

*Government submission to the Standing Committee on Legal and Social Issues
Inquiry into end of life care choices*

The submission

The Victorian Government believes all Victorians are entitled to quality end of life care, which relieves pain and suffering, and provides empowering support to family, friends and carers.

With advances in medicine, research and technology, we are living longer than ever before. This is of course positive, but it presents significant challenges for our health system. Over the last decade, Victoria has focused on building a specialist palliative care workforce and a quality system to support patients, families and the sector to deliver high quality care.

While much has been achieved, there is more to do to address the growth in demand lead by our ageing population and rising community expectations about the care, services and supports required to deliver a dignified, quality end of life experience.

End of life issues are often a confronting and difficult matter for people to talk about. But community attitudes to these issues are changing.

We know that more people want to be cared for at home. Most want to be with their family and friends and enjoy as good a quality of life as possible, for as long as possible.

People also want a choice in their end of life care, which is not dictated by 'the system'.

To that end, the Minister for Health, the Hon Jill Hennessy MP, on behalf of the Victorian Government, is pleased to provide this submission to the Standing Committee.

This submission addresses the end of life, palliative care and advance care planning implementation framework in Victoria and the factors impacting on growing demand, including:

- A population that is growing and ageing;
- Changes in disease profiles;
- Patterns of service utilisation;
- End of life care preferences; and
- A growing understanding that involving people in health decisions can improve their outcomes and quality of life.

This submission:

- Considers research from a wide range of sources, as well as local data and feedback from services and consumers about the issues impacting on the delivery of good end of life care, and
- Builds on the presentation provided to the Standing Committee by the Department of Health and Human Services (the Department) on 23 July 2015.

Growing demand for palliative care and advance care planning

Our growing and ageing population, combined with the prevalence of chronic progressive disease and people's preferences about care, is increasing demand for Victoria's palliative care services.

Palliative care is an approach that improves the quality of life of patients and their families with life-threatening illnesses, through the prevention of suffering, which includes physical, psychological and spiritual suffering.

In the past decade, demand for palliative care has increased by an average of 4.9 per cent every year. Forecasts, up until 2018-19, show demand for palliative care continuing to grow on average by four per cent per year.

Demand for both inpatient (bed based and consultancy services) and community (home based) palliative care, including paediatric specific services has also steadily increased. In 2007-08, there were just over 11,000 episodes of community palliative care. Based on current activity trends, there will be about 26,278 episodes of community palliative care in 2014-15.

For inpatient palliative care services, there were just over 5,000 separations in 2007-08. Based on current activity trends, there will be approximately 7,800 inpatient palliative care separations in 2014-15.

In addition, palliative care input into acute patient care in hospitals has almost doubled over the last 10 years from 10,782 episodes in 2004-05 to over 20,000 episodes in 2014-15.

A population that is growing and ageing

In 2011, Victorians over the population age of 65 accounted for 14 per cent of the total population of over 5.5 million (777,500).

Approximately 39,000 people will die in Victoria each year. In 2013, 69 per cent of deaths were aged 75 years or over.

By 2031, it is forecast that Victoria's population aged over 65 years will account for 18.8 per cent of a total population of 7.7 million (1.4 million). Between 2011 and 2031, the number of people aged 65 years is predicted to rise 86 per cent.

The current average age of referral to palliative care is 76 years.

While the number of people aged 65 years and over is predicted to increase across the whole of Victoria, the greatest growth in palliative care demand is forecast to occur in metropolitan Melbourne.

Growth in the population 65 years and over will be most felt in metropolitan Melbourne, predicted to increase by an average 90 per cent by 2031. In the rural regions, growth is predicted to be an average of 78 per cent by 2031.

The highest increase in metropolitan Melbourne is forecast in the western region (at 136%), followed by the southern, northern, inner Melbourne and eastern regions.

Changes in disease profiles

Chronic disease and cancer accounted for around 60 per cent of all deaths in Victoria in 2013. These conditions included:

- Chronic respiratory disease, such as asthma, chronic obstructive pulmonary disease (COPD);
- Cerebrovascular diseases such as stroke;
- Organ failure such as renal disease and chronic heart disease;
- Cancers; and

- Neurological conditions such as motor neurone disease, dementia, Huntington's and Parkinson's diseases.

In Victoria, cancer accounts for 30 per cent of all deaths and other chronic diseases account for around 30-35 per cent. The remaining deaths are from a range of causes, including sudden deaths and trauma.

The growing and ageing population, combined with the prevalence of chronic progressive disease and people's preferences about care, is also changing the patterns of service utilisation in acute and palliative care inpatient settings and in community palliative care services.

Paediatric palliative care

Knowledge concerning the number of children with life-limiting illnesses is limited. The best international estimates of prevalence are that 15-16 per 10,000 children aged from birth to 19 years are likely to die prematurely from non-malignant life-limiting illness. The majority of children who access paediatric palliative care, suffer with neurodegenerative conditions, be they malignant or non-malignant in origin.

Victorian data clearly shows a pattern of deaths of infants and young people. The leading causes of death for those aged less than one year relate to disorders associated with gestation or the perinatal period and congenital malformations or chromosomal abnormalities. For children aged between one and 14 years the pattern changes with a greater percentage of malignancies (cancer) and degenerative disorders.

The needs of children and their families in regard to palliative and end of life care are quite unique. Often children in advanced stages of illness are fully dependent on others for all of their care. Parents generally provide this care as a natural extension of the parenting role with support from specialist palliative care providers and the support of family and friends. Often the parents forego work commitments to fulfill the carer role. Not only are the parents caring for their ill child, they are also supporting and sustaining their family unit through the process.

Palliative care and family support services provide the practical, clinical expertise and psychosocial supports to sustain families during the caring and subsequent bereavement phase.

Palliative care and end of life care in hospitals

People aged over 70 years account for almost half (46 per cent) of multi-day stays in hospital, and have on average four or more co-morbidities.

Regardless of age, the illness trajectory prior to death for people with a progressive disease results in increased disability. This is often associated with recurrent hospital admissions and progressive decline, particularly in the last year of life. In 2013, 55 per cent of all deaths in Victoria occurred in a hospital (all causes).

While over half of all people who die in Victoria die in hospital, the pattern of where people are dying in hospitals has changed over the last 10 years.

Deaths in acute beds have reduced from 73 per cent in 2004-05 to 63 per cent in 2013-14.

For those people who do die in an acute care bed, data is showing that they are more likely to have their end of life care needs identified and are more likely to receive palliative care intervention in 2013-14 than ten years ago. In 2013-14, 20,000 acute care separations had palliative care input into their care - up from 11,000 in 2004-05.

People dying in Victorian hospitals in 2013-14 were more likely to die in a palliative care ward than 10 years ago. Deaths in palliative care beds accounted for 28 per cent of all deaths in hospitals in 2013-14, up from 19 per cent in 2004-05.

The percentage of inpatient palliative care separations for people with chronic disease has risen 10 per cent over the last 10 years, accounting for 65 per cent of all separations in 2014-15. Deaths in emergency departments have remained stable at around five per cent.

These trends suggest that the community's end of life and specialist palliative care needs are increasingly being recognised across Victorian hospitals. This shows a distinct shift from simply prolonging life to maximising quality of life, and a move towards more supportive end of life care for the patient and their family.

Palliative care and end of life care in community palliative care services

End of life care is care where the primary intent of care shifts from cure or life-prolonging for people with a recognised life-limiting illness, to maximising quality of life and management of their symptoms.

The Grattan Institute report, *Dying Well* (2014), noted that between 60 and 70 per cent of Australians would prefer to die at home. In reality, only about 14 per cent actually do so.

Research has found that for people facing a life limiting illness, 90 per cent want to die at home. There is international evidence that involvement of palliative care can help meet people's wishes to die at home or in a home like setting. In Victoria, data shows that the percentage of people dying in their place of choice is higher for people registered with a community palliative care service. Data reported over 2013-15 show that for people who were registered with community palliative care and expressed a preference for where they would like to die:

- 51% who wanted to die at home did;
- 92% who wanted to die in a hospital did; and
- 87% who wanted to die in a residential facility did.

Increasing patient complexity

In 2011-12, stable phases accounted for 31 per cent of all inpatient palliative care activity. In comparison, unstable/deteriorating and terminal phases accounted for 69 per cent of palliative care activity. By 2014-15, stable phases had reduced to 26 per cent of all inpatient palliative care activity and unstable/deteriorating and terminal phases accounted for 74 per cent of palliative care activity.

In palliative care, patients' clinical changes along the illness trajectory are described as 'phases of care'. These phases; stable, unstable, deteriorating and terminal, indicate the level of care required and the potential complexity of their care needs, with 'stable' being the least complex and 'terminal' the most complex.

In 2011-12, stable phases accounted for 31 per cent of all inpatient palliative care activity. In comparison, unstable/deteriorating and terminal phases accounted for 69 per cent of palliative care activity. By 2014-15, stable phases had reduced to 26 per cent of all inpatient palliative care activity and unstable/deteriorating and terminal phases accounted for 74 per cent of palliative care activity.

In 2011-12, stable phases accounted for 43 per cent of all community palliative care activity and unstable/deteriorating and terminal phases accounted for 57 per cent of activity. By 2014-15, stable phases accounted for 33 per cent of activity and unstable/deteriorating and terminal phases accounted for 67 per cent of all community palliative care activity.

Patient complexity places additional strain on families and carers. Data collected by the Palliative Care Outcomes Collaborative, a national data collection lead by the University of Wollongong, shows that reporting of problems or increases in severity of illness by families or carers are highest as the patient moves closer to the terminal phase and is highest during this phase.

A review of Victorian community palliative care data over the last three years shows that palliative care providers spend about 50 per cent of their time working directly with the client and carer on managing

end of life and palliative care needs. Palliative care staff spend about 25 per cent of their time providing care directly to the client without carer input.

The remaining 25 per cent is spent working with the carer to provide them with:

- Support with practical training relating to the day-to-day care needs of the client;
- Training in the use of specialist equipment;
- Information about the anticipated illness trajectory in the coming days/weeks;
- Psychosocial support and bereavement care.

The growing prevalence of chronic disease, and the co-morbidities associated with chronic diseases (including dementia) near the end of life, is a likely contributor to the increasing complexity of patient needs reported by palliative care services.

Access to services

In addition to the increasing complexity of patient needs is the requirement to address ways to improve access for key groups of people. Research and data suggest that key groups continue to be underrepresented in palliative care, including people:

- From culturally and linguistically diverse communities;
- Living in aged care facilities and disability residential care services;
- Living in rural and remote areas; and
- From Aboriginal and Torres Strait Islander groups.

Research has identified numerous obstacles to the provision of palliative care in aged care, including:

- Inadequate staffing levels;
- A regulatory focus on rehabilitation;
- A lack of palliative care competencies;
- Failure to recognise treatment futility;
- Lack of communication amongst decision makers, residents and families;
- No agreement on a course for end of life care; and
- Failure to implement a timely end of life care plan.

In Victoria, palliative care training programs for nurses and doctors have supported increases in the palliative care workforce across rural and regional Victoria. This includes support to residential aged care facilities. This approach supports a care partnership between Commonwealth and State auspiced services.

The Department of Health and Human Services partners with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) to implement the Victorian Aboriginal Palliative Care Program. This program aims to improve access to, and enable, palliative care services to provide culturally appropriate care. Aboriginal people accessing admitted palliative care has continued to steadily grow from 0.14 per cent of palliative care separations in 2006-07 (n= 14) to 0.63 per cent (n= 46) in 2014-15.

Workforce issues

Building a skilled specialist palliative care workforce to meet increasing demand

The palliative care workforce is multidisciplinary and made up of nursing, medical, a range of allied health professions, psychosocial care, grief and bereavement, and spiritual care workers.

Victoria has seen a proportional increase in activity by healthcare professional groups in community palliative care. In 2007-08, 14 per cent of community palliative care contacts involved doctors, 21 per cent nurses, 18 per cent allied health professionals and 14 per cent psychosocial support staff.

In 2014-15 the activity profile altered significantly, with 23 per cent of contacts involving doctors, 63 per cent nurses, 20 per cent allied health professionals and 21 per cent psychosocial support staff.

Victoria's Palliative Medicine Training Coordination Program was established in 2009 to provide a focal point for attracting, retaining and supporting doctors to take up careers in palliative medicine. Since 2009, the program has supported 29 doctors to complete post graduate training that qualifies them as either a consultant physician in palliative medicine or a palliative medicine specialist.

In the regional centres, consultant physicians/specialists in palliative medicine support the regional palliative care consultancy services. These services provide expert advice and guidance to health services, general practitioners, aged care and disability services to manage the palliative care needs of their patients or clients. The medical workforce works in public and private services in metropolitan and regional centers.

In Victoria, access to specialist palliative care has also been supported by a nurse practitioner program. Up until July 2015, the nurse practitioner program has supported the endorsement of 18 palliative care nurse practitioners in Victoria. Six nurse practitioner candidates will be eligible for endorsement later in 2015-16.

Volunteers in palliative care

Volunteers play an important role in palliative care. Victoria's palliative care volunteers:

- Are predominantly female with an average age of 64 years;
- Work between one and four hours per week but more than 20 per cent work more than four hours per week;
- Average seven years duration of volunteering in the palliative care sector; and
- Are engaged with community palliative care service providers, at a value of over 80 per cent.

Training for the generalist health workforce

Research highlights the need for increased training across the generalist health care workforce in the fundamental principles of palliative care, such as symptom management and communication skills in order to support the early recognition of dying and provision of end of life care.

In Victoria, there are a number of initiatives that focus on building palliative care skills and an understanding of end of life care in the generalist health workforce.

The Centre for Palliative Care's Specialist Certificate in Palliative Care is a multidisciplinary course accredited by the University of Melbourne. The course explores the core concepts of palliative care including practice standards, symptom management, communication skills, evidence-based practice, non-cancer contexts, psychosocial issues, bereavement care, and care and support for carers. In 2014 there were 39 graduates. The Centre also provides free online training for health professionals caring for people living with a life-threatening illness and their families.

The Palliative Medicine Training Coordination Program has also supported 70 non-palliative care doctors to complete a clinical diploma in palliative medicine between 2009 to 2015. This qualification is

an adjunct to their medical qualifications. The aim of this program is to support doctors working in other clinical areas to be able to respond to the end of life care needs of their own patients and support other clinical team members in end of life care.

Service delivery in Victoria

Public palliative care is provided across Victoria and is delivered by designated palliative care inpatient hospital services (specialist wards and hospices); by community palliative care services (in people's homes, including aged care and disability services); through hospital-based and regional consultancy services: from state-wide services; and day hospices for respite care.

Palliative care services aims to provide care as close as possible to where people live.

In Victoria, 21 palliative care services provide 289 palliative care beds - 75 in regional Victoria and 214 in metropolitan Melbourne. There are 31 community palliative care services across rural Victoria and seven community palliative care services in metropolitan Melbourne.

Each metropolitan health service (excluding the Royal Women's Hospital, and the Royal Victorian Eye and Ear Hospital) has a palliative care consultancy service, while there is a Regional Palliative Care Consultancy Service in each of the five rural regions (Barwon South West, Hume, Gippsland, Grampians and Loddon Mallee).

Regional palliative care consultancy services play an important role in supporting small rural health services in providing end of life care for their local communities.

There is a growing interest in involving palliative care at an earlier stage for people accessing the health service system with progressive chronic disease. Service delivery that incorporates advance care planning and palliative care is one way to match the wishes of the person with the care and treatment provided.

Advance care planning in Victoria

Advance care planning identifies and documents an individual's future wishes and care preferences based on the values that are important in their life. Advance care planning has been shown to improve quality of care at the end of life, and increase the likelihood of a person's wishes being known and respected.

Advance care planning greatly improves the end of life care experience. Clients and families report being more satisfied with the end of life care provided and symptoms of anxiety, depression and post-traumatic stress in surviving family members are reduced.

Talking with children and families about the possibility or probability of death is one of the most difficult things for clinicians to do. However, avoidance denies children and families the opportunity to voice an opinion about the care they really want to receive, where they really want the care, and it may mean they do not have the chance to say and do things that are important to them. There is also evidence that suggests helping parents understand their child's prognosis reduces the likelihood of complex grief.

While there is a substantial body of evidence that supports the use of advance care planning and its benefits, the best way to implement advance care planning across developed countries is still emerging. Recent research suggests that utilising a multi-pronged approach, which aims to embed advance care planning into routine practice, delivers the best outcomes.

Research is also identifying new enablers for successful advance care planning with a focus on helping patients clarify values, helping families prepare for their role of substitute decision maker and helping communicate information to clinicians.

The Department of Health and Human Services sets key measures for Victorian health services implementing advance care planning. Current focus is on building organisational and workforce capacity, integrating advance care planning into routine clinical practice and investing in patient centered approaches. Trials to improve the transferability and mutual recognition of advance care plans through technology and communication protocols are also underway.

Measures seek to assist health services and the department to monitor progress against initiatives that improve the chances of successfully embedding advance care planning in routine health service practices.

A survey conducted in October 2014 sought to establish how public health services in Victoria were progressing against the first year measures outlined in the strategy. The survey found:

- 65 per cent of services had developed, or were developing, an organisation-wide advance care planning policy;
- 95 per cent had resources available to patients and families about advance care planning;
- 64 per cent had established or were developing a process where executive managers and clinical leaders received and responded to results of advance care planning quality audits; and
- 85 per cent had established, or were establishing, training and education activities for staff in advance care planning.

Promoting public awareness and engagement in end of life care and advance care planning

A lack of opportunities or capacity to talk about and plan for death are the most significant barriers to improving end of life care.

Recent research by the Health Issues Centre in Victoria (2015) identified varying degrees of readiness to engage in completing advance care planning forms. Participants in focus groups felt that a form took the attention away from the conversation. The research identified that participants felt that broad community engagement and support to talk about end of life care, and undertake advance care planning, was needed to build capacity in the community.

For clinicians, a lack of capacity to initiate discussions about death and dying contributes to the lack of communication and clarity about what people want for treatment and care at the end of life. Advance care planning can provide a structured approach to these conversations. In Victoria, training resources, communication prompts and supporting documentation and forms are available to support these conversations.

The existing legal framework

Advance care planning is being implemented within Victoria's current legal framework.

In Victoria, a refusal of treatment certificate is a legally binding health directive for a person who wants to express their wishes about their end of life care. In a refusal of treatment certificate, a person may only refuse treatment for current conditions. This is legislated through the Medical Treatment Act 1988.

A person may also appoint a substitute decision maker. There are multiple types of substitute decision makers that may be appointed in Victoria, each with different powers and different processes for appointment. A competent person may appoint an agent under the Medical Treatment Act 1988, who may make decisions in accordance with the person's wishes.

As of 1 September 2015, a competent person may also appoint an enduring power of attorney under the *Powers of Attorney Act 2014*. This person may be required to make medical decisions in the patient's 'best interests' under the *Guardianship and Administration Act 1986*.

The *Powers of Attorney Act 2014* also allows for a competent adult to appoint a support attorney to assist them with their decision making. The *Powers of Attorney Act 2014* was enacted to simplify the appointment and role of powers of attorney for financial and personal matters. While the Act allows a person to appoint an attorney for health matters, the broad scope of the Act means that end of life decision making in a health context is not specifically mentioned.

If a person is not competent, or becomes impaired because of illness or injury, a tribunal may appoint a guardian under the *Guardianship and Administration Act 1986*.

If none of the aforementioned has occurred, the *Guardianship and Administration Act 1986* allows a doctor to turn to a 'person responsible' to make a decision and establishes an order for determining who this may be.

A way forward

Victoria's population continues to grow and the current demand for palliative care is increasing by four per cent each year. With advances in medicine, research and technology, we are living longer than ever before. The Victorian Government is committed to thinking innovatively about what can be done to ensure Victorians have access to the best quality end of life care and that the future policy framework is reflective of and meets the broader community's needs.

We know that more people want to be cared for at home and have a choice regarding their end of life care. The decision of where care takes place should be up to the individual and not dictated by the 'system'. The health system needs to recognise the important role specialist palliative care services play, but also broaden the responsibility of good end of life care across the system.

Palliative and end of life care are not natural conversation topics for many people because of their confronting and personally challenging nature. As a community, we need to enable these conversations so that people can plan for their future.

To address this, the Government has committed to undertaking two key reforms to support end of life care choices in Victoria as part of a comprehensive End of Life Care Framework for Victoria.

These are:

- Enabling the statutory recognition of advance care directives so competent Victorians can document treatment preferences for future conditions, and articulate their end of life care wishes, and
- Undertake a program of appropriate improvements to palliative care services to provide responsive and appropriate, models in the Victorian community, and more home-based care.

An End of Life Care Framework for Victoria

A critical next step to advancing the provision of end of life care in Victoria is the development of a statewide end of life care framework.

A framework is required to ensure all Victorians receive the best quality end of life care and are supported to make clear end of life care wishes and preferences known and supported in practice.

The framework will include four priority areas:

- Improving the capacity of, and access to, specialist palliative care;
- Better matching what people want and what is provided;
- Improving integration across service delivery; and
- Increasing knowledge about end of life care amongst all clinicians and services.

This framework will be developed through a stakeholder and community consultation process and will engage key groups in its implementation.

The consultation will focus on seeking feedback on actions that will improve the delivery of end of life and palliative care.

Statutory recognition of advance care directives

The Victorian Government has committed to providing Victorians a greater say in their end of life care.

By recognising advance care directives in the law, competent Victorians can document treatment preferences for existing and/or future conditions and articulate their end of life care wishes. By giving competent Victorians a choice in how they are cared for, clinicians will make decisions based on patients' values and preferences.

The law should support engagement in values-based conversations relating to palliative care, end of life care and advance care planning. The legislative foundation plays an important role in clarifying people's choices within the end of life care framework.

The Government is currently considering a number of legislative options enabling the statutory recognition of advance care directives. The options will be assessed against a number of principles to ensure the best approach that supports end of life care choices reform. Options will be assessed based on the degree to which they address:

- Reducing confusion about the status of advance care plans and health decision making agents;
- Supporting person centered care and patient self-determination;
- Providing certainty for doctors, patients and the community;
- Supporting a focus on the discussions between patients, families and clinicians;
- Allowing responsiveness of advance care directives to changing circumstances;
- Allowing for the provision of information that supports substitute decision makers in their advocacy role;
- Allowing for the provision of information that supports clinicians in specific treatment decisions;
- Ensuring transparency of decision making; and
- Providing appropriate checks and balances.

Developing a community engagement and education campaign about the new legislation, and why it is important to talk about end of life care will be a core component of effective legislative reform and implementation.

A framework that addresses the multi-pronged nature of end of life care choices is being developed that focuses on:

- Building capacity at the patient-clinician and organisational levels;
- Empowering communities to talk about end of life care;
- Providing a legislative approach that clarifies end of life care decision making; and
- Monitoring progress against clear system measures.

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