

**PALLIATIVE CARE SA (PCSA) SUBMISSION TO**

**SOUTH AUSTRALIAN PARLIAMENT**

**JOINT COMMITTEE ON END OF LIFE CHOICES**

**Prepared by PCSA**

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**PALLIATIVE CARE SA**

Unit4 213 Greenhill Road

Eastwood SA 5063

(08) 82711643

[www.pallcare.asn.au](http://www.pallcare.asn.au)

**Authorised by:**

Professor Gregory Crawford MBBS, MPHC, MD, FRACGP, FAChPM

Chair

PCSA Board

**Who is Palliative Care SA?**

Palliative Care South Australia (PCSA) is a not for profit organisation and is the peak body for palliative care in South Australia. PCSA is dedicated to supporting people living with chronic, life limiting and terminal illness and those who care for them. Our mission is to influence, foster and promote the delivery of quality palliative care for all. We advocate for the needs, rights and interests of people who are dying and those who care for them, to ensure no-one in our community is overlooked when they are facing death. We bring an independent voice on Palliative Care issues and have a key role in bringing together major stakeholders – service users, practitioners, professionals and the community of South Australia.

PCSA has been operating for almost 40 years, has over 700 members and has relationships and partnerships with a large number of stakeholders. PCSA is a member of Palliative Care Australia – the national peak body for palliative care in Australia.

**The implementation of an efficient, effective and acceptable Voluntary Assisted Dying (VAD) Scheme in South Australia** **comprising all the appropriate legal and medical protections, will only be successful if the provision of quality palliative care to all South Australians irrespective of geographic location or socio-economic status, is delivered at the optimum level.**

**Recommendations**

1. The implementation of an efficient, effective and acceptable Voluntary Assisted Dying Scheme in South Australia comprising all the appropriate legal and medical protections, will only be successful if the provision of quality palliative care to all South Australians irrespective of geographic location or socio-economic status, is delivered at the optimum level.
2. Voluntary Assisted Dying should not be introduced to cover gaps in appropriate systems reform and funding in palliative care and the Joint Committee endorse the provision of extra resources as advocated by PCSA.
3. The outcomes of the review of the Advanced Care Directives Act be reviewed by the Joint Committee and to advocate for an increase in resources and commitment to increase education on the importance and value of Advanced Care Directives to both the community and the medical profession.
4. The development of good and robust data and evidence of how funding is provided, be implemented, to ensure the impact of VAD legislation on the health system is clearly identified.
5. The VAD Guiding Principles developed by PCA be considered by the Joint Committee for inclusion in SA legislation.
6. The Joint Committee take into account the particular needs of South Australia in drafting VAD legislation.
7. The Joint Committee align its recommendations with the necessary level of funding resources to ensure the successful implementation of any proposed legislation changes.
8. The Joint Committee engage PCSA to assist in scoping and drafting the VAD legislation and community consultation processes as has been successful in WA.

**Introduction**

PCSA welcomes the opportunity to provide this submission to the SA Parliament Joint Committee on End of Life Choices.

As you would expect given our charter the focus of our submission is on the role of Palliative Care in South Australia. Death and dying are not just a medical or health event, it is a human experience. Care needs to be person centred.

This philosophy is amplified by Palliative Care Australia's definition of palliative care –

“Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life.” [[1]](#footnote-1)

We are pleased therefore, to note that while the focus of the Joint Committee is on End of Life Choices, it also poses questions on the important role of palliative care in our community.

While we are neutral on our stance regarding voluntary assisted dying, we reject totally the introduction of voluntary assisted dying because there are gaps in systems reform and funding in palliative care.

**Our main thesis in relation to your important task is that the implementation of an efficient, effective and acceptable VAD Scheme in South Australia comprising all the appropriate legal and medical protections, will only be successful if the provision of quality palliative care to all South Australians irrespective of geographic location or socio-economic status, is delivered at the optimum level.**

It is noted that the Australian Medical Association (WA) in their submission to the WA Ministerial Expert Panel on Voluntary Assisted Dying (Final Report) makes a strong case that the ‘correction of deficiencies in palliative care and end of life decision-making must be a prerequisite to the introduction of voluntary assisted dying legislation for community and parliamentary debate’.[[2]](#footnote-2)

This is such an important area as in 2019-20 approximately 160,000 Australians will die – this is projected to increase to over 200,000 in the year 2030. The Productivity Commission has estimated that around 80,000 Australians could benefit from palliative care each year, and that their end of life journey can be punctuated with avoidable, or unwanted, admissions to hospital with the confusion, loss of dignity and loss of control that comes with it. Few of those who would prefer to die at home are able to do so. Providing community based palliative care instead of hospital care to those who would prefer it is potentially cost effective. Available evidence indicates that the savings from avoiding a single hospital admission for palliative care (costing about $11,000) over relatively few days, would more than cover the cost of providing community based care over a period of months (costing between $6,000 and $11,000).[[3]](#footnote-3)

A key policy position of PCSA is that there is an immediate need to develop evidence and plan ahead to support the increased need for person and family-centred, accessible, flexible and responsive palliative care.

PCSA is very grateful for the additional funding the SA State Government has committed to provide to 24/7 community focussed palliative care services but believes that there is a need for much more and targeted funding to palliative care.

We know that there is currently inequitable access to palliative care in South Australia; that there is a wide discrepancy between available services in the metropolitan area to that available in rural and remote regions, and unless there is significant change in the way it is funded and delivered, these inequities will continue to grow.

Access must be available to anyone with a life-limiting illness, regardless of their postcode, diagnosis, age, ethnicity, socio-economic status or place of care, to enable them to live as well as possible for as long as possible.

The National Palliative Care Strategy which was released by the Federal Government in 2018 states that ‘investment at national, state, and territory levels will be required to ensure that the systems and people are available to provide quality palliative care when and where it is needed’.

Without investment in a strong implementation plan, and recognition that palliative care is not just for the end of a person’s life, more Australians will continue to miss out rather than benefit from this person and family-centred care, where the primary goal is to optimise the quality of life.

The goals of the Strategy include:

* People affected by life-limiting illnesses receive care that matches their needs and preferences
* A skilled workforce and systems are in place to deliver palliative care in any setting
* People to understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care
* Knowledge and practice of palliative care is embedded in all care settings
* Everyone works together to create a consistent experience of palliative care across care settings
* Robust national data and a strong research agenda strengthen and improve palliative care[[4]](#footnote-4).

Statistics released by the Australian Institute of Health and Welfare in 2018 provide a strong argument for urgent increased investment in palliative care service delivery. The report highlights South Australia had the highest rate of palliative care-related hospitalisations in all hospitals (38.5 per 10,000 population) and for private hospitals, South Australia recorded the highest overnight average length of stay (ALOS) at 15.9 days, and for public hospitals it was 10 days.[[5]](#footnote-5) This highlights the need for an increase in funding for specialist community palliative care to meet this growing demand and offset acute hospitalisation costs for palliative care patients.

The report indicates growth and ageing of Australia's population, and the corresponding increase in the prevalence of chronic, progressive and generally incurable illnesses has broadened the type of patient groups requiring palliative care.

**Improving Palliative Care Services in South Australia**

As stated in the most recent report by the AIHW (Australia’s Health 2018), people with lower socio-economic status do not receive the same access to palliative care as those with higher status[[6]](#footnote-6). In addition, people living in country South Australia do not have the same access to services. Palliative Care South Australia’s mission is to ensure all South Australians have equitable access (equal access for equal need) to palliative care, no matter their location or their socio-economic status.

The SA Health Performance Council ‘s Revisit review of South Australia’s Palliative Care Services Plan 2009‐16, November 2018, very eloquently summed up the state of palliative care in SA in its Executive Summary, quoted in part, as follows;

“..despite the early impetus to establish a sustainable, consumer‐centred and centrally coordinated model of end‐of‐life care, progress in achieving the 2009‐16 plan and its goals 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.

Confusion about the plan’s strategic intent, desired outcomes and explicit priorities also contribute. For consumers, families and carers, the lack of action has had real and significant impacts: less community‐based care than was promised, continued high levels of hospitalisation and acute care treatments, more pressure on carers, more disruption for consumers as they move between systems, delays in receiving care, and inconsistent quality of care.

For SA Health, it has meant ongoing pressure on financial, staff and other resources in many parts of the system. In short, consumers of palliative care cannot be sure they are more likely now than they were before the plan was introduced to receive the care they want, where they want it. They are no more certain now than previously that their choices about how and where they are cared for and die will be respected and met. They still cannot be assured of living and dying well at the end‐of‐life stage.

Consumers regard highly the expertise and compassion of palliative care specialists. New advance‐practice roles and regional and integrated service units, operating from the metropolitan local health networks, have centralised expertise and resources. There has also been some expansion of community care, including through the use of extended care paramedics. For South Australians able to access palliative care services there are proven positive outcomes but almost two years after the plan’s conclusion, there is much undone”.[[7]](#footnote-7)

The State Government’s commitment to invest an extra $16M over the next four years to build capacity and ensure equitable access to palliative care services is applauded, and this will go part of the way to:

* build 24/7 Community Palliative Care capacity so that people can be supported in their final stage of life at home, with the help of their GP and experienced palliative care community nurses.
* integrate palliative care across the acute care setting (relieve pressure on the acute system resulting in reduction of the numbers of terminally ill people in acute hospital beds including intensive care, and fewer emergency department presentations).

However, there is still greater need to increase targeted funding to ensure the increased demand for palliative care and services is met.

**Responses to the Terms 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**

South Australia has been a pioneer in end-of-life legislation. The Consent to Medical Treatment and Palliative Care Act, 1995 was the first time palliative care was mentioned in any legislation. It is excellent legislation and provides a framework for end-of-life care and enables patients to see treatment being withdrawn at their request; leading to Palliative Care potentially; and also leading to natural death.

The Advanced Care Directives Act 2013 improved on this legislation by providing a sound framework for end-of-life care and giving clarity about consent ages and some processes around those who do not have capacity or limited capacity to make decisions.

There are a number of issues in relation to assisting a person to exercise their preferences including ongoing education and health literacy which are not strongly evident in our health system. There is evidence that even in the actively involved general practice population there is misunderstanding about current consent, of the legislation and the provisions it actually provides. But it is not only the health community but the whole of our community which needs a much greater focus on death literacy and health literacy, and it could be framed around the ACD legislation

PCSA is a partner organisation in an NHMRC partnership grant about advanced care practice, end-of-life conversations, in vulnerable populations (people in acute care, Australian Aborigines, culturally and linguistically diverse people)[[8]](#footnote-8). Vulnerable groups in our community demonstrate significant barriers to discussing death and dying. Culturally and linguistically diverse people may not have the same self-autonomous view about decision-making. The needs of some vulnerable people in our community may require different practices and proposals in contract to the “one size fits all” approach that currently exists.

There is clearly no ongoing support in any material way about the Advance Care Directives legislation and its application, even in local health networks, let alone in the whole of our community. While Palliative Care SA provides education sessions around advance care directives, the take up by the community has not been extensive.

The outcomes of the review of the ACD Act should also be of great interest to the Joint Committee on End of Life Choices and if necessary advocate for an increase in resources and commitment to increase education on the importance and value of Advanced Care Directives to both the community and the medical profession.

People facing the end of their lives value good symptom control, clear decision-making, some sense of preparation, a sense of having made a difference in your life and that they want to be affirmed as whole people.[[9]](#footnote-9) This is supported by others confirming that pain and breathing, dignity, peace with dying, avoiding being a strain on loved ones, and having control over the situation are important goals.

It is also important to distinguish between the terminology used to describe the care provided before death. The Palliative Care Australia Service Development Guidelines have moved to distinguish palliative care and specialist palliative care as follows;

‘Specialist palliative care’ is seen as the care provided by a specialist palliative care team comprising a multidisciplinary team, with specialist skills, competencies and training. The term 'palliative care' relates to the core competencies and skills expected of all health professionals involved in caring for people living with a life-limiting illness.[[10]](#footnote-10)

So how well is palliative care constructed in South Australia and are people getting what they need? We think the short answer to that is: it's patchy; it is not adequate. For example, if a person is referred to a specialist palliative care service, they are likely to get good to excellent symptom control. Quality of palliative care and access are dependent on referral pathways, geography and personal resources. This is unacceptable.

There are large variations between rural/remote and metropolitan areas as to what sort of services people might be able to access. If people are referred to a specialist palliative care service, they are more likely to die, or be cared for and potentially die, in the site of their preferred place. All of the specialist palliative care services in Adelaide probably have home death rates of somewhere between 40 to 50 per cent.

To actually even have the conversation about where people want to die presupposes a level of health literacy and ability to talk about those issues. Practitioners look after a lot of people who do not really want to talk about death all the time. The responses to impending end of life are quite variable.

The manner in which community services are delivered in South Australia add layers of complexity and disparity in outcomes. There are differences between how Local Health Networks disperse funds to community and inpatient services and there is inconsistencies in the metrics of outpatient programs and home visiting programs.

State and Commonwealth Government jurisdictions add to the complexity and allow diversion of resources. ‘My Aged Care’ services are used to try to provide community packages of palliative care. There are some SA Health programs that will help the acutely dying or relatively short-term dying, but nurses coordinating those processes have to determine prognoses and try to fit them into programs. If you are under 65, then it is much harder to get services, equipment and other essential supports for people.

SA Palliative Care services support equal numbers of people older and younger than 65. There are barriers to referral. Some of those are health literacy and funding, and many are still missing out. Equally, it is known that people with non-cancer conditions are missing out, while most palliative care services would treat 20 per cent non-cancer patients and 80 per cent cancer patients.

Our main thesis is that, regardless of what decisions are made about voluntary assisted dying there is a fundamental need for a properly constructed, fully resourced palliative care service. That means that those who know about palliative care are more likely to be able to access the right care. There are still significant gaps in palliative care service provision in our community.

In Australia another barrier to community based EOLC is the ‘fee for service’ business model for general practitioner (GP) remuneration. GPs are not remunerated appropriately to cover the time or cost of visiting someone at home. There is a significant difference between the UK and Australia is the way in which General Practitioners (GP) are engaged, where GPs in the UK are salaried through the National Health Service (NHS). Their model enables home visiting without financial disadvantage and systems such as an EOL register support GPs where they have identified a patient to be living in the last year of life. [[11]](#footnote-11)

PCSA is advocating through PCA for COAG Health Ministers to advocate to the Federal Government for increases to be made in GP’s remuneration to provide realistic incentives for GP’s to cover the time or cost of visiting someone at home.

The other area requiring more attention is that of the care being provided in residential care facilities. These have become the “slow-stream hospices” of our health system. They are the place where, increasingly, people are dying, and there are large gaps in staffing levels, knowledge base, access to medications and access to good medical advice in hours and after hours. Greater attention needs to be given to the care being provided in residential aged care facilities, to ensure gaps in staffing levels, knowledge base, access to medications and access to good medical advice in hours and after hours are greatly improved.

Several Australian Institute of Health and Welfare (AIHW) reports have considered the use of aged care services before death. The 2018 AIHW review[[12]](#footnote-12) of the nearly 245,000 deaths of older Australians in the period July 2012 to June 2014 showed that four in five of the people in the study cohort had used an aged care program sometime before their death. Another AIHW study of aged care use before death showed that in all groups aged over 65, there was increased take-up of care in the last 6 months of life. The older a person was when they died, the more likely they were to have been accessing a care program at the time of death. Given the increasing number of older people and the related use of aged care services prior to death, aged care services are inevitably involved in providing care for older Australians at the end of their life. The extent to which they are appropriately resourced and have the necessary professional capacity to provide effective palliative care is being debated and is most likely to be given some attention by the Royal Commission into Aged Care.

As stated, palliative care can be provided by a range of different health providers and in different settings including the home and residential aged care with support from specialist palliative care if needed. There is evidence that palliative care is effective but there is variability in the availability and the strength of evidence for palliative care as an intervention in different settings.

The availability of palliative care is not limited to one type of illness but can assist all people with life-limiting illness, their families and carers. The World Health Assembly recognised that

“…palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service, that values patients’ need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received.” [[13]](#footnote-13)

The National Palliative Care Strategy affirms that palliative care is a person-centred approach with those affected by life-limiting illnesses at the heart of their care, surrounded by their community and supported by services. The types of palliative care and support that may be needed by an individual, their families and carers will vary and may include one or more of a range of formal and informal supports.

Palliative care may be required at any age. The needs of children and young people, and their parents and families, are often quite different from those of people facing the end of life at a much older age. Cultural factors, such as kinship and community, and end-of-life practices and rituals of Aboriginal and Torres Strait Islander people need to be considered to enable cultural capability of palliative care services for Aboriginal and Torres Strait Islander people. People with differing illnesses (such as cardiovascular disease, dementia or cancer) will have differing physical, psychosocial and spiritual needs over various timeframes.

Because people’s palliative care requirements will differ and will also change over time, it is important that their needs and preferences are assessed regularly and that services are able to adapt accordingly. This includes the needs of families and carers as well as the person with a life-limiting illness.[[14]](#footnote-14)

Finally, there is a need for improved data. Data is required about allocated funding, about how it is spent, and on who receives service and what the patient level outcomes and goals are and whether they are met. Current data capture of these issues is unreliable and at best patchy and inconsistent. Even the Health Performance Council data about acute hospital palliative care service cannot differentiate between that service provided by currently SA Health funded multidisciplinary palliative care teams and that which is only consultation level support. We need good and robust data and good accounting and this will be even more critical if Voluntary Assisted Dying is introduced as it will have significant change to the nature of palliative care practice. We are confident the State Government will want good and robust data and evidence of how effective targeted funding to palliative care is, in order to be able to clearly identify the impact of VAD legislation on the health system.

**(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 VAD regime has been described by the Victorian Government as the “safest and most conservative model in the world” with 68 safeguards. Many of these safeguards relate to the process of accessing VAD. This process is complex with detailed procedures outlined in the legislation. It includes the involvement of at least two doctors, tightly prescribed procedural steps and progressive reporting to the new VAD Review Board.

In an article by Ben P White, Lindy Willmott and Eliana Close of the Australian Centre for Health Law Research, Queensland University of Technology titled “Victoria’s voluntary assisted dying law: clinical implementation as the next challenge” they outline a number of challenges as follows;

* Implementation of the VAD legislation into clinical practice must balance two important policy goals. It must facilitate access to VAD, but restrict that access to only those who are eligible under the legislation.
* Designing implementation processes to achieve both goals will be challenging given the law’s complexity. This complexity was by design, with the rigorous and prescriptive VAD process aiming to attract political support for a conservative model.
* The effective conversion of legal standards into medicine is a known challenge in health law and regulation. This is particularly so here because the VAD legislation mandates detailed intervention into clinical practice — indeed it arguably creates a new area of clinical practice.
* The engagement of key health and medical stakeholders, as well as people likely to seek VAD, in designing how the regime operates will be critical.
* An example of this is the prohibition on doctors and other health professionals initiating VAD discussions with patients (section 8, VAD Act). Clear guidance is needed on how to clinically implement this legal prohibition yet maintain meaningful end-of-life discussions with patients. Expertise from health professionals who regularly engage in these conversations will be important when designing how this aspect of the law is implemented.
* Another example is regulating the VAD medication. The implementation process will need to determine not only which medication to use and in what doses, but also address the logistics for meeting detailed legal requirements of how the substance is to be prescribed, handled, stored and (unused portions) returned.[[15]](#footnote-15)

Willmott et.al. also state that an opportunity to translate the VAD law into practice is through a clinical network with expertise in facilitating and educating about VAD. While its long-term success would depend on clinical leadership, the implementation process could “seed” development of a network of VAD doctors who would then support other clinicians. Such clinical networks exist in different forms in other countries where VAD is legal, such as SCEN (Support and Consultation on Euthanasia in the Netherlands) and LEIF (Life End Information Forum) in Belgium. Such networks develop clinical expertise and guidance that not only promotes high quality, patient-centred care but also outlines medically appropriate processes that comply with the VAD law.

A designated 18-month implementation period has seen an Implementation Taskforce appointed, and work is underway on projects including developing clinical guidance, models of care, medication protocols and training for doctors participating in voluntary assisted dying (VAD).

The authors believe that the designated 18-month VAD implementation period provides scope to address these challenges and create the necessary clinical, legal and administrative infrastructure. This can be contrasted with Canada, where political delays led to their medical assistance in dying law coming into effect without an extended opportunity to prepare.

The Victorian implementation process also has the benefit of being well resourced, including in relation to expertise. The Implementation Taskforce comprises individuals with extensive clinical, legal and policy experience with many also being members of the earlier Ministerial Advisory Panel (which provided detailed recommendations informing the draft legislation).

The government-sponsored process also has a high level of support from the Victorian Department of Health and Human Services to facilitate effective implementation. Finally, the process can draw on the experience of implementing VAD (both positive and negative) in other jurisdictions, including the recent Canadian experience.

The authors conclude that the implementation of Victoria’s VAD law is critical for whether it achieves the dual policy goals of facilitating access to VAD by eligible people, while ensuring this access is limited only to this cohort. Translating this complex law into appropriate clinical practice will be challenging. Victoria has strategically designated both time and resources to a period of planned implementation.[[16]](#footnote-16)

By contrast, Frank Brennan, Calvary Health Care Sydney, Palliative Care (MBBS, Dip Obs, DCH, FRACP, FAChPM, FACLM, LLBLaw) {a physician and lawyer} states in a recent article that the Victorian legislation aims for precision. Medicine, on the other hand, operates in a landscape of uncertainty. So, when the two disciplines meet to focus on issues vital to Euthanasia/Physician Assisted Suicide (E/PAS) legislation, there may be problems. Those issues include the prognostication of illness, decision-making capacity, screening for depression, the possibility of undue influence and the use of life-ending medications (with likely inter-individual variability in effect). As physicians, we know we cannot be certain about these issues. The laws strain to achieve certainty in language and effect. The law seeks, but medicine cannot provide, such certainty, and yet, with E/PAS, both disciplines must be highly conscious of the irreversible consequences for not getting things right. There is, therefore, an inherent tension at the centre of any E/PAS law. For law is entering the domain of not only medical uncertainty but also the mystery of the human psyche and interpersonal relationships. Uncertainty and mystery are not solid foundations for any legal statute.[[17]](#footnote-17)

The Western Australian Government has undertaken to introduce legislation in the second half of 2019 to provide for voluntary assisted dying. The final report of the Ministerial Expert Panel on Voluntary Assisted Dying, recommends a number of Guiding Principles which should be included in the WA legislation to help guide interpretation. It is considered that these guiding principles are worthy of consideration by the Joint Committee. The Guiding Principles are as follows;

* 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.[[18]](#footnote-18)

It is interesting to note that the while the Victorian legislation presented WA with an opportunity to examine the approach taken in Victoria, the circumstances of WA needed to be taken into account, including cultural diversity and geography. The SA Joint Committee also needs to take into account the particular needs of South Australia.

The WA approach differs from the Victorian legislation in a number of ways, including;

* That a prohibition on health practitioners starting a discussion about VAD not be adopted in WA.
* That if a doctor conscientiously objects to participate in VAD they have a responsibility to offer to refer the person to another doctor for assistance. Victoria has not included this requirement in their VAD legislation.
* The timing of the written request in the VAD process in Victoria is different from that proposed in WA – that it occurs between the first verbal request and the first assessment while in Victoria the written request takes place after the person has completed the two assessments and has been determined eligible.
* Victoria is the only jurisdiction that makes it compulsory for the assessing medical practitioners to have completed approved assessment training before undertaking assessment for eligibility for VAD.
* The process must not disadvantage people living in rural and remote parts of WA. The use of telehealth as well as secure electronic information exchange would assist to enable reliable and secure access for people across the State. For rural health practitioners the availability of peer support alongside training and education requirements would be an additional measure to ensure safe and high quality service provision.
* The Victorian requirement of departmental approval by a senior bureaucrat for VAD should not be a feature of the WA model. [[19]](#footnote-19)

Palliative Care Australia is in the final phase of reviewing its Position Statement on Euthanasia and VAD. It plays an active role in ensuring that palliative care and end-of-life care is strongly responsive to the needs, preferences and values of people, their families and carers and that people should be able to access appropriate palliative care support, regardless of income, background, diagnosis or prognosis. [[20]](#footnote-20)

Furthermore, Palliative Care Australia (PCA) has taken a leadership role in developing a number of Guiding Principles for Voluntary Assisted Dying. [[21]](#footnote-21) PCA has developed these guidelines in the knowledge that legislation that legalises voluntary assisted dying is being introduced or being considered by a number of jurisdictions and that this will pose many ethical, personal and professional issues for health professionals, care workers and volunteers who are providing care to people living with a life-limiting illness, or working in or engaging with organisations providing any level of palliative care. They followed a Board Delegation Study Tour to the USA and Canada from which a paper Reflections and Learnings

was published and these principles developed and tested at a national symposium earlier this year. PCSA’s Deputy Chair was a member of this delegation and co-author of the document. She is willing to share these findings directly with the Joint Committee.

The purpose of these guiding principles is two-fold:

1. To ensure appropriate care is provided to a person living with a life-limiting illness at all times; and,

2.To maintain appropriate, respectful and cooperative relationships between health and care professionals.

There are seven guiding principles of equal importance that are designed to sit alongside legislation (if applicable), organisational ethical frameworks or professional codes of conduct. Underpinning these principles are the fundamental elements of palliative care:

The Guiding Principles[[22]](#footnote-22) are:-

1. People living with a life-limiting illness are supported and respected whether or not they choose to explore or access voluntary assisted dying.
2. People exploring voluntary assisted dying will not be abandoned.
3. Respectful and professional behaviour towards colleagues and co-workers regardless of their views on voluntary assisted dying.
4. Effective communication is an important part of quality care.
5. Ongoing development of knowledge, skill and confidence is required to provide competent and safe care to people living with a life–limiting illness
6. Self-care practice is a shared responsibility between individuals, colleagues and organisations.
7. Continue to learn from evidence and evolving practice to drive quality improvement in voluntary assisted dying.

**Note:** There is a link to the Guiding Principles below but PCSA will be forwarding the Guiding Principles to the Joint Select Committee under separate cover.

While we expect that a range of professional organisations will make their views and positions known to the Joint Committee, we nevertheless make note of a few organisations positions as follows;

We understand that the Australian and New Zealand Society of Palliative Medicine, an organisation comprising membership of mainly palliative care physicians, is reviewing their position statement at the moment. This organisation is a member of PCA and has participated in the development of VAD Guiding Principles.

We note that the Australian Medical Association (AMA) position statement on euthanasia is that they currently do not support euthanasia.

The Royal College of General Practice (RACGP) recognises that changes to the law are a matter for society and government and all health professionals must operate within the boundaries of state and federal law. The RACGP supports patient-centred decisions in end-of-life care, and respects that this may include palliative care and requests for voluntary assisted dying. Any legislation must:

* protect both patients and doctors from coercion
* ensure doctors are not compelled in any way to participate
* have clear eligibility criteria
* support the optimisation of end of life and palliative care services.

RACGP’s position statement is designed to ensure that both patients and general practitioners (GPs) are supported when legislation for voluntary assisted dying is being considered and implemented.

**International legislation/experience**

No doubt the Joint Committee will be undertaking its own detailed analysis of international legislation and experience, and while we have not undertaken an exhaustive analysis of international legislation and /or experience we have chosen to highlight some of the key issues to be taken into consideration in framing VAD legislation.

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

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

The Quebec Act Respecting End-of-Life Care states that every person whose condition requires it has the right to receive end-of-life care, inclusive of palliative care and medical aid in dying.

Although not specified within The Belgian Act on Euthanasia, the integrated nature of the Belgian model of end-of-life care includes the option of eligible patients accessing euthanasia as part of the palliative course.

A review undertaken for Palliative Care Australia by Aspex Consulting, made a number of key findings;

* that the palliative care sectors following the introduction of assisted dying for each of the Canada, Quebec and Belgium jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.
* Learnings from the implementation of assisted dying legislation in international jurisdictions reveal an increased focus on, and public policy attention towards, end-of-life care. It is noted that the implementation of legislation may drive a stronger focus on upholding patient choice and autonomy, and there may be opportunities to introduce system improvements in palliative care, either as a direct or indirect consequence of the planned implementation of assisted dying.
* In Belgium, there was an intentional drafting of parallel sets of legislation covering assisted dying and palliative care system resourcing.
* In other jurisdictions, there were indirect system improvements in palliative care that occurred alongside the introduction of assisted dying.
* Similarly, in Canada, the assisted dying legislation requires that to be eligible for assisted dying, patients must be first advised of available service options to reduce suffering, inclusive of palliative care.
* In other jurisdictions, there were indirect system improvements in palliative care that occurred alongside the introduction of assisted dying. This reflected the focus that was placed upon end-of-life care as a whole and the increased focus and public policy attention directed to the sector.
* It reflected debate around the importance placed upon assisted dying as a complement to palliative care and not as an alternative to palliative care.[[23]](#footnote-23)

In the Palliative Care Australia 2018, Reflections and Learnings – Assisted dying in Canada and the United States Report[[24]](#footnote-24) the delegation heard many times that those participating in Medical Assistance in Dying (MAID) in Canada were concerned about some uncertainties regarding the Canadian legislation. There are also reviews underway regarding whether the legislation should be extended to apply to mature minors, individuals with mental illness, and a request made in an advance directive. There are also some Constitutional challenges relating to the legislation in progress through the legal system.

The delegation’s impression was that regulation could have benefited from palliative care expertise being involved as early as possible. Failing to consider palliative care and how it sits with the provision of MAID, has resulted in a retrospective management of how these practices can co-exist for the benefit of the patient. MAID is now regarded as one possible option at the end of life, and it is therefore important for the palliative care community to be part of conversation around its regulation. Being part of the conversation would enable the palliative care community to advocate for access to health services generally including palliative care, and ensuring there is a sufficient workforce to deliver palliative care as well as MAID.

The extent to which the relationship between palliative care and their patients was affected by MAID was explored by the delegation. It became obvious very quickly in Canada two years since legalisation that relationships with patients was paramount and the issue of non-abandonment of patients was predominant in all conversations.

In Oregon where the legislation has been in place for nearly two decades, the delegation heard that palliative care works closely with physician assisted dying providers to ensure the patient is at the centre of all care. The concept of non-abandonment was very important in all of their consultations.

As has already been outlined that in the development of legislation to cover voluntary assisted dying there is high potential of conflict and tension between the objectives of a legal framework and the realities of medical practice. PCSA is concerned that there be a workable balance but that at all times the wishes of patients are met and that adequately resourced palliative care is always available to those members of our community who need it. We are concerned that there is good forward planning and comprehensive consultation with all key stakeholders in the development of any new legislation. While we wish to see a workable regime developed, we are concerned that there are sufficient safeguards in the system to avoid routinisation of voluntary assisted dying practices developed over time. Most emphatically, we do not want to see the main reason that voluntary assisted dying is introduced is due to gaps that could be fixed through appropriate systems reform and funding in palliative care.

**(c) what legislative changes may be required, including an examination of any federal laws that may impact such legislation;**

In the event a VAD legal framework is supported in South Australia separate legislation will be required.

The Victorian legislation and the recommendations of the WA Joint Select Committee and the WA Ministerial Expert Panel on VAD, plus the experiences in international jurisdictions, should provide a sound basis for development of new legislation but as was highlighted in the WA reports, the unique features of SA will need to be taken into account.

We strongly urge the Joint Committee to address all the key legal and medical protections and particularly, ensure the strongest safeguards around the availability of drugs in the community.

**(d) any other related matter.**

**Pursuing End of Life strategies**

In her December 2018 Churchill Fellow Report, Catherine (Kate) Swetenham, Clinical Director, Southern Adelaide Palliative Services, listed in her findings a number of barriers and enablers to EOLC strategies being successful. We believe these strategies should be considered by the Joint Committee.

The barriers include;

* Failure to identify those living in the last year of life.
* Delayed conversations with patients and their families about goals of care.
* Advance Care Directives (ACD)/ Advance Care Planning (ACP) being seen as the first step to addressing EOL.

The enablers include;

* Working in partnership across the acute and community settings.
* The GP model in the NHS – supports home visits and management of EOL 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 EOL clinical leads to improve experience of dying across the health system.[[25]](#footnote-25)

**Funding differentials**

It is interesting to observe the stark contrast in the level of funding provisions for palliative care in most other jurisdictions (as at 2019 Budgets), compared with that of South Australia, differences in population notwithstanding -

* Queensland - the biggest funding announcement in over a decade for palliative care (possibly ever for palliative care in Qld) an additional $17Mil over the next 2 years.
* Victoria - In relation to the budget allocation for specialist palliative care in Victoria this is around $160M for 2019-20, including the $72M increase in palliative care funding over the next 4 years announced in the 2019 Victorian budget this year. (to provide a comparison. In Victoria, around 40,000 Victorians die each year and on this basis the specialist palliative care funding (which includes projects, not just services) amounts to $4,000 per Victorian death).
* NSW - -2019 Budget - $27.1 million for palliative care support, as part of the Government’s $100 million palliative care package.
* WA - an extra $41 million was allocated in the 2019 Budget - $31 million to additional palliative care services in regional and rural WA over 3 years, $5 million of extra capital works in Carnarvon for a palliative care hospital service and $5 million for the VAD process.
* Federal Budget - additional $32.8m committed by the Federal Government to palliative care in the 2018 Federal Budget.
* Tasmania - $800 000 for Palliative Care Clinical Nurse Educators over two years
* ACT - The 2019-20 Budget provided additional investment in clinical research in priority health areas including cancer, type 2 diabetes, cardiology, nursing, mental health, women and children, dementia, palliative care and population health (Amount for PC not broken down).

This overview highlights that with the exception of Tasmania, ACT and even the Federal Government, the level of funding directed to palliative care in South Australia needs urgent attention. We implore the Joint Committee to align its recommendations with the necessary level of funding resources to ensure the successful implementation of any proposed legislation changes. For far too long we have observed the introduction of new legislation and programs being made without the commensurate level of resources required to ensure positive and sustainable implementation outcomes which benefit the community.

In the fastest ageing mainland state in Australia[[26]](#footnote-26), it is critical to ensure service availability for all South Australians. Palliative Care South Australia is on record seeking the State Government to invest an extra $24.5M a year for the next four years to build capacity and ensure equitable access to palliative care services. This will enable standards-based palliative care is available to all who need it. The additional funding would provide for the following;

* $14M per year to build Community Palliative Care capacity so that people can be supported in their final stage of life at home, with the help of their GP and experienced palliative care community nurses.
* $6M per year to integrate palliative care across the acute care setting (relieve pressure on the acute system resulting in reduction of the numbers of terminally ill people in acute hospital beds including intensive care, and fewer emergency department presentations).
* $500K per year to PCSA to support the South Australian Government’s Palliative Care Policy Framework, particularly in the areas of community engagement and building death literacy and compassionate and supportive communities. (PCSA currently receives less than $90,000 per annum funding from SA Health).
* Fully implement the pre-election commitment of $4M over four year to expand current specialist palliative care services to 24/7.

**Conclusion**

We wish to restate our main thesis in relation to your task is that the implementation of an efficient, effective and acceptable VAD Scheme in South Australia comprising all the appropriate legal and medical protections, will only be successful if the provision of quality palliative care to all South Australians irrespective of geographic location or socio-economic status, is delivered at the optimum level.

Thank you for the opportunity to provide this submission to this very important undertaking. We believe we have outlined a number of key considerations and recommendations for the Joint Committee and if PCSA is able to assist the Committee in its deliberations in any way we would be more than happy to do so.

Finally, we believe that given our key role as the peak body for palliative care in South Australia and our vast reach into the community, the palliative care profession and palliative care services, PCSA is in a unique position to be able to assist the Joint Committee to scope and draft the VAD legislation, and provide the mechanism to facilitate community consultation (as PCWA in Western Australia has done) that would best suit the needs and aspirations of the South Australian community. We stand ready to be called upon to undertake this very important task.

**GUIDING DOCUMENTS USED TO COMPILE THIS SUBMISSION**

**PCSA**

Submission to SA Government regarding additional resources required for Palliative Care in SA

**PCA**

Palliative Care-Service Delivery-2018 Chapter 3

Definition of Palliative Care

Guiding Principles-Voluntary Assisted-Dying

Aspex Consulting - Experience internationally of the legalisation of assisted dying on the palliative care sector, October 2018

Palliative Care-Reflections and Learnings - Assisted dying in Canada and the United States, November 2018

**SA**

Health Performance Council of SA. November 2018. Revisit review of South Australia’s Palliative Care Services Plan 2009‐16: a report by the Health Performance Council of SA. Adelaide, SA: Government of South Australia

**WA**

WA Ministerial Expert Panel on Voluntary Assisted Dying (Final Report)

**VICTORIA**

<http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/%24FILE/17-061aa%20authorised.pdf>

**QUEENSLAND**

<https://www.parliament.qld.gov.au/documents/committees/HCDSDFVPC/2018/AgedCareEOLPC/ip-agedcare-14Feb2019.pdf>

Palliative Care Queensland - submission to the 2019 Queensland Parliament Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying - April 2019

**NATIONAL/INTERNATIONAL**

Productivity Commission 2017, Introducing Competition and Informed User Choice into Human Services, Report no 85, Canberra, P.7.

National Palliative Care Strategy, 2018, Canberra.

Churchill Trust Swetenham, C, 2017To successfully implement an End of Life Care Strategy for SA

Medical Journal of Australia – Victoria’s Voluntary Assisted Dying Law Clinical Implementation - Next Challenge (White, Willmott and Close), QUT

Internal Medicine Journal - The Victorian Voluntary Assisted Dying Act comes into operation, Frank Brennan, Calvary Health Care Sydney.

Shared Priorities for the End-of-Life Period Lois Downey, MA, Ruth A. Engelberg, PhD, J. Randall Curtis, MD, MPH, William E. Lafferty, MD, and Donald L. Patrick, PhD, MSPH Department of Health Services (L.D., R.A.E., W.E.L., D.L.P.), School of Public Health and Community Medicine; and Division of Pulmonary and Critical Care Medicine (L.D., R.A.E., J.R.C.), Department of Medicine, Harborview Medical Center, University of Washington, Seattle, Washington, USA.

1. <https://palliativecare.org.au/what-is-palliative-care> [↑](#footnote-ref-1)
2. Submission: Australian Medical Association (WA) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019). [↑](#footnote-ref-2)
3. Productivity Commission 2017, Introducing Competition and Informed User Choice into Human Services, Report no 85, Canberra, P.7. [↑](#footnote-ref-3)
4. National Palliative Care Strategy, 2018, Canberra. [↑](#footnote-ref-4)
5. Palliative care services in Australia, Web report: 22 May 2019, AIHW P.4. [↑](#footnote-ref-5)
6. Australian Institute of Health and Welfare 2018. Australia’s health 2018. Australia’s health series no. 16.

AUS 221. Canberra: AIHW. [↑](#footnote-ref-6)
7. Health Performance Council of SA. November 2018. Revisit review of South Australia’s Palliative Care Services Plan 2009‐16: a report by the Health Performance Council of SA. Adelaide, SA: Government of South Australia.p.iv. [↑](#footnote-ref-7)
8. NHMRC Project - Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy, Eliott et al. [↑](#footnote-ref-8)
9. Shared Priorities for the End-of-Life Period Lois Downey, MA, Ruth A. Engelberg, PhD, J. Randall Curtis, MD, MPH, William E. Lafferty, MD, and Donald L. Patrick, PhD, MSPH Department of Health Services (L.D., R.A.E., W.E.L., D.L.P.), School of Public Health and Community Medicine; and Division of Pulmonary and Critical Care Medicine (L.D., R.A.E., J.R.C.), Department of Medicine, Harborview Medical Center, University of Washington, Seattle, Washington, USA [↑](#footnote-ref-9)
10. <http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf> - Chapter 3 [↑](#footnote-ref-10)
11. <https://www.churchilltrust.com.au/media/fellows/Swetenham_C_2017_To_successfully_implement_an_End_of_Life_care_strategy_for_SA.pdf> [↑](#footnote-ref-11)
12. https://www.aihw.gov.au/getmedia/fe037cf1-0cd0-4663-a8c0-67cd09b1f30c/aihw-aus-222.pdf.aspx?inline=true [↑](#footnote-ref-12)
13. National Palliative Care Strategy 2018 P.6. - World Health Assembly, 2014 [↑](#footnote-ref-13)
14. National Palliative Care Strategy 2018 P.6 [↑](#footnote-ref-14)
15. <https://www.mja.com.au/journal/2019/210/5/victorias-voluntary-assisted-dying-law-clinical-implementation-next-challenge> (White, Willmott and Close) [↑](#footnote-ref-15)
16. Ibid. [↑](#footnote-ref-16)
17. Frank Brennan, Calvary Health Care Sydney, The Victorian Voluntary Assisted Dying Act comes into operation, Internal Medicine Journal ·June 2019 [↑](#footnote-ref-17)
18. Ministerial Expert Panel on Voluntary Assisted Dying Final Report (undated) health.wa.org.au [↑](#footnote-ref-18)
19. Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper (undated) health.wa.gov.au [↑](#footnote-ref-19)
20. <http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/05/PalliativeCare-Consensus-statement.pdf> [↑](#footnote-ref-20)
21. <https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/06/PCA-Guiding-Principles-Voluntary-Assisted-Dying.pdf>

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23. Aspex Consulting - <https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf> [↑](#footnote-ref-23)
24. <https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/PalliativeCare-Reflections-and-Learnings_FINAL.pdf> [↑](#footnote-ref-24)
25. <https://www.churchilltrust.com.au/media/fellows/Swetenham_C_2017_To_successfully_implement_an_End_of_Life_care_strategy_for_SA.pdf> [↑](#footnote-ref-25)
26. [https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Ageing%20Population~14](https://www.abs.gov.au/ausstats/abs%40.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Ageing%20Population~14) (Tasmania has highest percentage of people over 65 years at 19%, followed closely by SA on 18%) [↑](#footnote-ref-26)