration requesting their life be terminated, the doctor may comply with this request.

Termination of life on request and assisted suicide remain criminal offences. Defences inserted into the Penal Code by the Act require the doctor to report the case as euthanasia or assisted suicide to the municipal pathologist, who then passes the file to the relevant Regional Euthanasia Review Committee (RERC) to assess whether the doctor has acted in accordance with the requirement of due care. If not, the case is referred to the Public Prosecution Service. Between 1999 and 2016, 93 cases were referred (0.17 per cent of reported cases) but no prosecutions were brought.

In 2017, 6,585 deaths, some 4.4 per cent of deaths in the Netherlands, were notified to the Regional Euthanasia Review Committees. Of those notifications:

- 95 per cent were by physician administration;
- 250 cases were self administration;
- 80 per cent of deaths occurred at home;
- 85 per cent of notifications were by the GP;
- 64 per cent had cancer;
- 6 per cent had a neurological condition;
- 12 per cent had multiple conditions, e.g. cancer and heart disease;
- 65 per cent were aged over 70;
- three were minors aged 12 to 17;
- 166 were in early stage dementia, with the capacity to make an informed decision;
- three had advanced dementia;
- 81 had a psychiatric disorder.

(Sub 95, p 20; Sub 66, p 485; Sub 73, attachment, "Assisted Dying Regimes", Professor Penney Lewis, Kings College London, p 4)

The patient's suffering need not be related to a terminal illness and is not limited to physical suffering such as pain. It can include, for example, the loss of personal dignity, or increasing personal deterioration, or the fear of suffocation. Related to the due care criteria, there must be no reasonable alternative in light of the patient's situation. In cases of a physiological disorder, the patient's reasonable decision to refuse a realistic treatment possibility (curative or palliative) that might ease the suffering does not preclude a request for euthanasia. Conversely, where the suffering is psychiatric, the patient may not reject a realistic alternative to relieve the suffering, although patients are not required to undergo every conceivable form of treatment. (Sub 73, attachment, "Assisted Dying Regimes", Professor Penney Lewis, Kings College London, p 2)

Both doctors and nurses may refuse to assist in performing or preparing for euthanasia and cannot be censured for failing to comply. In the case of a refusal, however, the doctor must refer the patient to another clinician who may be willing to grant the request. (Sub 33, p 4) The state-funded program, Support and Consultation on Euthanasia in the Netherlands (SCEN) trains physicians to be consultants and to provide support and advice for doctors treating patients at the end of life. The "vast majority" of reported euthanasia cases involve a SCEN consultant. (Sub 73, attachment, "Assisted Dying Regimes", Professor Penney Lewis, Kings College London, p 3)

## **Belgium**

Belgium legalised voluntary euthanasia in designated circumstances in 2002. Unlike the Netherlands, there had been few criminal prosecutions in euthanasia cases prior to its legalisation, so legal change came from outside the judiciary. The *Belgium Act on Euthanasia 2002* permits euthanasia if the person 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". There is no requirement of a terminal illness although, if the patient is not expected to die "in the near future", there is a mandatory consultation with a psychiatrist or relevant specialist, plus a waiting period of at least one month. The patient's request must be in writing and signed by the patient, and must be "durable", with the doctor being satisfied that the request is completely voluntary and that the patient is in a state of constant physical or mental suffering. The doctor must explain information regarding the patient's health condition and life expectancy and both must consider there to be no reasonable alternative to the patient's situation. The law allows only doctors to perform euthanasia. Assisted suicide is not explicitly covered, although Belgium's monitoring body, the Federal Control and Evaluation Committee on Euthanasia, has accepted cases of assisted suicide as falling under the law.

In 2013, the law was extended to permit access for children, if they have the "capacity of discernment", i.e. they are able to demonstrate an understanding of the absolute consequences of the request. Other requirements are that the parents approve the decision, death is expected in the short term and the child must be in great pain, with no treatment to alleviate the distress. The doctor must also consult a child psychiatrist or psychologist to discuss the case. (Sub 66, p 485, 486; Sub 73, attachment, "Assisted Dying Regimes", Professor Penney Lewis, Kings College London, p 1)



## **Luxembourg**

The Law on Euthanasia and Assisted Suicide came into force in 2009 and is closely based on Belgium law, although it permits assisted suicide as well as euthanasia. (Sub 73, attachment, “Assisted Dying Regimes”, Professor Penney Lewis, Kings College London, p 1)

## **Switzerland**

The law in Switzerland is governed by its *Criminal Code*, under which both euthanasia and assisting a suicide are unlawful; euthanasia in all circumstances and assisted suicide if done for selfish motives. The latter provision in the Code has not changed since 1942. Although euthanasia is not permitted, the separate offence of murder at the victim’s request carries a lower minimum sentence than murder. (Sub 66, p 486; Sub 73, attachment, “Assisted Dying Regimes”, Professor Penney Lewis, Kings College London, p 1)

## **UNITED STATES OF AMERICA**

VAD is permitted by legislation in Oregon, Washington, Vermont, California, Colorado, the District of Columbia, Hawaii, Maine and New Jersey – the “Oregon-model states” – where the statutes are closely modelled on Oregon with its two-decade history of VAD. In Montana, VAD is legal by way of a court decision, which concluded that consent provides a statutory defence to a charge of homicide. (Sub 64, p 4; Sub 66, p 486, 487; Sub 73, attachment, “Assisted Dying Regimes”, p 1)

### **Oregon and the “Oregon-model states”**

Many US states allow legislation to be enacted if a majority votes for an initiative placed on the ballot following a petition signed by a minimum number of voters. Oregon voters passed the first *Death with Dignity Act* in 1994 by a majority of 52 per cent, permitting the provision of a prescription for lethal medication to be self-administered by the patient. It was controversial, however, prompting a number of unsuccessful legal challenges. It came into effect in 1997. Washington state passed an almost identical Act in 2008, as did Colorado in 2016. In 2013, 2015, 2016 respectively, Vermont, California and District of Columbia passed statutes very similar to the Oregon Act. Hawaii passed legislation in 2018, Maine and New Jersey in 2019. (Sub 64, p 4; Sub 73, attachment, “Assisted Dying Regimes”, p 1, 2)

Since 1997, Oregon’s eligibility requirements have permitted:

- residents of Oregon, 18 years or older;
- to receive prescriptions for self-administered lethal medication from their doctors;
- provided the patient is “capable”, that is able to make and communicate decisions about their health care;
- and has an incurable and irreversible disease expected to lead to death within six months, the starting period for palliative care funding.

Other safeguards in the Act:

- the patient must make one written and two oral requests to their physician, the latter separated by at least 15 days;
- two witnesses must attest that the patient is acting voluntarily and is not being coerced to sign the request;
- the patient’s primary physician and a consultant must:
  - confirm the diagnosis of a terminal condition and the prognosis;
  - determine that the patient is capable;

- refer the patient for counselling if either believes that the patient’s judgement is impaired by depression or some other psychiatric or psychological disorder;
- the primary physician must also inform the patient of the potential risks and probable result of taking the medication to be prescribed, as well as all feasible alternatives, such as comfort care, hospice care, and pain-control options.;
- physicians must report all prescriptions they write for lethal medications to the Oregon Department of Human Services, as well as each death resulting from the ingestion of the prescribed medication;
- the law contains conscientious objection provisions. (Sub 66, p 487; Sub 73, attachment, “Assisted Dying Regimes”, p 2, 3, 4; Sub 88a, p 2)

Ann Jackson is considered an authority on end of life issues and options, including Oregon’s *Death with Dignity Act* (ODDA), having been the Executive Director and Chief Executive Officer of the Oregon Hospice Association between 1988 and 2008. She advised that the Act has facilitated more open and honest conversations between dying patients and their physicians and more careful evaluation of all end of life options, regularly leading to reassurance rather than an eventual direct request for end of life medication. Over a third of those who are eventually granted a prescription for life-ending medication do not use it – for many it is simply “emotional insurance”. Such reassurance and peace of mind can result in a general improvement in patients’ wellbeing, with some outliving their original prognosis. Ms Jackson clarified: “dying people who want this choice, do not want to die, they want to exercise control over an imminent and inevitable death. Using the ODDA is always a last resort”. (Sub 74, p 1, 4, 6)

The Act has remained unchanged over the past 20 years and the safeguards have not broadened since the law was enacted. Accordingly, fears of a “slippery slope” have not eventuated and there have been no proven cases of coercion. In over 98 per cent of people dying under the Act, there have been no reported complications. For those few others, the complications are those that are commonplace among people at the very end of life. The process is monitored and controlled by stringent criteria, mandatory state reporting by the medical team, and medical board oversight, with the Department of Justice investigating any concerns that ever arise. The 21<sup>st</sup> Annual Report of Oregon’s *Death with Dignity Act*, in February 2019, confirmed there have been no abuses of the Act, with its safeguards continuing to protect dying Oregonians, including the most vulnerable. (Sub 74, p 1, 4)

The Act requires the Oregon Health Authority to collect information about the patients and physicians who participate and publish an annual statistical report:

- since 1997, prescriptions have been written for a total of 2,217 people;
- 1,459 people (65.8 per cent) have died from ingesting the medications;
- during 2018, 249 people received prescriptions under the Act, compared with 219 during 2017;
- as of 22 January 2019, 168 people had died during 2018 from ingesting the medication, including 11 who had received the prescriptions in previous years, an increase from 158 during 2017;
- patient characteristics were similar to those in previous years:
  - most patients were aged 65 years or older (79.2 per cent);
  - most had cancer (62.5 per cent), then neurological disease (14.9 per cent), and heart/circulatory disease (9.5 per cent);
  - most patients (87.5 per cent) died at home;

- patients were commonly white (97.0 per cent) and well educated (47.3 per cent had at least a baccalaureate degree);
- during 2018, two physicians were referred to the Oregon Medical Board for failure to comply with ODDA requirement.

(Oregon Health Authority, Oregon Death with Dignity Act, 2018 Data Summary, p 3, 5, 6)

Hospice and palliative care in Oregon is consistently rated among the best in the United States and assisted dying has not had a negative impact. Of those who use the Act, 90 per cent are enrolled in hospices – the gold standard for pain and symptom management – with hospices being adamant that people do not choose assisted dying because they are in pain. No hospice in Oregon denies a patient access to care because they intend to use the Act, neither will a hospice turn away a dying patient who cannot afford to pay. Accordingly, in Oregon there is no excuse for anyone to die in pain and suffering. (Sub 74, p 5)

## CANADA

VAD became lawful in Canada with *An act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* passing in 2016. The legislation was in response to the Supreme Court decision in February 2015 of *Carter v Canada (Attorney General)*, which found that the blanket prohibition on assisting a person to die was overly broad and in breach of the *Canadian Charter of Rights and Freedoms*. The Supreme Court struck down the criminal prohibition of assisted suicide in the federal *Criminal Code* on the grounds that it infringes the rights of competent adult patients with a grievous and irremediable medical condition causing enduring and intolerable suffering who consent to an assisted death.

The Court granted a one-year suspension, subsequently extended by four months, to allow the Parliament of Canada to craft a regulatory regime. During the extension, individuals were permitted to access assisted dying by making a court application. In June 2016, the Parliament of Canada enacted a statute amending the *Criminal Code* to permit medical assistance in dying, defined as:

- 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 a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

(Sub 7, attachment 2, p B; Sub 66, p 487, 488; Sub 73, attachment, “Assisted Dying Regimes”, p 2)

The legislation has a range of eligibility criteria that the patient must:

- be over the age of 18;
- be capable of making health decisions;
- have made a voluntary request;
- have given informed consent;
- have a grievous and irremediable medical condition, which has four criteria:
  - a serious and incurable illness, disease or disability;
  - an advanced state of irreversible decline in capability;
  - that illness, disease or disability or that state of decline must cause the patient enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable;

- their natural death must have become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time they have remaining.

Other safeguards include:

- a physician or nurse practitioner must ensure that the patient is eligible under the access criteria;
- a second independent physician or nurse practitioner must provide a written opinion confirming eligibility;
- the patient must wait at least ten days after signing the request, unless both the first and second clinicians consider death to be fast approaching or the patient may soon be unable to provide informed consent;
- conscientious objection provisions for clinicians.

Canada has published four “interim” reports that indicate the urgency around developing and implementing the policies and procedures, with limited community awareness and participation of health authorities and medical professionals in the process. Annual reports with more comprehensive data are to commence in early 2020. Although the law allows the patient to select self-administration or physician administration, between December 2016 and October 2018 all but six of the 6,749 people who used the medication chose physician or nurse practitioner administration, with death almost always occurring through intravenous delivery of the lethal substance. Approximately five per cent nominated nurse practitioner administration, more commonly in rural areas with less access to a VAD trained physician. The numbers account for approximately 1.12 per cent of all deaths in Canada.

(Sub 7, p attachment 2, p B; Sub 73, attachment, “Assisted Dying Regimes”, p 2, 3; Sub 88, p 25; Sub 95, p 19; *Reflections and Learnings, Assisted dying in Canada and the United States*, PCA, p 5)

## Quebec

Legislation was first enacted in Quebec with *An Act Respecting End-of-Life Care*, coming into effect in December 2015. The stated objective of the Act is “to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy”. It legalised medical aid in dying (MAID) for patients over the age of 18 at the end of life, who must have capacity, be informed and be acting freely. The Act requires that the patient suffer from a serious and incurable illness; be in an advanced state of irreversible decline in capability; and experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable. A consulting physician must confirm the fulfilment of the legal requirements. Conscientious objection provisions apply. Unlike the European models, the Act regulates end-of-life care more broadly and includes both palliative care and MAID. (Sub 66, p 487; Sub 73, attachment, “Assisted Dying Regimes”, p 2, 3, 4)

The legislation followed a report in March 2012 from the Quebec National Assembly’s Select Committee on Dying With Dignity, after visiting permissive jurisdictions in Europe. In Marshall Peron’s view, that report is “arguably the most comprehensive report ever conducted” into the issue, with reference to the law and practice relating to treating patients approaching death, the role and limitation of palliative care, public attitudes and recommended reform. The Committee concluded that allowing MAID would not harm society’s most vulnerable since there are ways to define and structure the process to avoid any risk of abuse. (Sub 6, p 3, 4)

## COLOMBIA

In 1997, the Colombian Constitutional Court ruled that a physician should not be prosecuted for ending life at the repeated request of a terminally ill patient who is suffering unbearably, as the physician's action is justified. The Court called on Congress to establish a regulatory regime to vindicate the fundamental right to die with dignity but, despite a number of Bills, no progress was made. In 2014, the Court reviewed the case of a terminally ill patient who had repeatedly and unsuccessfully sought euthanasia, ordering the Ministry of Health to direct health care providers to establish local expert committees to respond to requests for euthanasia.

A national expert committee wrote the Resolution that came into force in 2015. It requires requests, which must be free, informed and unequivocal, to be approved by a special three-person, multi-disciplinary, hospital-based committee, comprising a specialist in the patient's condition (not the treating physician), a lawyer, and a psychiatrist or clinical psychologist. The patient must be in the terminal phase of an illness or serious pathology, which is progressive, incurable and irreversible, with death predicted in the relatively short term. The committee also has responsibility for ensuring that the assistance in dying is provided within strict time limits, and for accompanying the patient and their family members. A retrospective reporting requirement is also imposed. (Sub 73, attachment, "Assisted Dying Regimes", p 2, 3, 4) On 9 March 2018, Colombia passed a resolution permitting euthanasia of children aged seven or over in compliance with a judgement of the Constitutional Court. It required the Department of Health and Social Protection to issue a "regulation that guarantees the right to death worthy of children and adolescents." (Sub 66, attachment: "Does the voluntary assisted dying act ... , footnote 121)

The Committee received criticism of VAD in these countries, with some submissions arguing that they constitute "unrefuted" evidence of "horrendous 'unintended' consequences" in Oregon, the Netherlands and Belgium. A number argued that the Netherlands has gone "seriously astray" and that the "slippery slope" is "manifest" in "euthanasia progressing effortlessly" from those suffering a terminal illness to no physical illness at all, from others who gave consent to involuntary euthanasia, and "from being a measure of last resort to one of early intervention". In addition, Belgium "grotesquely" extended its laws to allow child euthanasia without any age restriction, while in Oregon, during the last four years, the number opting for euthanasia or assisted suicide nearly doubled. (Sub 58, p 1, 2; Sub 72, p 1; Sub 87, p 1, 2; Sub 93, p 1)

But evidence before the Committee revealed that the majority of overseas jurisdictions limit access to VAD to adults. Only Belgium, the Netherlands and Colombia permit requests for VAD to be made by children under the age of 18 and this occurs in practice in very rare cases. Similarly, while Belgium, the Netherlands and Luxembourg permit advance requests for VAD, they, too, are only acted on infrequently in these jurisdictions. (Sub 66, attachment: "Does the voluntary assisted dying act ... , p 20, 21) The "slippery slope" or "floodgate" fears of the House of Lords in 1994 have not been realised anywhere. Rather, the rigorous legal requirements that have been developed would seem to be achieving the desired intent. (Sub 50, p 4) Further rebuttal exists in that Oregon's law has remained unchanged over the past 20 years; its criteria and the associated safeguards have not broadened since the law was enacted. (Sub 74, p 4)

Dignitas reported that rates of assisted dying in Oregon and in the Netherlands:

showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. ... Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.” (Sub 75, p 20)

## **AUSTRALIA**

### **Victoria**

The Joint Committee travelled to Victoria in October 2019 to gain a better understanding of the Victorian *Voluntary Assisted Dying Act (2017)* and the processes that resulted in the passing of the legislation. The Committee met with a broad range of witnesses including medical professionals trained in providing VAD options, medical practitioners who questioned the role of VAD within the medical profession, palliative care representatives and academics. The issues raised by the witnesses mirrored evidence the Committee heard in South Australia, particularly the impact of palliative care on the terminally ill and the need for palliative care to be appropriately funded to ensure the highest level of care with the aim of providing a “good death”.

The Committee met with representatives from the Victorian Department of Health and Human Services. The Department was able to provide the Committee with a detailed overview of how the VAD scheme operates, including discussions about training, safeguards and supports for patients and practitioners. The Committee had further discussions with the Legal and Social Issues Committee of the Victorian Parliament about their experience of inquiring into end of life choices.

The Voluntary Assisted Dying Bill 2017 was introduced into the Parliament of Victoria on 21 September 2017 as a Government Bill. It followed a recommendation to legalise VAD from the Legislative Council’s Social and Legal Issues Committee Inquiry into End of Life Choices. The Committee had reported in June 2016, with two dissenting reports and 49 recommendations, mainly about improved support for community palliative care, advance care planning and the need to legalise assisted dying. The government then appointed a Ministerial Advisory Panel (MAP) with a multidisciplinary approach to consider the recommendations of the Inquiry and develop “a safe and compassionate voluntary assisted dying framework for Victoria”. The Panel consulted broadly, seeking input on eligibility requirements, the request and assessment process, and oversight and governance. An interim discussion paper was released in May 2017. The final report went to the Minister for Health in July 2017.

The *Voluntary Assisted Dying Act 2017* was passed by both Houses in November 2017, following marathon sittings. The law came into effect on 19 June 2019 after an 18-month period of implementation to establish practical aspects, such as the model of care, the medications to be used, and the clinical guidelines. In addition, extensive consultations were undertaken with all stakeholders in public forums and with focus groups to develop the policies, guidelines, forms, resources and procedures for the implementation of the Act. The VAD Implementation Taskforce oversaw the process. (Parliamentary Research Paper, p 10; Sub 7, attachment 1, p C, p D; Sub 95, p 17;)

### **The Victorian *Voluntary Assisted Dying Act 2017*:**

- the person must be aged 18 years or more;
- the person must:
  - be an Australian citizen or permanent resident;
  - be ordinarily resident in Victoria;
  - 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 VAD;
- 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 (or 12 months for neurodegenerative conditions);
  - is causing suffering that cannot be relieved in a manner that the person considers tolerable;
- all registered health practitioners are prohibited from initiating a discussion about VAD (directly or indirectly) or suggesting VAD to a person in the course of providing care;
- the first request for VAD, clear and unambiguous, must be made by the person to a medical practitioner, which triggers a very detailed request and assessment process;
  - the request must be made voluntarily and without coercion;
  - that practitioner, if available and willing to be involved, becomes the co-ordinating medical practitioner;
  - who then conducts the first eligibility assessment;
- if the person is eligible, the coordinating medical practitioner refers the person to another medical practitioner;
  - if the second medical practitioner accepts the referral, they become the consulting medical practitioner;
  - who conducts the second eligibility assessment, the consulting assessment;
- medical practitioners who wish to be involved with VAD must have particular qualifications and experience:
  - both must be either a medical specialist or a vocationally registered general practitioner;
  - one must have practised for at least five years after completing their fellowship with a specialist medical college or vocational registration;
  - one must also have expertise and experience in the disease, illness or medical condition expected to cause the person's death;
- if the coordinating or the consulting medical practitioner assesses the person as being eligible for VAD, they must:
  - provide information about diagnosis, prognosis and possible treatment options;
  - advise that the person may decide at any time not to seek VAD;
  - be satisfied that this information is understood;
  - be satisfied that the person is acting voluntarily and their request to access VAD is enduring;
- the person who has been assessed as eligible to access VAD by the coordinating and consulting medical practitioners must then make two further requests for VAD;
  - one is a written declaration, witnessed by two people, that VAD is sought voluntarily and that the nature and effect of seeking VAD is understood;
  - the second is the final request, which can be made verbally;

- this final request must be made at least nine days after the first request and at least one day after the consulting assessment, although the nine day period can be shortened if the person is likely to die first;
- the last step in this stage is for the person to appoint a Contact Person, whose duties include returning unused VAD medication to the pharmacy and being a contact point for the VAD Review Board;
- after undertaking a final review to ensure the VAD process has been complied with, the coordinating medical practitioner must then apply to the Department of Health and Human Services for a VAD permit for either self-administration or practitioner administration;
  - the Department will decide whether or not to issue the permit within three business days;
- for self-administration, on prescribing the VAD medication the coordinating medical practitioner must inform the person:
  - how to take the medication;
  - how it must be stored in a locked box;
  - there is no obligation to proceed with VAD;
  - of the duty, including the Contact Person, to return the unused VAD medication to the pharmacy;
- the dispensing pharmacist also must inform the person of this same information when dispensing the VAD medication and include some of this information on the labelling statement;
- once dispensed, the person may take the VAD medication at a time of their choosing;
- with practitioner administration, the coordinating medical practitioner is responsible for the VAD medication, so the above information requirements do not apply;
  - the person must make a further fourth request for VAD, an administration request, in the presence of an independent witness, immediately before the coordinating medical practitioner administers the VAD medication;
  - the coordinating medical practitioner must be satisfied that the person has capacity, is acting voluntarily and without coercion, and the request for VAD is enduring;
- medical practitioners and other health practitioners are allowed to conscientiously object to their participation in VAD:
  - they are required to accept or refuse the role of coordinating or consulting medical practitioner within seven days but have no duty to refer a person to another medical practitioner who is willing to be involved in VAD;
  - they also have the right to refuse to:
    - provide information about VAD;
    - participate in the request and assessment process;
    - apply for a VAD permit;
    - supply, prescribe or administer a VAD substance;
    - be present at the time of administration of a VAD substance;
    - dispense a prescription for a VAD substance;
- the Review Board is a new independent statutory body with overall oversight of the VAD system and a primary function of monitoring activity under the Act to ensure compliance;
  - this includes reviewing each case where VAD has been requested to ascertain compliance with legal requirements;
  - it must also evaluate overall patterns and trends of access to VAD, such as possible instances of “doctor shopping”, i.e. overuse of one or more medical



- practitioners who repeatedly find a person eligible for VAD despite other medical practitioners finding them to be ineligible;
- the Review Board will be supported in its oversight function by the mandatory reporting obligations imposed on medical practitioners, dispensing pharmacists and others by the Act;
- in addition to reporting to the Review Board, all deaths of people who were the subject of a VAD permit are notifiable to the Coroner, although these deaths are not investigated as possible suicides;
  - a medical practitioner attending a person who has died must notify if the person was the subject of a VAD permit, and state their knowledge or belief whether or not the person died as a result of VAD, or VAD was not administered;
  - these deaths are also notifiable to the Registrar of Births, Deaths and Marriages;
  - however, VAD is not required to be recorded as the cause of death on the death certificate;
- the Victorian Civil and Administrative Tribunal (VCAT) has jurisdiction to only review assessments by a coordinating or consulting medical practitioner about residency and decision-making capacity, as these are questions of fact;
  - VCAT does not review clinical issues such as disease-related eligibility criteria;
- registered health practitioners, including medical practitioners, nurses, allied health practitioners and pharmacists, are required to report colleagues to the Australian Health Practitioner Regulation Agency (AHPRA) if they believe another registered health practitioner:
  - has initiated a discussion about VAD or suggested it to a person;
  - has offered to provide VAD to a person not eligible under the Act;
- this reporting obligation also applies to health practitioners' employers, such as hospitals or institutional care providers;
- there are several new offences under the Act, broadly modelled on offences in force in some US states, that are designed to promote compliance and deter people from intentionally acting outside the law, relating to:
  - coercing a person to access VAD;
  - administering VAD medication to a person who has been issued a self-administration permit;
  - acting contrary to a practitioner administration permit;
  - a Contact Person failing to return unused or remaining VAD medication after the person's death;
  - falsifying forms and statements;
  - failing to report to the Review Board;
- the Act specifically protects medical practitioners who provide VAD in accordance with the Act from any criminal or civil liability, or liability for professional misconduct or contravention of a professional code of conduct;
  - it also protects those (including health practitioners, family or carers) who assist or facilitate a request for VAD.

Victoria has created four positions as VAD Care Navigators to be the point of contact for people requesting VAD, friends and family, health professionals, health administrators and anyone needing support to navigate the VAD system. The Care Navigators will have access to funding to support people, particularly in rural areas, who need to travel for a medical assessment or need support to identify a VAD trained medical practitioner. (Sub 95, p 29)

Dr Rodney Syme, VAD advocate and former President of Dying with Dignity Victoria, submitted that the Victorian Government had to design an Act, which would be seen to address the arguments of the opposition, thereby influencing its complex bureaucratic structure. Two common arguments against reform were that vulnerable people would be persuaded to end their lives by relatives and by doctors. In Dr Syme's 27 years of counselling, he has never encountered the former; it is far more likely that relatives will attempt to dissuade requests and action. From his personal experience and from around the world, doctors are extremely reluctant to provide assistance and will only do so as a last resort. Nevertheless, such arguments affected the construction of the Victorian law. (Sub 88a, p 2)

Overall, the regime is very narrow in scope and has a large number of safeguards, 68 in total, allowing the Victorian Premier and others to describe it as the "safest and most conservative scheme in the world".

(Sub 7, attachment 2, "Future of assisted dying reform...", p A; Sub 66, attachment 2, "Does the Voluntary Assisted Dying Act ...", p 16, p 23, 24, 25, 30, 31, 32, 33, 35; Sub 95, p 28; Sub 105, p 14)

## **Western Australia**

In 2017, a Joint Select Committee on End of Life Choices was established by the Parliament of Western Australia. The Committee undertook an Inquiry into the need for laws in Western Australia (WA) to allow citizens to make informed decisions regarding their own end of life choices, with similar Terms of Reference to those currently being utilised in the South Australian Inquiry. The Committee handed down its report, *My Life, My Choice*, to both Houses of Parliament on 23 August 2018, outlining 52 findings and 24 recommendations, grouped into three distinct areas:

- Advance Care Planning, including Advance Health Directives;
- End of Life and Palliative Care;
- Voluntary Assisted Dying.

(WA Government Response, Joint Select Committee on End of Life Choices Report, *My Life, My Choice*, p 3, 5)

The WA Government instructed the Department of Health and the Department of Justice to implement the Committee's recommendations relating to VAD, including developing legislation. A Ministerial Expert Panel was established to provide expert advice on the development of VAD legislation.

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

The Ministerial Expert Panel's final report recommended its Guiding Principles be included in the legislation to help interpretation:

- every human life has intrinsic value;
- a person's autonomy should be respected;
- people have the right to be supported in making informed decisions about their medical treatment and should be given, in a manner they understand and is culturally appropriate, information about medical treatment options, including comfort and palliative care;
- people approaching the end of life should be provided with high quality care, including access to specialist palliative care, to minimise their suffering and maximise their quality of life;

- a therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained;
- people should be encouraged to openly discuss death and dying, and their preferences and values should be encouraged and promoted;
- people should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences;
- people are entitled to genuine choices regarding their treatment and care; this should be regardless of their geographic location and take into account their ability, as well as individual cultural and linguistic needs;
- people should be supported in their right to privacy and confidentiality regarding their choices about treatment and care preferences;
- people who may be vulnerable to coercion and abuse in relation to end of life choices and decisions should be protected;
- all people, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics. (Sub 105, p 16)

The Voluntary Assisted Dying Bill was introduced into the Western Australian Parliament in August 2019. It passed on 10 December 2019.

#### **The Western Australian *Voluntary Assisted Dying Act 2019*:<sup>7</sup>**

- the person requesting VAD must be aged 18 years or over;
- the person must be an Australian citizen or permanent resident who has been ordinarily resident in Western Australia for at least 12 months;
- the person must have been diagnosed with at least one disease, illness or medical condition that is:
  - advanced, progressive and will cause death;
  - on the balance of probabilities will cause death within a period of 6 months (or 12 months for neurodegenerative);
  - is causing suffering that cannot be relieved in a manner that the person considers tolerable;
- the person must have decision-making capacity in relation to VAD;
  - must be acting voluntarily and without coercion;
  - must have an enduring request for access to VAD;
- the person must make three separate requests for VAD: a first request, a written declaration and a final request;
- the first request must be clear and unambiguous;
  - made during a medical consultation;
  - made verbally or in another way, e.g. by gestures;
- if the patient has been assessed as eligible for access to VAD by the coordinating and consulting practitioner, they may then make a written declaration that must be witnessed by two people who meet specific requirements;
- if the patient is unable to sign the declaration, a person may sign on behalf of the patient, if so directed:
  - the person:
    - must be 18 years of age;

---

<sup>7</sup> The Committee received no submissions providing an analysis of the WA legislation. This summary of the Act is taken from data on the WA Department of Health website and the Act itself: <https://ww2.health.wa.gov.au/voluntaryassisteddying>  
[https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc\\_42491.pdf/\\$FILE/Voluntary%20Assisted%20Dying%20Act%202019%20-%20%5B00-00-00%5D.pdf?OpenElement](https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc_42491.pdf/$FILE/Voluntary%20Assisted%20Dying%20Act%202019%20-%20%5B00-00-00%5D.pdf?OpenElement)

- must not be a witness to the signing of the declaration;
  - must not be the coordinating practitioner or consulting practitioner;
  - must sign in the patient's presence;
- the final request cannot be made before the end of the designated period:
  - 9 days beginning on the day on which the patient made the first request; or
  - until after the day on which the consulting assessment confirmed the patient as eligible;
  - unless the patient is likely to die, or to lose decision-making capacity;
- two medical practitioners must independently assess the person as eligible;
- the medical practitioners must:
  - hold specialist registration and have practised the medical profession for at least 1 year as the holder of specialist registration; or
  - hold general registration and have practised the medical profession for at least 10 years as the holder of general registration; or
  - is an overseas-trained specialist who holds limited registration or provisional registration and meets the requirements approved by the CEO for the purposes of this subparagraph;
  - not be a family member of the patient, be a beneficiary under a will of the patient, or otherwise benefit financially or in any other material way from the death of the patient;
- the medical practitioners may also refer the person for additional assessments if required;
- the medical practitioner who accepts the first request becomes the coordinating practitioner who:
  - must assess whether the patient is eligible for access to VAD;
  - must not begin the first assessment without completing approved training;
- if assessed as eligible, the coordinating practitioner must inform the patient:
  - the diagnosis and prognosis;
  - the treatment options available and the likely outcomes of that treatment;
  - the palliative care and treatment options available and the likely outcomes;
  - the potential risks of self-administering or being administered a VAD substance likely to be prescribed and the expected outcome of death;
  - that if the decision is self-administration, the patient must appoint a Contact Person;
  - that they may decide at any time not to continue the request and assessment process or not to access VAD;
- if the patient is assessed as eligible, the practitioner must refer the patient to another medical practitioner for a consulting assessment;
- the practitioner who accepts the referral becomes the consulting practitioner, who:
  - must not begin the consulting assessment without completing approved training;
- VAD may be through self-administration or practitioner administration of the VAD substance:
  - this decision is made in consultation with the co-ordinating medical practitioner;
  - if self-administration, the person must appoint a Contact Person who has specific responsibilities, including return of any unused substance;
  - if practitioner administration, this may be a medical practitioner or a nurse practitioner;

- throughout the process, the person must be informed of many different aspects relating to VAD, as well as their treatment and palliative care options;
- the process must remain voluntary and free from coercion;
- the person can withdraw or revoke their involvement at any stage;
- health practitioners are able to refuse to participate, prescribe the substance or be present in VAD for any reason, including conscientious objection;
- health care workers must not initiate discussion about, or suggest, VAD to a person to whom they are providing health or professional care services;
- medical practitioners or nurse practitioners can, however:
  - provide information on VAD if, at the same time, they also inform the person about treatment and palliative care options available to them and the likely outcomes of that care and treatment;
  - provide information about VAD at the person's request;
- A person is eligible to act as an administering practitioner if:
  - a medical practitioner who is eligible to act as a coordinating practitioner;
  - a nurse practitioner who has practised the nursing profession for at least 2 years as a nurse practitioner;
  - the person has completed approved training;
  - the person is not a family member of the patient;
  - the person does not know or believe that they are a beneficiary under a will of the patient, or may otherwise benefit financially;
- if self-administration, the coordinating practitioner is authorised to prescribe a VAD substance sufficient to cause death;
- if practitioner administration, the administering practitioner is authorised, in the presence of a witness, to administer the prescribed substance if satisfied:
  - the patient has decision-making capacity;
  - the patient is acting voluntarily and without coercion;
  - the patient's request for access to voluntary assisted dying is enduring;
- the death certificate must not include any reference to VAD;
- within 2 business days after prescribing a VAD substance, the coordinating practitioner must complete the administration decision and prescription form and give a copy to the Board and, if self-administration, a copy of the Contact Person appointment form;
- a person who dies as the result of the administration of a prescribed substance in accordance with this Act does not die by suicide.

### 5.3 Term of reference (c)

*What legislative changes may be required, including consideration of:*

- (i) *The appropriateness of the Parliament of South Australia enacting a Bill in similar terms to Victoria's Voluntary Assisted Dying Act (2017); and*

As evident previously, there were many who appealed to the Committee to oppose any legislative change to enact VAD in South Australia, whether in terms of the Victorian Act or otherwise.

As to the appropriateness of a similar Bill being enacted in South Australia, while there were a few in support, many advocates for VAD expressed their concerns and disappointment with the Victorian legislation.

The AMA (SA) highlighted the long consultation and development of Victoria's Act, followed by an 18-month implementation period. The result was a well-resourced framework of governance, monitoring, education and support for consumers and health practitioners. Accordingly, South Australia should monitor the Victorian experience before introducing similar legislation here, in which case the protections and framework must be similarly robust. The association's president, Dr Chris Moy, reiterated that Victoria should be "the test case", given their vigorous process. Accordingly, he recommended that South Australia "stick with that level of protection" at the outset. (Sub 110, p 10, Evidence, p 42) Dying for Choice also endorsed Victoria's extensive and professional consultation process as a useful model for the South Australia Parliament. (Sub 60, p 76)

Similar praise for Victoria's "un-hurried and comprehensive approach" came from Emeritus Professor Ian Maddocks. He favoured "drawing on the work done in Victoria and elsewhere" so that the State need not "start from scratch", nor take as long. In his view, a further reason for an unhurried momentum for the introduction of VAD is the desirability of federal agreement to consider a nation-wide law. (Sub 80, p 1) Dr Ted Arnold also called for legislation to be uniform across the country so that 'Australians all' can benefit uniformly from VAD legislation. He could "see a re-run of the railway gauge story as being of no benefit to the nation as a whole". Sub 45, p 1)

The Australian Healthcare and Hospitals Association (AHHA) submitted an article<sup>8</sup> that documented Victoria's extensive "social change" process, via a multidisciplinary Ministerial Advisory Panel. The authors (members of the panel) judged that the principle of wide-ranging consultation and communication with the community and the media achieved the goal of a movement away from the "medicalisation of life events" to the "empowerment of individuals autonomously planning their own end of life". The process was defined as "a tangible example of democracy at work". (Sub 7, attachment 1, p A, D, E)

Dr Rodney Syme, however, was critical of the long implementation process. In his view, an 18-month delay is excessive and should be reduced; it is punitive. Since it has been estimated that 150 people a year would use VAD in Victoria, the delay equated to 225 people being denied VAD during that period. Moreover, evidence from the first three months of operation revealed "anything but a smooth implementation". Relevant information about the law is lacking in both the community and the medical profession, the training process is inadequate, and intra-medical knowledge regarding cooperation has been found wanting. (Sub 88a, p 4)

Although indicating his support for Victoria's legislation, Professor Maddocks recognised that the Act disappointed many advocates for change with its "clear exclusions, ... restrictive eligibility criteria, and its necessary diligent processes of referral and reporting". As a consequence, "relatively few dying persons will be eligible

---

<sup>8</sup> O'connor, M. M., Hunt, R. W., Gardner, J., Draper, M., Maddocks, I., Malowney, T., & Owler, B. K. (2018), "Documenting the process of developing the Victorian voluntary assisted dying legislation", *Australian Health Review*, 42(6), 621-626: <https://doi.org/10.1071/AH18172>

to access Voluntary Assisted Dying”. (Sub 80, p 1, Appendix 2, p 1) That theme was expanded upon repeatedly.

Doctors for Assisted Dying Choice acknowledged the laudable aim behind the protections but deemed the Victorian law with its 68 safeguards to be cumbersome, difficult to understand, and confusing for patients and health practitioners. They cited the international organisation EXIT that concluded there were more than 100 criteria to be satisfied, despite the patient being near the end of their life and seeking relief from their suffering. The end result can only be to add further stress to those it was intended to assist. (Sub 67, p 16, 17) Meredith Reardon also argued that the 68 safeguards were “too many ‘hoops’ for the dying person to jump through” as, with that level of bureaucracy, the person would find it virtually impossible to complete the process. (Sub 17, p 1)

Marshall Perron, former Chief Minister of the Northern Territory, urged the Committee “not to mirror” the complexity of the Victorian legislation. He contended that a safe, responsible VAD law can be drafted to regulate the relationship between eligible patient and medical professionals without “141 clauses and 8 forms”. With that in mind, he and others referred the Committee to a new draft Bill drawn up in April 2019 by Professor Ben White and Professor Lindy Willmott that offers a “workable, safe, practical legislative option” without Victoria’s complexity. (Sub 6, p 5) The Clem Jones Group highlighted the same “model Bill”, submitting that it would provide “a solid base” for the timely delivery of VAD in South Australia. They cited Marshall Perron’s endorsement of the Bill at the Queensland Parliamentary Inquiry, when he deemed it the “best” he had seen, superior to the Victorian law and the proposals by the Western Australian Expert Panel. (Sub 79, p 11)

Several other submissions, while “broadly supportive” of the Victorian VAD Act, also identified features that are “excessive” and “overly cautious” in an apparent attempt to “address all possible risks and to include all possible safeguards”. Nicholas Cowdery, AO, QC, reasoned that such a profusion of safeguards may mean that, at a practical level, VAD becomes unachievable for many citizens, especially those in lower socio-economic groups. Unnecessarily, it then becomes “an issue of equity”. While those already accessing VAD – which occurs everywhere, even though unlawful – may not be unduly affected, there is a risk, in attempting to cover all possible contingencies, of entrenching those existing unregulated and unaccountable practices. (Sub 50, p 5, 6; Sub 53, p 11)

Ian Leader-Elliott, Emeritus Fellow, Adelaide School of Law, identified two impediments to patient autonomy in the Victorian Act that should not be adopted: that the patient’s disease, illness or medical condition must be incurable; and that it must be a condition that will cause death, which is expected within six months. Both incurable and the prognosis of anticipated death within six months should be eliminated. Rather the criterion should be based on extreme or intolerable suffering resulting from an illness, disease or medical condition, preferably without the requirement of a timeframe prognosis. As some medical conditions are of indefinite duration, the suffering of those who cannot look forward to release by impending death may be even worse than that of a terminal disease. Elimination of a timeframe, however, would be a radical change from existing Australian models for reform and, although “highly persuasive”, would perhaps be unlikely to gain approval in South Australia.

Accordingly, Mr Leader-Elliott argued that the requirement should be a 12-month prognosis of death, rather than 6 months, given the uncertainties of medical predictions of anticipated death. A short prognostic period, with paperwork and multiple medical appointments, does not allow patients, who may be in acute distress, to alleviate their pain until very late in their illness, with all the indignity and suffering that entails. In his opinion, the effect of an extra-statutory qualification of incurability is likely to result in uncertainty of diagnosis and divergence of opinion among practitioners, dying patients, their families and the public at large, when clarity is highly desirable. As such, the requirement of incurability presents opportunities for “polemical attack” by those wholly opposed to VAD, on religious or other grounds. (Sub 52, p 1, 2, 3, 4 5; also Sub 73, p 3)

Dying with Dignity NSW criticised other features they deemed excessive, which will make it difficult for patients to access VAD in a timely manner. The need for Department of Health and Human Services’ approval for every prescription means patients must navigate an assessment by two doctors, plus a specialist or psychiatrist if required, but also wait on a bureaucratic decision. (Sub 53, p 11, 12) Doctors for Assisted Dying Choice, too, were critical that those patients who endure such an exhaustive process are then dependent on the final approval being delegated to a public servant – the Secretary of the Review Board – who has had no contact with the patient and probably no experience in the disease from which the patient is suffering. They recommended to the Committee Oregon’s *Death with Dignity Act*, which is 12 pages in length compared with Victoria’s 130 pages; both achieve the same outcome. (Sub 67, p 16, 17)

Agreeing that the Victorian VAD law is “the most conservative in the world”, Dr Rodney Syme contended that some of the restrictions are “unnecessary and sometimes cruel impediments” to those who are suffering and those seeking to help. He criticised the prohibition on the doctor discussing VAD with a patient unless the patient formally requests VAD, apparently to prevent doctors trying to persuade patients to this option. Although the Act states that raising VAD in a general discussion of end of life options is “unprofessional conduct”, this is clearly in conflict with medical ethics of providing full information of treatment lawful options. Moreover, in light of the relative lack of knowledge in the community regarding the law, this is a serious potential inhibition of informed discussion and consent. (Sub 88a, p 3)

Doctors for Assisted Dying Choice saw the restriction on medical practitioners initiating discussion of VAD as extraordinary. It is a fundamental interference in the relationship between clinician and patient and does not apply to any other doctor-patient relationship in Australia. Nor is it a component of assisted dying laws in any jurisdiction where assisted dying is lawful. They also saw the requirement that one of the doctors must be a specialist in the disease as reflecting on the ability of the doctors concerned and imposing a criterion that cannot be satisfied; availability of specialists is limited, especially in rural areas. Availability of a specialist who is also willing to assess the patient and sign the form is even more restrictive. (Sub 67, p 16)

Dr Syme outlined several failings with the law in that some patients have had difficulty in locating the two doctors to support their choice, or in finding the documents to prove their Australian citizenship, while some hospitals are refusing to even consider VAD. But he deemed the requirement for a specialist to be one of the assessors to be the “most



serious flaw” in writing and interpretation of the Act. He acknowledged the necessity for assessing doctors to be experienced, thus the need for fellowship of Colleges and time lines since graduation. But, while the Act does require one doctor to have “relevant experience and expertise”, it does not specify that one must be a specialist. This became an interpretation arising from debate in the chamber but is a serious error from a functional point of view; it is not required in any other Act. As noted above, the immediate effect is to seriously diminish the number of available doctors, especially when combined with the appropriate right to conscientious objection. This interpretation is having a “disastrous effect” on the implementation of the Victorian Act. While assessing doctors need “reasonably contemporaneous specialist opinion regarding diagnosis, prognosis and treatment”, this can be readily provided by specialist report rather than personal examination. He, too, stressed that specialists are hard to locate, creating significant delay in a process where time is critical in reducing suffering. As a result, people are dying before their assessments are completed; the problem is exacerbated in provincial areas. (Sub 88a, p 2, 3)

Disability advocacy group, *My Body My Choice*, explained that to require a person with a disability who is suffering unbearably to attend an additional medical consultation with a specialist they may have never met is unfair and unwarranted. They outlined the logistics: waiting for the appointment, arranging transport and a carer, telling the story again to a new person, the anxiety in hoping that person will understand what they are saying; finding the funds for the specialist consultation. It all becomes an insurmountable barrier for a person with a disability. (Sub 89, p 9)

The Act’s medical training requirements presented another implementation problem. Dr Syme considered the training for doctors in the operation of VAD is complex, even for some very experienced clinicians, and inhibiting to participation. As such, the training process should be modified. Moreover, as the training process was not available or publicised until the Act was virtually in operation, this led to serious delays in assistance while the time-consuming training was completed. Again, patients died during this time. Any required training should be available and encouraged well before the Act comes into operation. Further to that, the lack of information in the community regarding supportive doctors who have completed training led many people to wait until their circumstances were dire before approaching a doctor, usually their GP, for assistance. If their GP was not supportive, the suffering patient was in limbo, as the refusing GP had no necessity to refer. Since a GP who is supportive must obtain the support of a specialist in the illness concerned, if his usual specialist of first referral refuses, the GP, too, is in limbo, leading to more delay. Dr Syme argued that, just as doctors are appropriately allowed to conscientiously object, they should have an obligation to inform patients in their practice of their position. Vague statements have seen too many people being misled, only to encounter a refusal when making a formal request. (Sub 88a, p 3, 4)

Dr Syme commended the Victorian Government for “wisely” appointing VAD Care Navigators to provide advice and assistance to patients and doctors whenever requested. Even so, “these excellent persons” had no knowledge of who had completed training, or who might be supportive. Although those details have gradually become available, there is still a significant lack of information, creating delay and increased suffering. Dr Syme’s understanding is that the Department of Health and Human Services has recently provided Care Navigators with information about medical training. He

recommended that, at the outset, government establish a confidential list of supportive trained doctors for Care Navigators to ensure smooth operation of the law. (Sub 88a, p 3)

The advocacy group for VAD for people with disabilities, *My Body My Choice*, stated that navigating the large number of steps in Victoria's Act would, in effect, have the unintended consequence of discriminating against people with a disability. Accordingly, they called for a number of different provisions:

- one request for VAD;
- one medical assessment, confirmed by a nurse practitioner;
- one witness – the same witness to be used for each step requiring a witness;
- a disability interpreter, nominated and known by the person with the disability, who can interpret their communication in all consultations and discussions relating to a request for VAD;
- the appointment of Care Navigators to guide the person through the request process;
- no VAD permit;
- a minimum seven day waiting period from the time of initial request to being able to acquire the prescribed drug;
- the criteria of unbearable suffering, and death being a reasonably foreseeable outcome of the condition, with no specified time until death;
- palliative care to include VAD, with the palliative care team permitted to discuss VAD as an option;
- the person to nominate self administration or doctor administration;
- VAD to be allowed as an end of life care option in an ACD;
- dementia to be approved as a eligible condition for requesting VAD and in an ACD.

The additional inclusions in a VAD framework proposed by *My Body My Choice* would ensure a more equitable access to a compassionate end of life choice. (Sub 89, p 8, 14, 15)

SAVES put forward a similar list to the above amendments, with the additional requirements of:

- two requests (not one as above), the first to be oral and written and one final request;
- provisions to protect participants from harassment;
- the coordinating medical practitioner to report to the Review Board after administration of the substance. (Sub 95, p 32)

Jocelyn Hall, President of Dying With Dignity Queensland Inc. (DWDQ), lodged a personal submission with the Committee. She was critical of the length of residency requirement, maintaining that 12 months is too long. People who are acutely unwell may move to South Australia to have the support of family but some who have met all other criteria may die before they have complied with the lengthy residency requirement of the Victorian legislation. (Sub 102, p 2) Dr Syme was of a similar mind. While acknowledging that the 12-month residency requirement to prevent VAD tourism is “sensible”, he noted the practical requirements in the Act have inhibited access on technical grounds for people who clearly meet all the medical requirements. (Sub 88a, p 3)

Ms Hall also urged the South Australian Inquiry to at least consider the very difficult topics of:

- the eligibility of children – “anyone who has seen a child die could not agree with an age limit that automatically excludes young people who are less than eighteen years old. Children do not die easily. Their little bodies hang onto life even when they say ‘I just want to go to sleep forever’ as I heard (anecdotally) that a little boy with a terminal illness said to his mother”;
- impaired cognitive ability – people who have an ACD completed while they had an unimpaired cognitive ability, that states they request a medically assisted death should they reach certain loss of cognitive ability, should be eligible if they fulfil all other criteria. (Sub 102, p 2)

The World Federation of Right to Die Societies strongly advised that South Australia does not “copy” the Victorian legislation, nor pass an act in similar terms. The main principles of any South Australian law should be focussed on the presence of a voluntary and well-considered request, and of a situation of unbearable and hopeless suffering. Experience with this type of limited criteria in Belgium, the Netherlands and Luxembourg since 2002 and Canada since 2015 has demonstrated that the fears addressed in the debates in Victoria are not justifiable. Accordingly, the legislation does not need “extra due care criteria” that effectively makes access to the legal right to a free choice at the end of a person’s life practically impossible. (Sub 64, p 5)

Dr Rosemary A Jones urged the Committee to focus only on the patient, not on the family, the doctors, administrators or the general public at large. “The only player in this game is the patient.” As such, the complexities of the recently legislated provisions in Victoria are profoundly unacceptable. “Let’s see if we are really the clever state and let’s see whether the clever state can bring in some legislation that is more streamlined, will work better and will be responsive to the patient’s needs.” (Sub 8, p 2)

Dr Michael Sorokin encapsulated the parameters of the debate:

The wondrous challenge of the medical profession is to balance the need for the relief of suffering with the dictum to do no harm. Those who work on the principle that life is a Divine gift and must never be voluntarily surrendered are entitled to do so but those who consider that Compassion is the guiding principle on which the practice of Medicine is based are equally entitled to a less rigid view on the gift of Life and its surrender. A modern Society should be able to encompass within its law the expression of both points of view. (Sub 36, Addendum)

(ii) *An examination of any federal laws that may impact such legislation;*

Dying with Dignity Victoria advised that early information from the Victorian Department of Health and Human Services indicated that the possible difficulty of finding two qualified medical practitioners, particularly in the regions, could be overcome by the use of telehealth techniques. Accordingly, only one medical practitioner would be required to conduct a face-to-face assessment of the person, while the second practitioner could do this by telehealth, typically videoconferencing. It became evident, however, that this would be in conflict with Section 474.29 of the

Commonwealth's *Criminal Code Amendment (Suicide Related Material Offences) Act 2005* – using a carriage service for suicide related material. Additionally, the Department has now prohibited any person-specific information, assessment or discussion being conducted by telephone, Skype or email, restricting significantly a person's ability to access VAD. (Sub 88, p 18)

SAVES explained further. There is emerging evidence the Victorian Government has encountered difficulty in implementing the policies and procedures to manage requests for VAD from an unanticipated interpretation of Commonwealth laws on telecommunications. The Victorian Minister of Health has advised that no information about VAD can be communicated using a phone, through email, or using telehealth for medical assessments, although these forms of communication are used for all other medical processes. Doctors registered for VAD have been informed that they may risk prosecution if they use telehealth – phone or the internet - to undertake VAD medical assessments because the consultation may be interpreted as “inciting suicide”. Care Navigators in Victoria have also been advised that they are unable to provide information over the phone; all information about VAD must be provided in face-to-face meetings. Moreover, family members of a person requesting VAD may be caught under the same laws, which were originally designed to counter cyber bullying. Accordingly, SAVES argued that these restrictions must be resolved urgently for VAD to be available to people who are suffering at the end of life and are unable to travel to face-to-face meetings or consultations. (Sub 95, p 48)

Dr Carolyn Lawlor-Smith had identified the difficulty of getting “all the bits of information between each other.” She asked, “Are we going to use faxes? Are we going to post them? The post in South Australia is pretty terrible. We haven't got any encrypted way of sending them at the moment. We can't send emails because they are not encrypted. We are not allowed to send email as GPs”. Essentially, if doctors are to send documents between different organisations, they and the information must be protected. (Evidence, p 5)

SAVES identified another possible impact of federal law. The Victorian Government has authorised one hospital pharmacy service in Victoria to supply all drugs used for VAD. The drug most often associated with VAD overseas, and used illegally in Australia until now, is Nembutal, generic names pentobarbital or pentobarbitone, but federal laws prohibit the import of Nembutal for use by anyone other than a veterinary surgeon. Although the Victorian Government has selected a different combination of drugs for use by VAD patients, Nembutal is known as a fast acting and effective drug. It would be useful if Commonwealth laws would allow the import of Nembutal for use in VAD. (Sub 95, p 48; also Sub 18)

On 29 March 2020, the Minister for Health announced that telehealth services would be expanded to all Australians in response to the COVID-19 pandemic. ‘Whole of population’ telehealth services were introduced on 30 March 2020. While the new COVID-19 items were initially available only to patients and providers with or at risk of the virus, this requirement has now been lifted and the services are available to all Medicare-eligible persons for the treatment of any condition, and can be provided by any practitioner qualified to provide the service in line with normal MBS arrangements: <https://www.racgp.org.au/running-a-practice/practice-resources/medicare/medicare-benefits-schedule/new-items-for-covid-19-telehealth-services>

## 5.4 Term of Reference (d)

*Any other related matter.*

### **Nursing support at end of life**

Sandra Bradley, RN, PhD, Advance Care Consultant, called for funding for dedicated 24/7 nursing staff for the last two weeks of a person's life so that the person could die in their home, without their family members being the primary carer. Currently the death rate in South Australia is approximately 20,000 people per year, with two thirds of those deaths being predictable. Providing three nurses 24/7 for two weeks at the end of life for those 15,000 people would cost approximately \$176,400,000.00 (\$35/hr x three nurses x eight hour shifts x 14 days x 15,000), far less than the cost of people dying in hospital. By employing nurses and guaranteeing the community they will have assistance, the government will be providing what the community wants: help in supporting their loved one to die at home and in helping families accept death and dying. The government will also be employing more of the nursing students that Dr Bradley teaches at Flinders University, in an occupation with greater need than emergency or children's wards. (Sub 2, p 3)

### **The medical profession**

Doctors for Assisted Dying Choice submitted a list of relevant observations:

- the needs of the dying person should be predominant – other individuals and bodies must defer to the dying person;
- the Joint Committee should not be misled by statements from a few peak medical bodies with a multiplicity of agendas. They may have little experience of care of the dying but remain unrestrained in their adverse comments;
- while those opposed to VAD express concerns about the adverse effect on doctors and the practice of medicine, the experience is the reverse: patients who are assisted to die and their families are grateful;
- it is anticipated that only a minority of doctors will wish to utilise the provisions of the law, as will only a small number of patients. It is similarly anticipated that those doctors opposed to the provisions will be required by law to pass on the Duty of Care to a more sympathetic practitioner, and that this would be effected without rancour;
- to suppose that doctors will find the act of terminating a life too difficult would be to underestimate how often practitioners cope with distressing experiences in the normal course of their duties in conventional practice. (Sub 67, p 18)

### **Survey questionnaire**

Michael T Boesen *et al* submitted that a majority of citizens and certainly most senior citizens would endorse the concept of voluntary euthanasia being available to people who do not have a terminal illness and/or who have more than 12 months to live. A well-designed sample survey should be undertaken in South Australia to determine views concerning all aspects of VAD, including making voluntary euthanasia available to people who do not have a terminal illness or a short time to live. To that end, the eight signatories have developed a questionnaire, attached to their submission, which could be used to determine views on many aspects relating to possible implementation of provisions for VAD. They offered *pro bono* professional advice and assistance in the design of survey instruments and methodology, and in the analysis of data. (Sub 73, p 5)

## **Advance Care Directives**

The Grattan Institute put forward that South Australia should work with the Commonwealth to ensure nationally consistent legislation to underpin ACDs. In support of that goal, they recommended a public education campaign about the limits of health care as death approaches, and the need to focus on end of life care. (Sub 22, p 1)

SAVES called for a person to be able to nominate VAD in their ACD and for dementia to be a criterion for VAD and listed in an ACD. (Sub 95, p 49)

## **End of life strategies**

PCSA provided details of a number of barriers and enablers to successful end of life strategies.<sup>9</sup>

The barriers are:

- failure to identify those living in the last year of life;
- delayed conversations with patients and their families about goals of care;
- ACDs being seen as the first step to addressing end of life.

The enablers are:

- working in partnership across the acute and community settings;
- the GP model in the NHS that supports home visits and management of end of life without the need for a fee for service consultation, as GPs are salaried NHS employees;
- free access to medicines – “Just in case prescribing”;
- appointment of end of life clinical leads to improve experience of dying across the health system.

## **Palliative care funding**

PCSA highlighted the stark contrast in the level of funding provisions for palliative care in most other jurisdictions compared with that of South Australia, differences in population notwithstanding. (Sub 105, p 23)

## **6. Acknowledgements**

The Select Committee extends its thanks to those who provided information and evidence to its inquiry.

Hon. K. J. Maher

**Chairperson**

13 October 2020

---

<sup>9</sup> Catherine Swetenham, 2017 Churchill Fellow, *To Study End of Life Care Strategies and the barriers and enablers to their implementation in Ireland, United Kingdom and Canada*, December 2018:  
[https://www.churchilltrust.com.au/media/fellows/Swetenham\\_C\\_2017\\_To\\_successfully\\_implement\\_an\\_End\\_of\\_Life\\_care\\_strategy\\_for\\_SA.pdf](https://www.churchilltrust.com.au/media/fellows/Swetenham_C_2017_To_successfully_implement_an_End_of_Life_care_strategy_for_SA.pdf)

## **Appendix 1: Index to Witnesses**

Public evidence was received from the following persons and organisations:

### **Tuesday, 16 July 2019**

Professor Arnold Gillespie & Dr Carolyn Lawlor-Smith - Doctors for Assisted Dying Choice  
Dr Roger Hunt, Senior Consultant, Central Adelaide Palliative Care Service  
Professor Gregory Crawford, Professor of Palliative Medicine, Discipline of Medicine, University of Adelaide

### **Tuesday, 17 September 2019**

*Australian Medical Association (South Australia)*

Dr Chris Moy, President  
Dr Samantha Mead, Chief Executive Officer  
Ms Karen Phillips, Senior Policy, Media & Communications Advisor

*Australian Nursing and Midwifery Federation (SA Branch)*

Ms Tracy Semmler-Booth, Professional Officer/Team Leader,  
Ms Ros Hewlett, Manager, Professional and Workplace Services  
Ms Lee Thomas, Solicitor, Union Legal SA

Mr Kevin Hardy, Palliative Care Nurse Head, Calvary Hospital

### **Thursday, 13 February 2020**

Mr David Whittle, State Coroner  
Mr Anthony Schapel, Deputy State Coroner

### **Wednesday, 18 March 2020**

*SA Health*

Mr David Holden, Clinical Lead Palliative Care  
Ms Helen Chalmers, Executive Director Health Services, Programs & Funding

*South Australian Voluntary Euthanasia Society (SAVES)*

Ms Frances Coombe, President  
Ms Julia Anaf, Vice President  
Ms Anne Bunning, Policy Advisor

*Palliative Care South Australia*

Mr Mark Waters, Executive Director  
Ms Helen Walker, Deputy Chair

### **Tuesday, 26 May 2020**

Rev Mike Mills, State Minister, Baptist Churches SA  
Archbishop Geoffrey Smith, Anglican Archbishop Diocese of Adelaide and Primate of the Anglican Church of Australia  
Bishop John Henderson, Bishop of the Lutheran Church of Australia

Bishop Greg O'Kelly SJ, Apostolic Administrator of the Adelaide Archdiocese and Bishop of Port Pirie  
Jenny Brinkworth, Director, Catholic Communications  
Pauline Connelly, Chancellor of the Adelaide Archdiocese  
Greg Crafter AO, Catholic lay representative

## Appendix 2: List of Submissions

The following persons and organisations made written submissions to the Committee which were related to the Terms of Reference of the Committee and were resolved to be published by the Committee:

	NAME		NAME
1	Mr Richard Egan Australian Care Alliance	37	Lorna Bessell
2	Ms Sandra Bradley	38	Shayne Higson
3	Dr Julia Anaf PhD	39	Jacqui Possingham
4	Judith King (confidential)	40	Voluntary Euthanasia Party -NSW
5	Anne Johnson	41	Jason Oliver
6	Marshall Perron	42	Belinda Teh
7	Aust. Healthcare and Hospitals Assoc,	43	Emily Nicholson
8	Dr Rosemary Jones	44	Adrian Heard
9	Jenny Parfitt (to be redacted)	45	Ted Arnold
10	Dr. Cheryl Wilson	46	Andrea Griffith
11	Ray Hillier	47	Mary Priest
12	Zuzana Huljak	48	Mary Simpson
13	Phil Browne	49	Hon. Nick Goiran MLC
14	John Flynn	50	Nicholas Cowdery
15	Dr John Willoughby	51	Noelene Bearn
16	Norma Jamieson	52	Ian Leader-Elliot
17	Meredith Reardon	53	Dying with Dignity NSW
18	Dr Margaret Denton	54	Lyn Leader-Elliot
19	Melva Whibley	55	National Secular Lobby
20	Spyridon Couvalis	56	Leni Wells
21	Kate Meddick	57	Vivien Donahue
22	Grattan Institute	58	Jim Dominguez
23	Phyllis Wagner	59	Graham Adams
24, a, b	Keith Usher	60	Dying for Choice
25	End of Life Choice Society NZ	61	Karen Eckermann
26	Vivien Donohue	62	Hon. Sandra Kanck
27	Dr Peter Gregory	63	Dinny Laurence
28	Christians Supporting Choice for Voluntary Assisted Dying	64	The World Federation of Right to Die Societies
29	Nancy Wood OAM	65	Geoffrey Williams
30	David Coombe	66, a, b	Australian Centre for Health Law Research
31	COTA	67	Doctors for Assisted Dying Choice
32	Right to Life Australia	68	Colin Harwood
33	Gerald Versteeg	69	Church of the Flying Spaghetti Monster
34	Harry and Annette Joyce	70	New Zealand Association of Rationalist and Humanists
35	Margaret Wood	71	John Obeid
36	Michael Sorokin	72	John Martin



	NAME		NAME
73	Michael Boesen and others	97	Dr Peter Allcroft
74	Ann Jackson	98	Australian Family Coalition
75	Dignitas	99	Medical Insurance Australia (MIGA)
76	Christian Medical & Dental Fellowship of Aust	100	Dr John Hayes
77	Syndicated Australian Voluntary Euthanasia Youth Advocates	101	Calvary
78	Lutheran Church of Australia, SA-NT District	102	Jocelyn Hall
79	Clem Jones Group	103	Assoc Prof Timothy Kleinig
80	Prof Ian Maddocks	104	Dying with Dignity Queensland
81	Australian Psychologists Society	105	Palliative Care SA
82	Michaela Okninski	106	Australian Nursing and Midwifery Federation (SA Branch)
83	Andre Mauchle	107	Martyn Evans and Margaret Brown
84	Dying with Dignity Tasmania	108	Pharmaceutical Society of Australia
85	Thomas Bunning	109	Anglican Diocese of Adelaide
86	Australian Christian Lobby	110	Australian Medical Association (SA)
87	Alan Tyson	111	SA Health
88, 88a	Dying with Dignity Victoria	112	Nadine Coutts
89	My Body My Choice	113	Kieran Tapsell
90	Prof Ian Olver	120	Go Gentle Australia
91	FamilyVoice Australia	121	Australian and New Zealand Society of Palliative Medicine
92	HammondCare	122	Health Performance Council
93	Dr Robert Pollnitz	123	South Australia Police
94	HOPE: Preventing Euthanasia and Assisted Suicide Ltd	124	Michaela Okninski
95	South Australian Volunteer Euthanasia Society	125	Dr Elizabeth Summerfield
96	Elizabeth Drake	126	Catholic Archdiocese of Adelaide and Port Pirie Diocese