Palliative Care

Services that support quality of life

Victorian Parliamentary Standing Committee
on Legal and Social Issues

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Odette Waanders, CEO, Palliative Care Victoria
10 June 2015
Good evening everyone. My name is Michael Bramwell and I am the Chair of Palliative Care Victoria. Joining me is Odette Waanders, the CEO.

Thank you very much for the invitation to provide you with an introductory briefing about palliative care and its role in supporting Victorians with life-limiting illnesses and their families to live, die and grieve well.

Please feel free to ask us questions during our presentation tonight, and at any time during your deliberations.

We have brought an information pack, which we hope will be useful.

This includes:

• a copy of our presentation
• a booklet about palliative care
• Palliative Care Victoria’s Call to Action for 2015-19
• Some stories of people with a life limiting illness and palliative care volunteers
• Copies of the Dreamers are also available for those who would like to read it. This includes photographs of 40 people receiving palliative care and their reflections on life, death and dreams.
Broadly, these are the topics we will cover this evening. If questions arise or matters you wish to discuss, please raise them and don’t feel you need to wait until the end.
Palliative Care Victoria was formed in 1981, early in the development of palliative care services in Victoria. We represent palliative care services – 87 organisations are among our members – as well as people with a life limiting illness and their families, and those with an interest in palliative care.

As the peak body, our roles are both community and sector facing. We are the ‘go to’ organisation for people seeking information and services at a very vulnerable stage in their lives.

Our strategic priorities include raising community awareness of palliative care, building community capacity to deal with issues of dying, death, grief and loss and improving access and responsiveness for diverse communities – including Indigenous Australians and people from culturally and linguistically diverse communities.

We also undertake activities to ensure a strong, innovative palliative care sector, including information and education, advocacy and policy development and collaboration with other key stakeholders.

Palliative Care Victoria is a founding and current member of Palliative Care Australia.
Palliative care was founded by Dame Cicely Saunders in the UK. She established St Christopher’s Hospice in 1967 and her vision was to provide holistic care that promotes quality of life, supports the person and their family and enables people to receive care and die at home or in homelike environments.

Palliative care was initiated in Victoria by charitable organisations – the Melbourne City Mission and the Order of Malta. Most palliative care services in Victoria are provided by public health services and community charities.

In 2001, Palliative Medicine was recognised as a specialty in Australia.

Palliative care is still a relatively new specialty and area of service provision, with significant variability in its development across Australia. This means that there is still work to be done in Victoria and Australia to ensure it is fully integrated and available across the health and care sectors.
What is palliative care?

“Palliative care is for the living. It helped us get our lives back on track.”
Palliative care focuses on promoting the person’s quality of life and dignity. The presentation notes include a definition from the World Health Organisation. A key element of palliative care philosophy and practice is that it does not intend to hasten death.

The World Health Organisation has defined palliative care as:

“An approach that improves the quality of life of patients & their families facing the problems of a life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and
- includes those investigations needed to better understand and manage distressing clinical complications.”
What does palliative care include?

- **Care planning**: values, goals & choices
- **Personal comfort and wellbeing**: pain & symptom management, physiotherapy, etc.
- **Emotional support**: counselling, spiritual & cultural care
- **Quality of life**: to make the most of life; volunteers provide support

The starting point of palliative care is a comprehensive holistic assessment of the person with a life limiting illness as well as the support needs of their carers.

Impeccable needs assessment includes identifying and discussing their needs, understanding what is important to them and discussing their goals of care.

This process and conversation informs the care that is provided by the palliative care team, which is reviewed with the ill person and their carers on a regular basis and as the need arises.
Help for carers and families

- Respite care
- Advice on how to provide care and counselling
- Help to find appropriate legal and financial assistance
- Practical assistance - equipment, travel to appointments
- 24 hour access to phone support

This slide shows the kinds of support available to assist carers who provide the mainstay of care. The majority of people prefer to receive care at home.

So a key focus of palliative care is supporting and partnering with those carers throughout the person’s illness and providing support through bereavement.

The recent report by the Victorian Auditor General on the inquiry into palliative care identified the need to improve access to respite care and 24 hour support.
Personal experiences of palliative care
Moira chose to participate in the Dreamers Project. This involved an interview with the project author, Pippa Wischer, about her reflections on life, death and dreams.

Palliative Care Victoria asked Pippa to include in four recorded interviews some additional questions about how they found out about palliative care and what difference it made to their life.

This is the completely unscripted response by Moira and George to those questions.

The video is available at:

https://www.youtube.com/watch?v=RE8CJlhcsA
If you have time, we would encourage you to watch some other short videos produced for Palliative Care Australia that illustrate the range of people who receive and benefit from palliative care.

The link to each video in youtube is below the photograph.

Mamaduke was diagnosed with cancer at 15 months of age. About 1% of palliative care recipients are aged 14 years or under.

The Victorian Paediatric Palliative Care Program and Very Special Kids provide care to these children and their families in inpatient, community and hospice settings.
Kaye Sales

“Palliative care has provided me with incredible emotional support... I feel secure and safe and fully understand they will be supportive through this last period of my life.”

“From the moment a person is diagnosed with a life limiting illness would be the ideal time to link them to palliative care.”

Watch video at bit.ly/kaye-video

Kaye suffered from mesothelioma.
Both Bassam and Kaye highlight the importance of palliative care being offered early in the disease trajectory. In Bassam’s situation his cancer was too advanced for treatment. He agreed to clinical trials but these were unsuccessful.

Effective pain management by the palliative care team enabled him to make the most of the remaining time with his family and friends.
Who can palliative care assist?
Who can benefit from palliative care?

Palliative care assists people with life-limiting conditions who need specialist palliative care support, including

- People with cancer, end stage chronic diseases such as organ failure, dementia, degenerative conditions
- People of all ages, cultures and beliefs

This slide shows 4 people receiving palliative care who participated in the Dreamers Project. As you can see they represent a diversity of ages and backgrounds.

The benefits of palliative care are not limited to people with cancer or in the older age range.

Palliative care should be available to all people with a life limiting illness who have complex needs that would benefit from its holistic approach and focus on improving quality of life.
Palliative care originated with the care of people with cancer.

As you can see from the top diagram, cancer has a more sudden onset and shorter illness trajectory prior to death compared with other chronic conditions, although this is changing as cancer treatments become more effective in extending life.

Palliative care is also beneficial for other chronic and life-limiting conditions.

The middle diagram shows the illness trajectory that is typical for heart and lung failure – both leading causes of death. There is a steady decline with periods of acute deterioration. It can be difficult to give a prognosis regarding the person’s remaining length of life.

The bottom diagram shows the prolonged trajectory of deteriorating health status due to frailty and dementia. Given the duration of the illness, it can make it more difficult for health providers to know when to refer to specialist palliative care. This is particularly challenging in aged care settings where the ratios of qualified health professionals and are relatively low and it can be difficult to get good GP coverage.

In Victoria, palliative care services provide consultancy support to aged care facilities, as well as some education, but this is an ongoing challenge given the high levels of staff turnover and limited funding for provision of complex care.
Specialist palliative care can be provided alongside active treatment and it is advisable to refer people to palliative care earlier in the disease trajectory.

Palliative care offers specialist support that complements the care provided by the person’s GP, and other specialists and health providers.


One of the triggers is if the physician would not be surprised if the person were to die within the next 12 months.

There is a need for education of health professionals to identify triggers for referral to palliative care and to ensure the person receives the best end of life care possible.
The role of specialist palliative care varies depending on the needs of the person and their family, the trajectory of the illness and the capacity of other health and care services to meet their needs.

For example, a person with a life limiting illness with well-controlled symptoms may experience a sudden deterioration and require admission to a palliative care program for assessment and symptom management until their condition stabilises and they can be discharged to ongoing care in the community.

Some people may have a complex range of physical and psycho-social needs that require ongoing support by appropriate members of the specialist palliative care team.

The level of support provided by palliative care may be daily, weekly or much less frequently, depending on the needs of the person and their family.

In other cases, the persons palliative care needs may be able to be met by their primary health care providers, as in scenario three in the diagram.
Palliative care services in Victoria
There are three main types of palliative care services in Victoria:

Inpatient, community – which includes care delivered to the person’s usual residence or at a day hospice, and consultancy.

There was an 80% increase in the number of people who received palliative care in the community in 2012-13 compared to 2008-09.

19 palliative care consultancy services provide consultancy in acute and community settings.

Four state-wide programs focus on special populations: paediatric, motor-neurone disease, HIV/Aids and Australian Centre for Grief and Bereavement.
A 2013 study of the Victorian palliative care workforce indicates that around 11% are physicians, 63% are nurses and 8% are allied health professionals. They work together as interdisciplinary teams.

Victoria is fortunate to have around 2000 trained palliative care volunteers. Around two-thirds of them contribute directly to supporting the quality of life of patients and their carers.

Your information pack includes 8 stories about people with life limiting illness and palliative care volunteers who support them. These were produced by Palliative Care Victoria for National Volunteers Week and National Palliative Care Week in May. To date, 6 stories have been published in community papers with a combined circulation of over 265,000, plus on ABC online and 774 radio.
In his report on recent inquiry into palliative care, the Victorian Auditor General noted that although most people would prefer to receive care and to die at home, only 35% of the palliative care funding is directed to community palliative care services.

International evidence shows that palliative care not only contributes to improved quality of life but also contributes to more effective use of health resources (see papers at “bit.ly/pcvlibrary-election2014”).

Increased investment in palliative care (which currently is less than 1% of expenditure on Victorian public hospitals) would benefit the Victorian health system as well as people with a life limiting illness and their families.
Access to palliative care
Most referrals to palliative care are from the acute hospital setting. Unfortunately, many are very late in the disease trajectory.

Raising community awareness of palliative care will assist people to ask their doctors for information and referrals at an earlier stage.
Low rates of use of palliative care services by people from culturally and linguistically diverse communities spurred the culturally responsive palliative care strategy undertaken by Palliative Care Victoria, the Ethnic Communities Council of Victoria and other partners over the past 2 years, with the support of a large philanthropic grant and some Government funding.
Between February 2014 and April 2015, 89 education sessions about palliative care were delivered in community languages to 2,280 participants from 8 ethnic communities in Melbourne.

Overall, 64% had no prior knowledge of palliative care and 90% reported that they learned new information about palliative care.

This work is continuing until 30 June, when the project funding ends.

Palliative Care Victoria is seeking further funding to enable this work to continue.

Michael recently gave a presentation at the 4th International Public Health and Palliative Care Conference in Bristol about this strategy.

It sparked considerable interest among the delegates particularly given its scope, the level of community engagement and success to date.
What are the benefits of palliative care?
There is now a significant body of international evidence on the benefits of palliative care which include those listed in the slide.

There is scope for considerable improvement in our capacity to support people to die at home, the preferred location for around 70% of people. However, in Victoria 52% die in a public hospital.

This will require more adequate investment in community palliative care and support for carers. This could be done on a cost-neutral basis by reducing avoidable and unwanted admissions to hospital.

Further information about this evidence is available via the link indicated on the slide.
Feedback from patients, carers & bereaved carers

Victorian Palliative Care Satisfaction Survey

• Funded by the Victorian Government, Department of Health
• Annual survey between February and May
• Conducted over 5 years, 2010-2014
• Unique in Australia and internationally
• 11,000 patients, carers and bereaved carers provided feedback over the 5 year period
• Average overall satisfaction > 4.6 out of 5

Around 11,000 Victorian palliative care patients and carers have contributed voluntary and anonymous feedback about their experiences of palliative care through the Victorian Government funded Palliative Care Satisfaction Survey over the last 5 years and the average overall satisfaction is was consistently rated very highly at 4.6 or more out of a maximum of 5.

There is no survey in 2015 but the Department has indicated that an experience survey will be developed to replace it, hopefully in 2016.
The overall level of satisfaction reported in 2014 shows consistent and high levels of satisfaction by patients and carers and for inpatient and community palliative care.
The areas of greatest satisfaction reported by respondents in 2014 included “The level of respect shown towards you as an individual” (top bar) and the care delivered by the palliative care team and their level of expertise.
This chart shows the overall priorities for improvement.

One of these priorities is to make it easier for people to know where to enquire about palliative care.

Palliative Care Victoria has received a $100K grant each year for the past four years to raise awareness of palliative care. Unfortunately, this grant ends on 30 June 2015.

Most palliative care in Victoria is delivered free of charge to the patient and family. The exceptions are charges for equipment loan and charges for some medications and supplies not covered by the PBS.

Nonetheless, there are significant financial burdens associated with the loss of income due to illness and the caring role.
Future directions
As this slide indicates, palliative care provision is currently between 16% and 40% less than the actual need based on these international population benchmarks of need.

The main population groups that are under-represented in palliative care service provision are:

- People with non-cancer life-limiting conditions, such as organ failure
- People with neuro-degenerative conditions, particularly dementia
- People from diverse backgrounds
Victoria’s growing and ageing population and the increasing incidence of chronic disease will also contribute to an increase in the need for palliative care.

We estimate a growth rate of around 8% over the next 4 years.

Over 150,000 Victorians will die within the next 4 years. The seven leading causes of death in Victoria are all chronic conditions that would benefit from palliative care.
The Victorian Auditor General noted that the palliative care policy framework for 2011-2015 provided a clear and ambitious agenda and that good progress had been made but that time required to deliver some of the complex goals had been under-estimated.

In its response to the Auditor-General’s report, the Department of Health indicated that it is developing an End of Life Care Framework that will be completed by 1 July 2017.

Given the need to avoid a policy vacuum, we hope that progress can be made so that it can be launched in 2016 and funded in the 2016 State budget.

Palliative Care Victoria supports its development as a priority and will contribute constructively to ensure the top 6 priorities we have identified are addressed.
A summary of these 6 key recommendations is included in the information folder.

Significant work is underway to build the capacity of Victorian health services to undertake effective advance care planning.

It is important that this is complemented by community engagement activities that build capacity to discuss issues of dying, death, grief and loss and also to raise awareness of palliative care and end of life care provisions so that they are able to participate fully and in an informed way in advance care planning.
At this stage we are uncertain about the funding available for palliative care for the next four years. Growth funding is needed to ensure palliative care services do not lose ground and are well placed to meet growing demand.

We are optimistic that there will be some positive announcements about increased funding for palliative care in 2015-16 and the following years.

There is recognition among all the parties in Victoria’s government that palliative care is important.

The Special Minister of State, Hon. Gavin Jennings, when he proposed the reference to this Committee in Parliament on 7 May, placed on record that the Premier and Minister for Health would during the life of this inquiry put in place appropriate improvements to palliative care, including a responsive, appropriate home-based palliative care model.

The Minister for Health indicated on 13 May at the Public Accounts and Estimates Committee that there are some significant investments in the budget around palliative care.

This will be most welcome in assisting the palliative care sector to address unmet need and the growing numbers of people with a life limiting illness and their families to receive the care and support they need to live well, to die well and to grieve well.
Questions & discussion

Thank you
STATE ELECTION 2014

CALL TO ACTION
2015-2019

To assist Victorians with a life limiting illness and their families to live, die and grieve well


Approved for distribution by the Board of Palliative Care Victoria
10 June 2014
CALL FOR ACTION SUMMARY

Increase investment in palliative care by $16.45 million a year:

Service Growth - $14.25 million a year
See recommendations 1, 2 & 3

Effectiveness & Efficiency - $2.2 million a year
See recommendations 4, 5 & 6

Allocate funding to improve equity of access and outcomes, as well as efficiency.

DESIRE OUTCOMES

- Palliative care services are responsive to the growing need and care choices.
- An increasing trend in home deaths and an associated decline in hospital deaths.
- Improved support for caregivers, including after-hours respite.
- Improved access to palliative care by groups currently missing out.

Positive Case Examples

Palliative care reduces use of hospital emergency

Moira is in her 70’s and is cared for at home in regional Victoria by her husband, George. She suffers from end stage chronic obstructive pulmonary disease. George says before palliative care Moira struggled - they would call the ambulance and end up in hospital a couple of times a month. The palliative care team prescribed medication, provided equipment, taught them helpful practices, visit regularly and can be called at any time. As a result, there have been no more ambulance calls or emergency admissions to hospital. George says that getting respite one afternoon a week and for a few days every couple of months enables him to re-charge his batteries and re-dedicate himself to caring for Moira. “Without that, I probably couldn’t exist under the strain,” says George.


Achieving the wish to die at home in rural Victoria

Jan was a 73 year old with advanced ovarian cancer who lived three hours' drive from the closest palliative care service in Gippsland. She did not have any family or extended network and wished to die at home. The palliative care nurse practitioner candidate (NPC) developed a care plan with Jane that involved utilising the remote area nurses. A trained volunteer who lived close by was enlisted to provide support to Jane. The NPC provided support to the remote area nurses caring for Jane and the volunteer. Jane died at home with her volunteer holding her hand.

Gaps in palliative care services make it difficult to achieve these outcomes in many situations. For example, one metro palliative care service found that short-term overnight respite for 15% of their patients would have enabled them to continue to receive care and die at home at a much lower cost to the health system, had the funding been available.

Recommendation 1: Increase community palliative care services.

Need: Population growth, ageing and the incidence of chronic disease will increase the need for palliative care. Increasing the availability of palliative care services will: improve equity of access and quality of life outcomes, assist more people to receive care and to die at their place of choice (for most people this is at home), and contribute to more effective use of limited health resources.

Actions: 1.1 Increase the overall supply of palliative care services to address the unmet and growing need for palliative care and end of life care.
1.2 Support the provision of community palliative care on a 24/7 basis, including greater capacity to provide in-home care and respite (including overnight) by appropriately trained staff and improved access to out-of-home respite and end of life care options in metro and rural areas and for particular population groups such as children and young adults.

Investment: $9.5 million per year

Recommendation 2: Expand palliative care consultancy services

Need: Victoria has less than half the recommended number of palliative medicine specialists and more are required to meet the anticipated growth in need for palliative care. Gaps in these services contribute to avoidable hospital admissions, difficulties in accessing advice after hours, and diminished access to expert advice for GPs involved in end of life care.

Action: Increase capacity to provide specialist palliative care consultancy services. Priorities include: patients receiving palliative care in the community; 24/7 access to address complex / urgent needs; gaps in rural provision; state-wide services including children and young adults.

Investment: $4.3 million per year
**PALLIATIVE CARE IN VICTORIA**

- Community: 15,323 people received palliative care at home in 2012-13 – **80% increase** since 2008-2009. Average cost per patient $2,570; 174 days average duration of care.
- Inpatient: 8,035 palliative-care related separations (94,384 patient days) in 2012-13. Average cost per patient separation (12 days) $5,995.
- Funding for palliative care in 2013-14 is $109.5M; **<1% of public hospital expenditure.**

**REASONS FOR ACTION**

- Current unmet & growing need for palliative care
- Lack of community awareness of palliative care
- Preference to receive care and die at home
- Integration of palliative care within health services a priority
- Improve health outcomes and resource use
- See overleaf for more information.

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**Recommendation 3: Close the gap in palliative care for Indigenous Australians.**

**Need:** In spite of higher rates of morbidity and mortality, Indigenous Australians have lower rates of use of palliative care services due to concerns about cultural safety. Indigenous Australians prefer to receive care and to die at home, connected to land and their extended family network. Research indicates that it is preferable for palliative care to be delivered under the auspices of an Aboriginal Health Service and in collaboration with mainstream palliative care services.

**Action:** Provide a culturally safe model of care whereby Aboriginal Health Liaison Workers at Aboriginal Health Services assist patients to access specialist palliative care and provide support, advocacy, and care coordination. Adjunct education, clinical placement and resource development will build the capacity of Aboriginal Health Services and palliative care services to provide culturally responsive palliative care.

**Investment:** $450,000 per year

**Recommendation 4: End of life care a priority for all Victorian Government funded health services**

**Need:** Over 300,000 Victorians are expected to die during the next 8 years; the majority will receive care in hospital and up to 52% will die there. Most health professionals have not received adequate education in care of the dying or discussing advance care wishes.

**Actions:** 4.1. Include high quality end of life care in the Statements of Priorities for all Victorian Government funded health services.

4.2. Provide education on palliative care and communications skills, including the use of key clinical triggers for referral to palliative care, to health professionals in Victorian Government funded health services. A priority focus should be health professionals working with patients with chronic illnesses that are leading causes of death.

**Investment:** $50,000 per year

**Recommendation 5: Increase community awareness and capacity**

**Need:** Lack of awareness of palliative care and lack of physician referral to palliative care services are common barriers to accessing these services.

**Action:** A community engagement program to raise awareness of palliative care, to build community capacity in dealing with issues of dying, death, grief and loss, and to encourage people to discuss and document their advance care wishes. This would include delivery of peer education sessions by trained and supported volunteers in partnership with COTA Victoria, as well as train the trainer education to build this capacity in other volunteer programs. A range of media, engagement events and communication channels would be used, including those relevant to specific target populations.

**Investment:** $400,000 per year

**Recommendation 6: Improve health care experience and performance**

**Need:** To improve equity of access and quality outcomes for consumers, as well as health system performance.

**Actions:** 6.1 Fund priority palliative care research projects in Victoria to improve consumer outcomes, responsiveness to under-served populations, and provide evidence of cost-effectiveness.

6.2 Strengthen palliative care clinical and research expertise through continuation of post-graduate scholarships and 3 new PhD scholarships/ placements.

6.3 Continue an annual survey of palliative care patients, carers and bereaved carers as this assists in measuring consumer outcomes and continuous quality improvement.

6.4 Seed, share and spread innovative approaches to improve referral pathways, fast track hospital discharge and enable people to receive care and die at home.

**Investment:** $1.75 million a year
ABOUT PALLIATIVE CARE

What is Palliative Care?
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation)

Who Can Benefit from Palliative Care?
Palliative care is beneficial for people of all ages with a wide range of life limiting conditions, including cancer, end stage organ failure, dementia, other neurodegenerative conditions and genetic disorders. It is provided on a needs basis from diagnosis and including bereavement.

PALLIATIVE CARE VICTORIA

Palliative Care Victoria is an independent not-for-profit peak body in Victoria. Established in 1981, we represent palliative care providers, consumers and their families, and those with an interest in palliative care in Victoria. We are a member of the national peak body, Palliative Care Australia.

Our desired outcomes:
Caring communities that are supportive and resilient in responding to life limiting illness, death, grief and loss.
Equity of access to quality palliative care when and where it is needed.
High quality palliative care achieved through a capable and compassionate workforce and a strong, innovative and effective service system.

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READING FOR ACTION

Increasing Need for Palliative Care Services
Population growth, ageing and chronic disease will continue to drive significant increases in the need for palliative care. There is also a significant level of current unmet need among specific populations.

Over 300,000 Victorians will die within the next 8 years. Unless current trends are turned around, 52% will die in Victorian hospitals and most without the benefits of palliative care.

More Effective Use of Health Resources
International and Australian evidence indicates that palliative care not only improves the quality of life of patients and their families, it also contributes to more cost-effective use of health resources.

A conservative analysis of available data indicates that the cost of palliative care services can be between 40% and 300% less expensive than care in an acute bed or intensive care bed.

Palliative Care a health care priority
The World Health Assembly passed a unanimous resolution on 23 May 2014 calling for the integration of palliative care into healthcare systems. Palliative care is an increasing health priority that can deliver improved patient and carer outcomes as well as contributing to improvements in the overall performance of the health system.

Support more Victorians to die at home
Home is the preferred place of care and place of death for most Victorians. However, only 25% die at home. Community based palliative care services need the capacity to provide clinical advice and carer support/respite on a 24/7 basis as required to support patient choice to die at home.

Community awareness of palliative care
Lack of awareness of palliative care and physician referrals to palliative care are key barriers to access. Community engagement will enable more people to be aware of the options and to discuss and document their advance care wishes.

Research, education and innovation
Investment in palliative care research, education and service innovation will assist Victoria to address forthcoming challenges arising from an ageing workforce and ageing population and the need to deliver better health outcomes more efficiently.

Further information and evidence