



2016 State Budget

CALL TO ACTION

Approved for distribution by the
Board of Palliative Care Victoria

Introduction

Palliative Care Victoria is an independent not-for-profit peak body. Established in 1981, our vision is that all people with a life limiting illness and their families are supported to live, die and grieve well.

We represent 187 members, including 93 organisations involved in providing palliative care, as well as patients and their families and others with an interest in palliative care. As a key source of information and referral, we receive numerous calls from the public that provide important insights about the need for palliative care and opportunities to address gaps and improve outcomes.

We welcome this opportunity to propose recommendations for pre-election policy commitments in the lead up to the 2014 Victorian election.

We value the political leadership and government support that has enabled Victoria to become a leader in the provision of palliative care in Australia.

Further investment in palliative care services is crucial as we head into a period of significant population growth and population ageing, as well as increasing incidence of chronic disease.

This will not only assist people with life limiting illnesses and their families to live, die and grieve well, but it will also contribute to better use of limited health resources.

These recommendations are based on extensive consultation with palliative care services and consortia throughout Victoria, other key stakeholders and available evidence.

Thank you for your consideration of these recommendations. We would welcome the opportunity to discuss them with you.



Michael Bramwell
Chair, Palliative Care Victoria Board



Odette Waanders
CEO

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The value of investing in palliative care

Quality of life and more effective use of health resources

Extensive research has found that palliative care services contribute to more effective and efficient use of health resources in ways that are consistent with the goals of care expressed by people with a life limiting illness and their families. This includes fewer emergency and hospital admissions, shorter lengths of stay, and the elimination of non-beneficial tests and treatments.^{1, 2, 3, 4, 5}

Importantly, the research also indicates that palliative care improves the quality of life of patients and their families, improves the management of pain and other symptoms, reduces caregiver burden and provides greater emotional support compared with usual care.^{6, 7, 8, 9}

Investment in palliative care essential for a sustainable and effective health system

The combined effect of population growth, population ageing and increasing chronic disease in the context of an ageing workforce and associated economic challenges will place significant pressures on the Victorian health system in the coming years and decades.

We need a health system that is better geared to supporting people with life limiting illness and their families to live, die and grieve well. This must be core business for our health services, along with health promotion and curative treatment.

Without increased investment in palliative care, many of the 300,000 Victorians who will die within the next 8 years¹⁰ will be treated by health services that continue to focus on curative intervention. Unless current trends change, over 150,000 of these people will die in a Victorian hospital (on average an extra 1,423 deaths each year compared to 2012).¹¹

Continuing current patterns of health service provision for people approaching the end of life will be unsustainable. Furthermore, this approach does not align with the preferences of most people – to receive care and to die at home.¹²

In 2012-13, the total expenditure on palliative care in Victoria was less than 1% of the operating expenditure on Victorian public hospitals.¹³ In 2012-13, palliative care for a person living at home in Victoria (for 174 days on average) cost less than 40% of an average inpatient stay of 3.2 days (excluding capital costs).¹⁴ An inpatient palliative care bed is less than 50% of the lowest bed day rate for a patient in acute care.¹⁴ Potential savings are more significant compared with high cost acute care, such as ICU, often associated with end of life care.

Increased investment in palliative care offers a win/win strategy that will lead to better quality of life, more effective use of health resources and a more sustainable health system.

Our recommendations are modest compared to the challenges and the potential benefits of further investment in palliative care; however, they provide a sound basis for future development.

Summary of recommendations

Increase investment in palliative care of at least \$16.45 million a year to respond to the growing need, promote equitable access and quality of life outcomes, and improve health system performance.

- a. Service Growth: Invest at least \$14.25 million a year to increase the availability and equity of access to palliative care services across Victoria. (Recommendations 1, 2 & 3)
- b. Effectiveness and Efficiency: Invest at least \$2.2 million a year in raising community awareness of palliative care and priority research, education and innovation initiatives. (Recommendations 4, 5 & 6).
- c. Allocation Principle: allocations of this new funding are applied to improve equity of access and outcomes, as well as efficiency. (Refer to Appendix, P26).

Recommendation 1 Increase the availability of community palliative care services

- a. Increase the overall supply of palliative care services to address the unmet and growing need for palliative care and end of life care.
- b. Support the provision of community palliative care on a 24/7 basis, including:
 - The provision of more in-home care and respite (including overnight) by appropriately trained staff, particularly when the patient is dying and can safely be cared for at home and/or the carer needs in-home respite for a period to maintain their health and wellbeing and continue their caring role;
 - Improve 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).

Recommendation 2 Expand palliative care consultancy services

Increase the provision of specialist palliative care medical and nurse practitioner consultancy services ('consultancy services') to support the clinical management of people with life limiting illnesses with complex needs and to build the capacity of other health professionals in supporting the provision of high quality care.

Priorities include:

- a. Increasing the provision of consultancy services to clients of community palliative care services.
- b. Improving the provision of consultancy services in rural regions – particularly poorly served areas such as the Hume region.
- c. Increasing consultancy capacity for paediatric and young adult patients.
- d. Providing 24/7 access to consultancy services to address complex / urgent needs that require specialised palliative care clinical expertise.
- e. Active participation of specialist palliative care consultancy services in community-based education and research to promote high quality care of people with life limiting illnesses.

Recommendation 3 Close the Gap for Aboriginal People & Torres Strait Islanders

Fund the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) to facilitate the provision of services by at least two Aboriginal Community Controlled Health Services (ACCHOs) in partnership with palliative care services. This would enable Aboriginal Health Liaison Workers to support culturally safe care through the provision of advocacy and support, and by coordinating care linkages for Aboriginal people and Torres Strait Islanders with life limiting illnesses. Adjunct orientation, education, clinical placement and resource development will contribute to increased capacity of ACCHOs and palliative care services in providing culturally responsive palliative care to Aboriginal people and Torres Strait Islanders.

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

- a. Include high quality end of life care in the Statements of Priorities for all Victorian Government funded health services.
- b. Provide education on palliative care and communications skills, including the use of key clinical triggers for referral to palliative care¹⁵ with a priority focus on health professionals working with patients with chronic illnesses that are leading causes of death. This could be provided using the expertise of the Victorian specialist palliative care workforce and academic units.

Recommendation 5 Increase community awareness and capacity

Ongoing funding to enable Palliative Care Victoria to develop and implement a community engagement program to raise awareness of palliative care, to build community capacity to deal with issues of dying, death, grief and loss, and to encourage people to discuss and document their advance care wishes. This would include the following strategies:

- a. A community awareness and engagement strategy using a range of media, engagement activities and communications channels tailored to specific target populations
- b. Delivery of peer education sessions by trained and supported volunteers in partnership with COTA Victoria and the provision of train the trainer education for other relevant Victorian peak bodies interested in building this capacity within their volunteer programs
- c. Development and distribution of information tailored to specific target populations including Aboriginal people, Torres Strait Islanders, people from culturally and linguistically diverse backgrounds, and specific chronic illness populations.

Recommendation 6 Invest in drivers to improve health care experience and performance

Investment in palliative care research, education and innovation strategies that will contribute to improvements in health care experience and performance, including:

- a. Priority-driven and clinically relevant palliative care research that will contribute to improvements in patient and carer outcomes (and their measurement), improved access and responsiveness for under-served populations, and provide evidence of cost-effectiveness.

- b. Post-graduate scholarships to develop the palliative care expertise of the Victorian health workforce and PhD scholarships and post-doctoral placements to strengthen Victorian palliative care research capacity.
- c. Continuation of an annual survey of palliative care patients, carers and bereaved carers which contributes to consumer outcome measurement and continuous quality improvement.
- d. An innovation program to seed, share and spread palliative care service innovations that contribute to improvements in patient and carer outcomes, improved access and responsiveness

The increasing need for palliative care

The forecast growth in Victoria's population, the ageing of its population and increasing rates of chronic disease will drive increasing needs for palliative care services over the coming decades. An indication of this is the forecast average 7.7% annual growth in the number of deaths in Victoria in the period 2013 to 2021. However, palliative care service capacity also needs to expand to improve equity of access and outcomes for people with a range of chronic illnesses and other population groups that are currently under-served by palliative care services.

Increasing need due to demographic and morbidity trends

- Population growth: The Victorian population is forecast to increase by nearly 900,000 (15%) from 5.62 million to 6.07 million during the 10 year period to 2021.¹⁶
- Ageing population: During the period 2011 to 2021, the Victorian 65+ population will increase by 40% (over one million people)¹⁷. Two-thirds of deaths in Australia in 2012 were among people aged 75 or more¹⁸ and the mortality rate increases with age.¹⁹
- Increase in chronic disease – chronic diseases are the leading cause of death and their prevalence is increasing²⁰. The leading causes of death in the 75+ population are coronary heart disease, cerebrovascular disease, dementia, chronic obstructive pulmonary disease, heart failure, influenza and pneumonia.²¹
- Increase in the number of deaths – In 2012, 35,750 people died in Victoria.²² In the 8 year period 2013 to 2021, around 307,973 people will die in Victoria²³ - an average increase in the number of deaths of 7.7% per year in the period 2013-2021. A recent UK comprehensive study on population-based estimates of the need for palliative care has indicated that between 69%-82% of those who will die need palliative care.²⁴

Current unmet need - improving equity of access

Currently the majority of palliative care services are provided to people with cancer.²⁵ This means that the current level of palliative care service provision is not an optimal baseline for responding to future growth in need. An additional growth in service capacity is required to improve equity of access by groups of people that currently have low rates of access to palliative care services, as outlined below.

- People with life limiting conditions other than cancer: palliative care has mainly focused on people with cancer. However, there is now growing acceptance of the value of early involvement of palliative care in assisting people with a wide range of life limiting conditions, such as organ failure and neurodegenerative conditions.²⁶ The following examples indicate the scope of need:
 - Chronic obstructive airways disease – In 2012, chronic lower respiratory disease was the fifth leading cause of death in Australia.²⁷ In 2007, COPD was certified as the underlying cause of 5,051 deaths in Australia among people aged 55 years and over.²⁸ However, in 2010-11, there were only 1,305 palliative-care related hospital separations for people with a principal diagnosis of COPD.²⁹ This suggests that, at best, less than 25% of people with chronic COPD access palliative care.

- o Dementia & Alzheimer's disease – 10,369 people died from these diseases in Australia in 2012, comprising 7% of all deaths.³⁰ In 2010-11, these diseases were the principal or additional diagnosis for 5% of palliative care-related hospital separations.³¹ The number of people with dementia in Victoria is forecast to increase from 52,500 in 2005 to around 83,600 by 2020.³² A recent Australian survey of 783 professional carers and 236 family carers of people with dementia reported difficulties in: accessing hospice care (68%); accessing palliative care specialists (58%); getting sufficient end of life care support in the community (>50%); and in ensuring the person they were caring for received adequate pain relief.³³
- o End stage renal disease – in 2012, there were 2,678 deaths in Australia due to renal failure.³⁴ However, there were only 1006 palliative care-related hospital separations for people with a principal diagnosis of renal failure across Australia in 2010-11.³⁵ This suggests that, at best, less than 38% of people with chronic renal failure access palliative care.
- Aboriginal people and Torres Strait Islanders

In June 2011, an estimated 47,333 Aboriginal people and Torres Strait Islanders were living in Victoria – a 57% increase compared with 2006.³⁶ Aboriginal people and Torres Strait Islanders have much higher death rates than non-Indigenous Australians. This difference persists across all ages and for all major underlying causes of death.³⁷ In 2012-13 in Victoria, Aboriginal people and Torres Strait Islanders were hospitalised at almost double the rate of other Australians and 1.2 % (17,735) of all Victorian public hospital separations were for Aboriginal and Torres Strait Islander people.³⁸ In 2012-13 only 3,517 (0.7%) of community palliative care service contacts involved people who identified as Aboriginal and/or Torres Strait Islander out of the 487,332 contacts to other Australians.³⁹
- People from culturally and linguistically diverse (CALD) backgrounds

At the 2011 census, 26.2% of Victorians were born overseas, an increase of 19.8% since 2006. Around 23% of Victorians spoke a language other than English at home, and over two-thirds of Victorians followed a total of 135 faiths.⁴⁰ The older CALD population is projected to grow by 44% in the 15 years from 2011 to 2026⁴¹ and to reach over 230,000 by 2026.⁴² In 2008/09, less than 7% of the 435,475 community palliative care service contacts were provided to people whose preferred language was not English; this increased to nearly 13% of the 446,283 community palliative care service contacts in 2012-13,⁴³ but is still well below the likely level of need as indicated by the data above.
- Children and young people with life limiting conditions

There are over 1.2 million children and young people aged 0 to 17 years resident in Victoria.⁴⁴ International data on the prevalence rate for children and young people likely to require palliative care services is 10-16 per 10,000 population aged 0-19⁴⁵ (a recent UK study has increased this rate to 32 per 10,000 population⁴⁶). Based on these prevalence figures there are likely to be between 1800 and 3,800 children in Victoria with a life-limiting condition. Around 30% have cancer and 70% have other pathologies - mainly neurodegenerative, metabolic and genetic.⁴⁷ In 2012/13, Very Special Kids provided services to 503 children with a life limiting condition and their families, and supported a further 302 bereaved families. The Victorian Paediatric Palliative Care Program based at the Royal Children's Hospital in Melbourne

provided palliative care to an average of 117 children during 2012-13; in the 10 months of 2013-14, this has increased by 10% and over the past three years, the average number of children supported by the program has increased by 16%.⁴⁸ The capacity of these state-wide services needs to expand to address current unmet need as well as new needs arising from population growth.

Improving referral and access rates to palliative care services for specific populations that have been missing out will result in increased need for these services over and above the demand arising from population increases and population ageing.

An indication of the catch-up required is that the number of palliative care-related separations from Victorian public hospitals in the 5 year period ending 2010-11 increased by an average of 10.5% per year⁴⁹ - a much higher rate than increases in population. The number of clients receiving community palliative care services increased by almost 80% in the five year period to 2012-13, an average annual increase of 16.5%.⁵⁰

Call to action summary

Increase investment in palliative care of at least \$16.45 million a year to respond to the growing need, promote equitable access and quality of life outcomes, and improve health system performance.

- a. Service Growth: Invest \$14.25 million a year to increase the availability and equity of access to palliative care services across Victoria. (Recommendations 2, 3 & 4)
- b. Effectiveness and Efficiency: Invest \$2.2 million a year in raising community awareness of palliative care and priority research, education and innovation initiatives. (Recommendations 5, 6 & 7).
- c. Allocation Principle: allocations of this new funding are applied to improve equity of access and outcomes, as well as efficiency. (Refer to Appendix).

Service Growth	Activities	Minimum New Funding
Recommendation 1	Community palliative care services - growth	\$5 million
	Improved after hours & carer support	\$4.5 million
Recommendation 2	Consultancy services	\$4.3 million
Recommendation 3	Aboriginal & Torres Straight Islanders	\$0.45 million
Sub- Total		\$14.25 million
Equity and Efficiency	Activities	
Recommendation 4	End of Life Care priority	\$50,000
Recommendation 5	Increase community awareness	\$400,000
Recommendation 6	Research funding	\$500,000
	Workforce development	\$540,000
	Annual Palliative Care Survey	\$360,000
	Innovation Fund	\$350,000
Sub-Total		\$2.2 million
TOTAL ANNUAL INVESTMENT (MINIMUM)		\$16.45 million

Recommendation 1

Increase the availability of community palliative care services

- a. Increase the overall supply of palliative care services to address the unmet and growing need for palliative care and end of life care.
- b. Support the provision of community palliative care on a 24/7 basis, including:
 - The provision of more in-home care and respite (including overnight) by appropriately trained staff, particularly when the patient is dying and can safely be cared for at home and/or the carer needs in-home respite for a period to maintain their health and wellbeing and continue their caring role;
 - Improve 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 sought At least \$9.5 million a year

Rationale

Meeting patients' preferences is an important outcome for health services and it has been argued that it is one of the ultimate measures of success in palliative care.⁵¹

Home is the preferred place of care and death for the majority (50-75%) of people living with a life-limiting illness and their caregivers and the majority (80%) do not change their preference during the course of the illness.⁵² Yet the majority of deaths in Victoria are in hospitals (52%) and this has remained steady over the past decade.⁵³

The structure and availability of healthcare resources appears to influence the place of death more than the actual preference of patients.⁵⁴

The involvement of palliative care teams has been found to increase the likelihood that patient and carer preferences for place of care and place of death are fulfilled.^{55 56} The provision of home-based palliative care can also reduce the frequency of in-patient hospital deaths and the use of hospital resources during the last 2 months of life.⁵⁷

A recent South Australian study found that lack of after-hours support and advice was the most frequently mentioned reason cited by carers to seek other care, such as hospital or hospice, for the person for whom they were caring.⁵⁸

The Department of Health in the UK has found that the provision of 24/7 services can avoid unnecessary emergency admissions to hospital and can enable more people at the end of their life to die in their place of choice.⁵⁹

A study of 1.5 million people from 13 countries has found that key factors influencing dying at home include: the use and intensity of home care, living with relatives, having extended family support, preferences and functional status.⁶⁰

The number of patients with a life limiting illness supported by Victorian specialist community-based palliative care services has increased by 80% between 2008-09 and 2012-13.⁶¹ However,

the proportion that died at home (24%) and in inpatient care (56%) changed little over the 5 year period.

By comparison, community-based specialist palliative care services in Western Australia achieve higher home death rates (around 60%). One of the contributing factors is the availability of on-call medical staff 24/7 and the provision of in-home respite by appropriately trained staff, where this is required.⁶²

Eastern Palliative Care reviewed 171 client deaths during a 3 month period to identify situations where respite for the carer by a registered nurse would have been helpful in assisting and sustaining the caregiver and supporting the care of the client. The review indicated that this would have been helpful for at least 15% of clients in their care during that period. Examples of situations where this would have been helpful include:

- Client died in hospital the day following the nursing visit (1 night of respite needed)
- Client admitted to hospital as carer could not manage seizures and died 3 days later (3 nights respite needed)
- Client admitted to hospital for last 4 days as family stressed with level of care (4 nights respite needed)
- Client in disability home – no overnight active staff (4 nights respite needed).⁶³

The Clinical Oncological Society of Australia and Cancer Voices Australia have also identified the need for 24 hour access to palliative care nurses or respite carers to provide the extra support and expertise needed to keep the patient comfortable at home as well as giving the family a sense of control during the final stages of the person's life. They argue that this approach would also lead to major cost savings by preventing ambulance use and admissions to emergency departments for palliative care.⁶⁴

Australian studies also confirm the important role of respite services in community palliative care:

- A night respite service enabled patients who would have been transferred to an inpatient setting for end-of-life care to die at home. Families were appreciative of the service and a limited cost comparison suggested costs were lower than if patients had been transferred to hospital or hospice.⁶⁵
- A mixed methods study conducted in 2009 found that, after adjusting for matching variables (age, gender and condition), patients receiving respite care delivered by enrolled nurses were 80% less likely to be hospitalised than historical controls, avoiding hospital costs and increasing caregiver satisfaction.⁶⁶

A Victorian study in 2009 of GPs and palliative care nurses found that poor communication and limited availability of after-hours services were the factors most likely to impact negatively on the palliative care of patients in the community. Strategies considered most likely to improve after hours services were individual patient protocols, palliative care trained respite carers and regular multidisciplinary meetings that included the GP.⁶⁷

Home-based palliative care is cost-effective and reduces the use of other health services according to a randomized controlled trial of 298 terminally-ill patients from two health maintenance organizations in two US States. Those who received in-home palliative care from an interdisciplinary team were more satisfied with care, more likely to die at home, less likely to visit an emergency department, and less likely to be admitted to hospital.⁶⁸

Community based paediatric palliative care, supported by dedicated children's hospices, contribute to improved quality of life for the patient and family, as well as reducing the number of hospital admissions and deaths in hospital.⁶⁹

Example of the need to strengthen community palliative care

In May 2014, Palliative Care Victoria received several calls from family members about the difficulty in finding appropriate care options for loved ones who were expected to die within weeks but who could no longer stay in inpatient care, where they had received respite, as the beds were needed for acute care. They were given very little information and found it very difficult to access appropriate care services.

The following letter appeared in 16 May 2014 edition of The Age.

Irrespective of whether euthanasia becomes legal in Australia, quality palliative care should always be an option, but I fear the sector is already under-resourced.

In March, my mother was admitted for two weeks of respite care into a well-respected hospice. This was where her in-home nursing care team was based. While there, her condition declined markedly. She had difficulty swallowing and required assistance to change position in bed. We had numerous conversations with doctors, pleading that she be allowed to stay. They refused, stating that as my mother entered on respite she must leave on the agreed date. My dying mother was moved twice in the last five days of her life; from the hospice to an aged-care facility where staff were wonderful but not equipped to cater for her needs, and then to a geriatric medical ward in a private hospital. There, for 48 hours, she finally benefited from true palliative care. It is not as easy to come by as people might think.

Lynda Moore, South Melbourne

Letter to the Editor, The Age, 16 May 2014

Positive Case Studies

- A family had been looking after their father who was dying at home. Family members were rotating the night shift to allow their mother to sleep. The family were becoming very tired when one family member had another emergency and could not stay overnight. The community palliative care service arranged for a palliative care registered nurse to provide overnight respite. The client died the next day with all family present.
- An elderly wife was caring for her dying husband at home. She was becoming very tired as her husband was calling out at night for help. Registered nurse respite was requested and provided for 2 nights. The client died at home.

These are exceptional examples⁷⁰; unfortunately, community palliative care services are unable to meet the need for overnight respite at current levels of funding.

Recommendation 2

Expand palliative care consultancy services

Increase the provision of specialist palliative care medical and nurse practitioner consultancy services ('consultancy services') to support the clinical management of people with life limiting illnesses with complex needs and to build the capacity of other health professionals in supporting the provision of high quality care.

Priorities include:

- a. Increasing the provision of consultancy services to clients of community palliative care services.
- b. Improving the provision of consultancy services in rural regions – particularly poorly served areas such as the Hume and Northern Loddon Mallee.
- c. Increasing consultancy capacity for paediatric and young adult patients.
- d. Providing 24/7 access to consultancy services to address complex / urgent needs that require specialised palliative care clinical expertise.
- e. Active participation of specialist palliative care consultancy services in community-based education and research to promote high quality care of people with life limiting illnesses.

Investment Sought At least \$4.4 million a year

Rationale

The Australian & New Zealand Society of Palliative Medicine (ANZPSM) recommends a minimum of one palliative care medicine specialist per 100,000 population. In June 2010, there were 23 palliative medicine specialists in Victoria – 29 fewer than the recommended ratio.⁷¹

Victoria's investment in the Palliative Medicine Training Program has been a very positive initiative; however, funded positions for graduates of this program are required to ensure this expertise is retained in Victoria.

Feedback from community palliative care services in metro and rural Victoria indicates the need for improved access to palliative medicine specialists and palliative care nurse practitioners. For example:

- Melbourne Citymission provides community-based palliative care to around 180 patients at any one time. Like most community palliative care services, due to funding limitations they do not employ a Palliative Medicine Specialist. Currently, it purchases 2 weekly sessions with a Palliative Medicine Specialist from a large health service. However, only a few patients can be seen during this time. When there is an urgent need, patients are likely to be admitted to hospital. Increased access to a Palliative Medicine Specialist would be beneficial to patients, avert some admissions to hospital and be of value in terms of professional development for the multidisciplinary palliative care team.⁷²
- The Hume region has noted that Specialist Palliative Medicine consultancy capacity is required within the region (rather than on an outreach basis from metro Melbourne);

having a resident Specialist Palliative Care Physician would help to build the capacity of GPs and other health services in the region to contribute to high quality palliative care.⁷³

A 7 month pilot conducted in the Hume region in 2013-14 aimed to enhance specialist palliative medicine services and scope the demand for a local palliative medicine workforce. A Palliative Medicine Registrar provided clinical consultancy and education in the region, under the supervision of Palliative Medicine Physicians. During this period 192 consultations were provided at a range of inpatient, outpatient and community settings across the region. Ten education sessions were also provided to palliative care staff and medical students in the region. The evaluation of the pilot recommended the establishment of two palliative care consultancy teams, led by palliative medicine physicians, to support existing community palliative care services and enable inpatient and hospital consultative models of care to be established.⁷⁴

The specialist palliative care nurse practitioner contributes not only direct clinical care, but also plays an important role in providing education to other primary care providers, such as district nurses, GPs and hospital health-care teams, as well as participating in clinical research.

Case conferences between specialist palliative care consultants and GPs are associated with significant reductions in service utilization, apparently by improving case coordination, enhancing symptom management and assessing and managing carer needs.⁷⁵

A systematic review of palliative care in rural settings in 7 US states and found that primary care professionals had inadequate knowledge related to pain and symptom management and emotional issues. It highlighted the need for a multi-faceted approach including strengthening links with local palliative care services to improve knowledge and care to patients.⁷⁶ Similar issues exist in Victoria; strengthening community-based palliative care consultancy services would improve equity of access to palliative care.

Palliative care consultations within acute hospitals have been associated with significantly increased rates of discharge to hospice, nursing home and the person's home compared with those receiving usual care.⁷⁷

Positive Case Studies

- Mr B lived in a rural low-level residential aged care facility, and preparations were in place for transfer to hospital for end-of-life care. Discussions with the palliative care consultancy service allowed transdermal analgesia and sublingual medications to be used, achieving good symptom control and allowing Mr B to receive end of life care at his residential facility. His family appreciated that his wish to remain at his residential facility was able to be accommodated.⁷⁸
- Ms C had metastatic cancer and was symptomatically stable on oral methadone. On displaying signs of deterioration, pre-planning discussions with the palliative care consultancy service enabled subcutaneous methadone to be sourced and the patient transitioned onto a syringe driver of methadone once entering the terminal phase. Ms C had stable symptom management and was consequently able to remain at home for her end-of-life care.⁷⁹

Recommendation 3

Close the Gap for Aboriginal People & Torres Strait Islanders

Recommended Election Commitments

Fund the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) to facilitate the provision of services by relevant Aboriginal Community Controlled Health Services (ACCHOs) in partnership with palliative care services. This would enable Aboriginal Health Liaison Workers to support culturally safe care through the provision of advocacy and support, and by coordinating care linkages for Aboriginal people and Torres Strait Islanders with life limiting illnesses. Adjunct orientation, education, clinical placement and resource development will contribute to increased capacity of ACCHOs and palliative care services in providing culturally responsive palliative care to Aboriginal people and Torres Strait Islanders.

Investment sought At least \$450,000 per year

Rationale

In June 2011, an estimated 47,333 Aboriginal people and Torres Strait Islanders (Indigenous Australians) were living in Victoria – an increase of more than 57% compared with 2006.⁸⁰

Indigenous Australians have much higher death rates than other Australians. This difference persists across all ages and for all major underlying causes of death.⁸¹ In 2012, there were 100 deaths of Indigenous Australians registered in Victoria.⁸²

Cardiovascular disease, diabetes (and associated renal failure) and cancer are leading causes of disease burden for Indigenous Australians and the incidence of these diseases is higher than for non-Indigenous Australians.⁸³

In 2012-13, Indigenous Australians were hospitalised at about 2.9 times⁸⁴ the rate of other Australians; in Victoria, this was 1.9 times the rate of other Australians.⁸⁵

In the same period, there were 2.7 palliative care-related separations in Australian hospitals per 1,000 Indigenous Australians compared to 1.6 palliative care-related separations per 1,000 other Australians.⁸⁶

In Victorian hospitals in 2012-13 there were 29 palliative care-related separations of Indigenous Australians compared to 8,006 for other Australians.⁸⁷

There is a lack of understanding about palliative care among Indigenous Australians, including Indigenous healthcare staff. This is paralleled by low levels of understanding of Aboriginal cultural beliefs, including those relating to dying, death and spirituality, among non-Indigenous health professionals.⁸⁸

Indigenous Australians prefer to receive care and to die at home, connected to land and their extended family network.⁸⁹ Caring for family members is preferred to inpatient care in mainstream services.⁹⁰ Referrals to palliative care services are unlikely to be taken up unless supported by cultural advocacy and/or participation by Indigenous Australian staff.⁹¹

Low referral rates to palliative care teams, and disparities in the provision of palliative care in rural and remote areas means that many Indigenous Australians do not receive appropriate symptom management or supportive care at the end of life.⁹²

The Victorian Aboriginal Palliative Care Program (VAPCP) has focused on improving understanding of Aboriginal culture among staff working in palliative care services and increasing understanding of palliative care among Aboriginal Health Workers and Aboriginal community organisations. While facilitating important advocacy, awareness-raising and education, the VAPCP has not had the capacity to undertake the development required to provide culturally responsive palliative care services for Indigenous Australians.

Key elements of culturally responsive palliative care identified through research with Indigenous Australians include: employing Indigenous Australian health workers; ensuring effective communication and respect for language; addressing psychosocial and practical problems; providing services in local communities; encouraging family meetings; organising educational activities; offering carer and escort support; and providing respite.⁹³

Research indicates that it is preferable for palliative care to be delivered under the auspices of an Aboriginal Community Controlled Health Service in collaboration and partnership with mainstream palliative care services. It is also important to train a critical mass of Indigenous Australian clinicians in palliation and end-of-life care.⁹⁴

A Western Australian initiative involving Indigenous Australian health workers providing information and yarning about advance care planning (ACP) at community gatherings was found to be helpful in raising awareness of ACP. Perceived benefits included: receiving the information in a comfortable and relaxed environment making it easier to discuss wishes with a doctor at a later stage; supporting family members who may otherwise have to make difficult decisions and preventing possible family disputes.⁹⁵

Positive Case Study

Illustrating the importance of liaison between the Aboriginal Health Service and palliative care

A young Aboriginal woman, Josie, returned to the Northern Mallee region following diagnosis with a life limiting illness. Her condition was unstable. She needed assistance with physical issues such as pain and nausea, psychosocial impacts of her recent diagnosis, concerns about guardianship of her infant, and spiritual care related to Josie's 'return to country' needs.

As a first point of call Josie contacted the local Aboriginal health service and was allocated a primary HACC worker. The HACC worker had completed a PEPA placement during the year and established relationships with palliative care services. The worker was able to identify that palliative care services would be appropriate for Josie and made a referral.

The HACC worker and palliative care service have met regularly to collaborate on a care plan to meet Josie's specific needs including planning for end of life care. Key services were identified and multidisciplinary meetings have facilitated a coordinated care plan and support, including HACC, GP, home pharmacy services, social support services related to financial affairs, maternal and child health care, accommodation support workers, and additional community nursing staff.⁹⁶

Recommendation 4

End of life care a priority for all Victorian Government funded health services

- Include high quality end of life care in the Statements of Priorities for all Victorian Government funded health services.
- Provide education on palliative care and communications skills, including the use of key clinical triggers for referral to palliative care⁹⁷ with a priority focus on health professionals working with patients with chronic illnesses that are leading causes of death. This could be provided using the expertise of the Victorian specialist palliative care workforce and academic units.

Investment Sought At least \$50,000 per year

Rationale

On 23 May 2014, the World Health Assembly adopted the first ever resolution to integrate hospice and palliative care services into national health services. The resolution urges countries to integrate palliative care into healthcare systems, to improve training for healthcare workers and to ensure that relevant medicines, including strong pain medicines, are available to patients.⁹⁸

Over half of the deaths in Victoria occur in hospitals.⁹⁹ If this pattern continues, around 154,000 Victorians will die in Victorian hospitals during the 8 year period from 2013 to 2021 and the number of deaths will continue to rise due to the impact of the ageing population.¹⁰⁰

A similar proportion of deaths occur in hospitals in England where Government policy requires that hospitals deliver high quality end of life care for patients and support for their families and those close to them.¹⁰¹ An audit of the care of 6,580 people who died in 149 hospitals in England in May 2013 in England found that major improvements need to be made to ensure better care of dying people. Ten key recommendations include: an annual audit of care of the dying by all hospitals and mandatory education and training in care of the dying for all staff caring for dying patients, including communication skills training and skills for supporting families and those close to dying patients.¹⁰²

The inclusion of high quality end of life care in the statement of priorities for all Victorian Government funded health services and associated education and reporting initiatives would be an important step forward in building the capacity of Victoria's health system to provide high quality end of life care.

The Health Performance Council of SA considers that better identification of people as being near the end of life would not only result in significant improvement in the quality of death for patients but also savings to the public health system.¹⁰³

Making end of life care a strategic priority has been beneficial in other countries, for example:

- Palliative care has been a government priority in Spain since the early 1990s. Increasing provision of palliative care has contributed to reduced hospital stays and use of emergency departments as well as an increase in the proportion of people dying at home. These trends have contributed to significant savings in hospital costs.¹⁰⁴

- Hawaii implemented a state-wide collaborative program, Kokua Mau, to improve end of life care. During 1999-2002 its activities included policy changes, public education and education for health professionals and lay ministries. These contributed to a significant increase in completed advance care directives as well as increased awareness and use of palliative care services.¹⁰⁵

Recommendation 5

Increase community awareness and capacity

Ongoing funding to enable Palliative Care Victoria to develop and implement a community engagement program to raise awareness of palliative care, to build community capacity to deal with issues of dying, death, grief and loss, and to encourage people to discuss and document their advance care wishes. This would include the following strategies:

- a. A community awareness and engagement strategy using a range of media, engagement activities and communications channels tailored to specific target populations
- b. Delivery of peer education sessions by trained and supported volunteers in partnership with COTA Victoria and the provision of train the trainer education for other relevant Victorian peak bodies interested in building this capacity within their volunteer programs
- c. Development and distribution of information tailored to specific target populations including Aboriginal people, Torres Strait Islanders, people from culturally and linguistically diverse backgrounds, and specific chronic illness populations.

Investment sought At least \$400,000 per year

Rationale

Almost two-thirds of adult Australians consider that death and dying is not discussed enough in the community.¹⁰⁶

Feedback from Victorian palliative care patients, carers and members of the public confirms the need to improve community awareness of palliative care. Focus groups conducted for Palliative Care Victoria between January and April 2014 found that participants in the general public groups had a very limited understanding of palliative care.¹⁰⁷ Patients and carer participants in the focus groups reflected on the difficulties they had encountered due to lack of information:

- *"The oncologists tell you nothing, they're doctors for God's sake, they should be more positive (about the options)." (Group 2, Day Centre Attendees, Palliative Care Service)*
- *"I didn't know about palliative care and my oncologist said, 'You'll need palliative care' (very little else)."* (Group 2, Day Centre Attendees, Palliative Care Service)
- *"My brother and my sister didn't understand the benefits of palliative care for my mother ... they didn't understand the pain relief specialised care." (Group 1, Families/ Carers)*
- *"I would have liked to have known about the dying process. I had no concept. I suddenly received a call saying, 'Your mum's going to die, she won't see the end of the week,' but I was thinking she was actually quite well early in the piece." (Group 1, Families/ Carers)*
- *"A bit of education about death and dying... would make a huge difference." (Group 1, Families/ Carers)¹⁰⁸*

Similarly, feedback from patients, carers and bereaved carers through the Victorian Palliative Care Satisfaction Survey has consistently identified knowing where to enquire about palliative care as one of the top 5 priorities for improvement.¹⁰⁹

Barriers to improving awareness of palliative care include: reluctance among the general public to talk about death and dying; incorrect assumptions about palliative care due to lack of information, limited coordination and continuity between health services, and lack of funding and resources to promote palliative care.¹¹⁰

Lack of awareness of palliative care and lack of physician referral to palliative care were the most commonly self-reported barriers to accessing specialist palliative care by oncology outpatients in a US study.¹¹¹

Whereas most approaches to innovation in healthcare focus on supply-side measures, evidence suggests that it is the mobilisation of patient, carer and public demand in relation to their preferred healthcare outcomes that is a key factor in successful innovation, especially when this is supported by a clear guiding vision and a disciplined approach to focused innovation.¹¹²

Increased awareness of palliative care, along with opportunities to express care preferences in a timely way through advance care planning, will provide the mobilisation required to drive greater innovation in how our community and our health services support people with life limiting illnesses to live, die and grieve well.

The Advance Care Planning Strategy for Victorian Health Services 2014-2018 will be most effective if it is complemented by community information and education strategies about advance care planning (which should include information about palliative care).

Advance care planning and end of life conversations with health professionals have been found to reduce health care costs in the last week of life.¹¹³ The absence of advance care plans or end of life conversations have been associated with more aggressive medical care and reduced quality of life in the final week of life."¹¹⁴

Recommendation 6

Invest in drivers to improve health care experience and performance

Investment in palliative care research, education and innovation strategies that will contribute to improvements in health care experiences and performance, including:

- e. Priority-driven and clinically relevant palliative care research that will contribute to improvements in patient and carer outcomes (and their measurement), improved access and responsiveness for under-served populations, and provide evidence of cost-effectiveness.
- f. Post-graduate scholarships to develop the palliative care expertise of the Victorian health workforce and PhD scholarships and post-doctoral placements to strengthen Victorian palliative care research capacity.
- g. Continuation of an annual survey of palliative care patients, carers and bereaved carers, which contributes to consumer outcome measurement and continuous quality improvement.
- h. A program to seed, share and spread palliative care service innovations that contribute to improvements in patient and carer outcomes, improved access and responsiveness for under-served populations, and provide evidence of cost-effectiveness.

Investment sought At least \$1.75 million per year

Rationale

The impact of population growth, population ageing and the increasing incidence of chronic illness will present significant challenges for the Victorian health system. Investing in research, workforce development and service innovation are important strategies for promoting high quality outcomes for patients and improving the overall cost-effectiveness of health services.

Research Funding

The role of the Palliative Care Research Network Victoria (PCRNV) is to foster a productive, collaborative and sustainable program of clinical and community intervention research aimed at enhancing the quality of palliative care. The PCRNV has undertaken a literature review and is nearing the completion of a consultation process to identify priority research projects for the next five years. Priorities identified to date include research that will contribute to improvements in patient and carer outcomes (and their measurement), improved access to and responsiveness of palliative care for under-served populations, and research that will contribute to evidence of cost-effectiveness.

Annual funding of at least \$500,000 is sought to undertake new research that will contribute value in these areas.

Workforce Development

Anticipated shortages in the supply of skilled researchers¹¹⁵ and qualified health professionals¹¹⁶ indicate that proactive strategies to develop palliative care clinical and research expertise in Victoria are needed.

Victoria has been successful in developing the palliative care expertise of health professionals working in Victoria through Post-Graduate Palliative Care Scholarships. These are available for health professionals working in specialist palliative care as well as primary health, aged care and acute care. The scholarship program has been very successful with high completion rates, career progression to more responsible positions, and reported improvements in clinical practice.¹¹⁷ Although the program has been funded for 7 years, there is uncertainty each year about whether it can proceed. Funding is sought for the continuation of the Post-Graduate Palliative Care Scholarship Program, which is administered for the Department of Health by Palliative Care Victoria.

The Palliative Care Research Network Victoria has indicated that there is a need to strengthen the palliative care research capacity through the provision of three PhD scholarships and three post-doctoral placements. These positions would be based with relevant Victorian palliative care academic centres and would contribute to priority palliative care research projects.

Annual funding of at least \$540,000 is sought for these workforce initiatives.

Annual Survey of Palliative Care Patients, Carers and Bereaved Carers

The Victorian Palliative Care Satisfaction Survey (VPCSS) has been a unique and important tool for collecting feedback from a total of 9,859 palliative care patients, carers and bereaved carers over the past five years. Survey reports provided to services have identified priorities for improvement. It assists services to not only meet the required standards of care but to provide the highest quality of service possible.¹¹⁸

The VPCSS has been funded by the Victorian Government for 5 years ending in 2014; further funding is required to continue collecting feedback from palliative care patients, carers and bereaved carers. This is consistent with the work of the International Consortium on Health Outcomes (ICHOM), which is currently developing standards for measuring patient outcomes for a range of conditions. Patient-reported measures are key elements of the standards developed by ICHOM to date.¹¹⁹

Annual funding of at least \$360,000 is sought for this annual survey.

Innovation Fund

During our consultations several palliative care services and consortia identified the need for funding to seed, share and spread innovations in palliative care. Key areas identified for innovative endeavour included:

- service models to support people to receive care and to die at their place of choice;
- fast track hospital discharge and care in the community for patients who wish to die at home;
- options for flexible, overnight and short-stay respite for carers, including in rural areas;
- protocols to include palliative care consultancy in the management of patient populations with chronic illnesses that are leading causes of death;
- effective and timely referral triggers and pathways to palliative care for specific conditions.

The 2012 Forum on Health Care Innovation by the Harvard Business School and the Harvard Medical School considered the role of innovation in driving improvements in health experiences, outcomes and system performance. Key imperatives for innovation identified, included:

- Organising services around the needs of patients rather than health services
- Empowering patients to be active participants in their own health/care
- Focusing on process improvements that increase value in healthcare
- Pushing care delivery out to the patient
- Better ways of distributing smaller innovative ideas.¹²⁰

An Innovation Fund of at least \$350,000 a year would provide access to the financial support, tools and processes needed for seeding, sharing and spreading innovations that improve patient and carer outcomes and health system performance with a focus on palliative care and end of life care.

Appendix 1 Equitable access and outcomes

Palliative care policy and funding arrangements should promote equitable outcomes. This means that palliative care services are:

- a) accessible on the basis of need and are responsive to the changing needs of people living with a life limiting illness and their families / carers
- b) inclusive and responsive to diversity, including: age, gender, ethnicity, culture, language, illness, disability, GLBTI, economic circumstance, geographic location, and usual place of residence
- c) provided in a timely way having regard to the priority and urgency of needs
- d) aligned with the needs and preferences of people with a life limiting illness and their families / carers.

Equity is promoted when policy and funding arrangements:

- use a population needs-based approach (such as an updated PCRAM formula) that takes account of the following on a regional basis:
 - o The estimated size of the resident population aged 70+
 - o The index of relative socio-economic disadvantage
 - o The distribution of Indigenous Australians and cultural diversity
 - o The access / remoteness index
- work towards peer pricing whereby services are funded at the same level to deliver the same quality outcomes with provision for adjustments to accommodate higher known costs due to client characteristics or location that increase the cost of service delivery (such as ATSI, CALD, remote location)
- result in the achievement of measurable outcomes that are important to palliative care patients and their carers.

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