

Ensuring Victorians can access palliative care and end of life care – when and where it is needed



Giving everyone the choice of palliative care

In 2016, 40,015 people died in Victoria. Population growth, ageing and chronic disease will drive increases in the need for palliative care and end of life care.

Palliative care and end of life care teams support Victorians with a life-limiting illness and their families to live, die and grieve well. High quality care is available at the right time, is responsive to a person's individual needs, preferences and situation, and where possible is delivered at their home or other preferred place. Currently not everyone in Victoria can access palliative care when they need it.

The need for additional investment

A commitment from the Victorian Government to provide an additional \$65 million per year is needed to support implementation of Victoria's *End of life and palliative care framework* and fund a range of measures to improve timely, local access to end of life and palliative care services to people across Victoria.

This document outlines three objectives and our recommended actions to respond to current and future need in Victoria.

SNAPSHOT: PALLIATIVE CARE IN VICTORIA

Home and nursing homes are the places where demand for palliative care is highest. Most people wish to receive care and, if possible, to die at home.

Evidence suggests that about 70 per cent of people who receive good quality community palliative care can die at home rather than in hospital or residential care.

Community palliative care – 16,084 people received specialist community palliative care at home in 2014/15. Average duration of care per patient was 130 days at a cost of \$2,574.

Inpatient palliative care – 6,702 separations from specialist palliative care inpatient services in 2014/15. Average duration per episode of care was 12 days at a cost of \$8,893.

Recognised need to improve access to palliative care

- Victoria's *End of life and Palliative Care Framework* requires substantial funding to support its implementation as a priority.
- In 2016, Victoria's End of Life Choices Inquiry made 30 recommendations to improve palliative care funding and access.
- In 2015, the Victorian Auditor General recommended improvements to improve access to palliative care, noting difficulties in meeting demand.
- The Productivity Commission has recently recommended substantial increases in the availability of palliative care in the community and in aged care facilities.

A distressed daughter worried about her father's future

A distressed daughter called us about her 92-year-old father who has multiple health issues and 10 per cent remaining kidney function. After six weeks in a Victorian public hospital for an acute infection he was discharged to respite care for four weeks while permanent care was arranged. She was concerned about his future care. No one had discussed his prognosis or palliative care with her father or his family.

One of the many calls PCV recently received from the public.

Objective 1

Increase community awareness and engagement

Victoria's *End of life and Palliative Care Framework* (the Framework) stresses the need to build community understanding in relation to advance care planning, palliative care and end of life care across metro, regional and rural Victoria.

Recommended actions

1. **Undertake a strategic community awareness campaign** in collaboration with relevant consumer, chronic disease and peak groups across Victoria. This would build and support their capacity to communicate and engage with consumers about palliative care and end of life care. Target: 20 participating organisations. Investment: \$1.5M a year.
2. **Engage communities face to face** on these sensitive issues. Using a proven collaborative approach with community organisations, trained volunteers and staff, facilitate small group sessions in relevant languages using tailored resources. Target participation: 20,000 Victorians. Investment: \$1.5M a year.

Objective 2

Increase specialist palliative care availability and capacity

A strong specialist palliative care workforce is needed to address complex needs, to provide education and clinical support to the broader health care workforce, and to achieve the goals of the Framework.

Recommended actions

- 3. Increase community palliative care services** to meet current and future need for care at home, including improved support for carers who provide most of the care.
Investment: \$14M a year.
- 4. Supplement last-days-of-life at home with more palliative care.** Access to in-home overnight care for the dying person at home by appropriately trained and qualified staff will relieve carers and reduce avoidable hospital admissions. Target: More than 5,000 nights of care at home.
Investment: \$5M a year.
- 5. Increase availability of consultancy palliative care.** Sixty per cent of these services cannot meet current demand. They facilitate the right care at the right place and at the right time in inpatient and community settings across Victoria.
Investment: \$13M a year.
- 6. Increase inpatient palliative care services.** The rate of palliative care related hospitalisations in Victoria increased by 10 per cent between 2010–2015, and 78.3 per cent of these admissions were public patients. Increasing inpatient services will improve capacity to meet this growing need. *Investment: \$7M a year.*

Objective 3

Develop workforce and service system capacity

The Framework highlights the need to build workforce and service system capacity across Victoria's health and aged care service system, with the support of specialist palliative care where there are complex needs.

Recommended actions

- 7. Increase access for residents in aged care services.** Specialist palliative care and end of life consultancy teams are needed to provide proactive and responsive specialist clinical support for aged care staff and GPs caring for residents with complex needs. Target: One team per 33 residential aged care facilities.
Investment: \$13M a year.
- 8. Improve after-hours access** to GPs and pharmacists with palliative care and end of life care expertise by providing education and by establishing effective links and protocols to facilitate access to urgent after-hours support. This could be facilitated through collaboration with Primary Health Networks.
Investment: \$4.5M a year.
- 9. Enhance workforce availability, education and models of care.** Education and workforce development programs are required to ensure staff with the requisite skills and expertise are available to meet the current and growing need for high quality palliative care and end of life care across Victoria's health and care system. Further innovation and collaboration is necessary so that service models and practices deliver the best outcomes for people with a life limiting illness, their carers, and the health system.
Investment: \$5.5M a year.

A neighbour concerned about a woman struggling to care for her ailing husband

We were contacted by the neighbour of an 82-year-old man with advanced lung disease who is bed-bound and cared for at home by his 80-year-old wife. The man is determined to die at home. A former patient of the local public hospital, follow-up treatment has been through visits to his GP's surgery but he can no longer manage this. His wife is struggling to care for him. Nobody had discussed community palliative care with them. The neighbour expects that the man will die before this can be put in place.

One of the many calls PCV recently received from the public.

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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