Department of Health

health

Strengthening palliative care: Policy and strategic directions 2011–2015

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Ministerial foreword

In this government's priorities, detailed in the *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan,* we outline the need to enable the health system to better support people with long-term chronic conditions, the ageing population and people with a life-threatening illness.

As the causes of death in developed countries change, so too has the way in which we provide care for people whose illnesses cannot be cured. Medical advances mean that more people are living longer with progressive and degenerative diseases. They require more pain and symptom management, emotional support and comprehensive care plans that ensure their wishes about how they are cared for and where they die are met.

Of all the people who die in Victoria each year, half would benefit from palliative care. Demand for palliative care is increasing at nearly five per cent per annum. Government, health services and the palliative care sector must work in partnership to meet this demand. There are a number of challenges that need to be addressed in order to ensure palliative care services continue to respond to the changing requirements of our growing and ageing population.

In *The Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan,* the government outlines priorities for the development and operation of the Victorian health system that will help us to create the people-focused, knowledge-focused system that Victorians deserve. These priorities include developing a system that is responsive to people's needs, improves Victorians' health experiences, expands service, workforce and system capacity, increases financial sustainability and productivity, and implements continuous improvements and innovation.

As part of its focus on improving the healthcare system, the government has committed new funding ($34.4 million) to palliative care over the four years of this policy, *Strengthening palliative care: Policy and strategic directions 2011–2015*, to meet growing demand for palliative care, particularly in rural areas and the growth corridors of metropolitan Melbourne. The actions outlined in this policy will equip specialist palliative care services in Victoria to meet growing demand for palliative care.

This policy provides details about the priorities and actions for palliative care and should be read in conjunction with the priorities of the *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan*. This policy outlines priorities, actions and impacts for seven strategic directions in palliative care:

1. Informing and involving clients and carers
2. Caring for carers
3. Working together to ensure people die in their place of choice
4. Providing specialist palliative care when and where it is needed
5. Coordinating care across settings
6. Providing quality care supported by evidence
7. Ensuring support from communities.

As part of providing palliative care, we have a responsibility to help people live as well as they possibly can until they die. Palliative care, in partnership with other services such as health, community, aged care and disability providers, has an important role to play in our community in helping people to live well, maintain hope and stay connected with their families and loved ones at this stage of their lives.

I am committed to ensuring that the actions in this policy are achieved. I look forward to working with you to ensure that all Victorians with a life-threatening illness and their families and carers have access to a high-quality palliative care service system.

The Hon. David Davis MP
Minister for Health

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Acknowledgements

This document was produced by the palliative care team, Integrated Care Branch, Wellbeing Integrated Care and Ageing Division of the Department of Health (the department).

The strategic directions outlined in this document are based on the evaluation of the implementation of the *Strengthening palliative care policy 2004–2009*. Many thanks to the members of the evaluation advisory group for their significant contribution to this work:

	Employing organisation
Ms Marian Allison	Melbourne Health
Ms Molly Carlile	North and West Metropolitan Region Palliative Care Consortium
Ms Danielle Clayman and Ms Lee Stamford	General Practice Divisions of Victoria
Mr Mark Cockayne	South East Palliative Care
Ms Catherine Duck	Melbourne Citymission Palliative Care
Dr Judi Greaves	Peter MacCallum Cancer Centre
Ms Catherine Hattersley	Hume Region Palliative Care Consortium
Associate Professor Peter Hudson	Centre for Palliative Care
Dr Jenny Hynson	Victorian Paediatric Palliative Care Program
Associate Professor Kate Jackson	Southern Health
Ms Florence Kingsley Matthews	Health Issues Centre
Mr Kevin Larkins	Palliative Care Victoria
Ms Bernie McKenna	West Gippsland Healthcare Group
Ms Jeanette Moody	Eastern Palliative Care
Ms Carita Potts	Ballarat Hospice Care
Ms Sue Salau	Palliative Care Victoria
Mr Geoff Anderson	Department of Human Services, Disability Services
Ms Amanda Bolleter	Department of Health, Palliative Care
Ms Maggie Fernie	Department of Health, Loddon Mallee Region
Ms Jo Hall	Department of Health, Palliative Care
Ms Jackie Kearney (Chair)	Department of Health, Palliative Care
Ms Ellen Sheridan	Department of Health, Palliative Care
Mr Lachlan Shield	Department of Health
Ms Margaret Summers	Department of Health, Aged Care

The department would like to acknowledge the stakeholders who participated in the consultation and who supported the development of this policy and strategic directions. In particular, the following services and consortia contributed to the practice examples and images in the document:

- Australian Centre for Grief and Bereavement
- Barwon South Western Palliative Care Consortium
- Centre for Palliative Care Education and Research
- Eastern Health Palliative Care Consultancy Service
- Gippsland Region Palliative Care Consortium
- Grampians Region Palliative Care Consortium
- Loddon Mallee Palliative Care Consortium
- Melbourne Citymission Palliative Care
- Motor Neurone Disease Association of Victoria
- North and West Metropolitan Region Palliative Care Consortium
- Peter MacCallum Cancer Centre
- Royal Melbourne Hospital
- Southern Health, McCulloch House
- Victorian Aboriginal Community Controlled Health Organisation.

The department particularly thanks the clients and their carers who shared their personal experiences of palliative care to inform this policy and strategic directions.

A word about terminology

Life-threatening illness

The term ‘life-threatening illness’ is used in this document because it is consistent with the World Health Organization (WHO) definition of palliative care. A wide range of terms are used by palliative care and related sectors, including ‘people living with a terminal illness’ and ‘life-limiting illness’. Palliative care terminology varies according to the setting in which it is provided, the client’s illness and condition, and the role that palliative care services perform in the client’s care.

The term ‘life-threatening condition’ is used in relation to paediatric palliative care to acknowledge that the majority of children receiving palliative care have a disability rather than an illness.

Clients and carers

The term ‘client’ is used in this document to describe the primary recipient of palliative care. This is consistent with the fact that most people spend the last year of their life receiving care at home (Skilbeck et al. 2005). Occasionally, the term ‘person’ or ‘patient’ is used where this is more appropriate.

The term ‘carer’ is used to describe the unpaid carer (usually a family member or friend) who provides the majority of care to the client (usually at home). Palliative care services and related sectors also use the term ‘family’ or ‘family caregiver.’ It is important to note that families can take a range of different forms including nuclear, sole parent or extended families, and may include close networks of friends and family members. Some people may not have a live-in carer or their carer may also be aged or have their own health issues. All of these forms and factors have implications for how care is provided to the client.

In this context, the term ‘carer’ does not include paid carers in services like aged care facilities, Health and Community Care (HACC), Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) or residential disability services.

Palliative care and end-of-life care

‘Palliative care’ is used throughout this policy to refer to the specialist interdisciplinary clinical practice of palliative care and the designated service system funded to deliver palliative care.

These services can support people with a life-threatening illness in a number of ways, including:

- **direct care** for people requiring specialist palliative care interventions
- **shared care** arrangements with other healthcare providers
- **consultation and advice** to other services and healthcare teams providing end-of-life care
- **education and training** on palliative care and end-of-life issues
- **undertaking and disseminating research** about caring for the dying and their families/carers.

‘End-of-life care’ is used throughout this document to describe care that is planned and delivered to a person at the end of their life. There is no set timeline that defines this phase but, due to illness or old age, many people will require responsive care as they approach death. Death is a normal part of the life cycle and all healthcare providers should be able to understand and contribute to the care of a dying person. However, some healthcare providers have more involvement in caring for the dying than others.

Generally speaking, health providers sit in one of three main groups, namely those that:

- have occasional involvement with people at the end-of-life
- have regular involvement with people at the end-of-life
- focus their clinical practice solely or substantially on caring for people with life-threatening illnesses.

Specialist palliative care services are not required to provide care for everyone at the end-of-life and, in many instances, the most valuable role specialist palliative care can play is to support other healthcare teams and professionals to provide end-of-life care to their patients.

Health, community and aged care providers

This term is used throughout the policy to refer to the broad range of services that are involved in providing care to clients with a life-threatening illness. It includes health services (acute, subacute and community), aged care services (including residential, community, Aged Care Assessment Services and aged care services and packages), general practitioners, Home and Community Care (HACC) services and disability services.

See Figure 2 for a diagrammatic representation of these relationships and a list of the types of services, clinicians and individuals that make up the primary treating team of people with a life-threatening illness and are involved in providing palliative care.

Executive summary

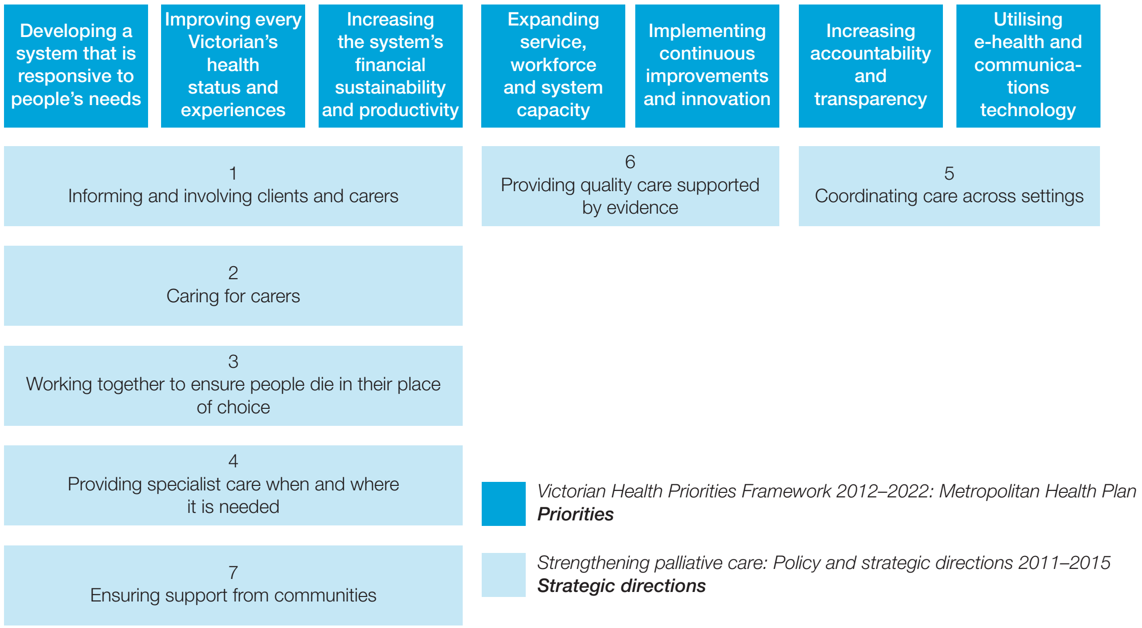
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. 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 patient's 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 (WHO 2010).

The *Strengthening palliative care: Policy and strategic directions 2011–2015* will guide the work of palliative care services, consortia and government from 2011 to 2015. The actions outlined in this policy will equip specialist palliative care services in Victoria to meet growing demand for palliative care. The strategic directions in this policy are consistent with the *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan*, which sets out the priorities for metropolitan, rural and regional and health capital planning into the future.

The links between these priorities and *Strengthening palliative care: Policy and strategic directions 2011–2015* are represented diagrammatically below.

Primary relationship between strategic directions and the *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan*



Developing a system that is responsive to people's needs	Improving every Victorian's health status and experiences	Increasing the system's financial sustainability and productivity	Expanding service, workforce and system capacity	Implementing continuous improvements and innovation	Increasing accountability and transparency	Utilising e-health and communica-tions technology
1 Informing and involving clients and carers			6 Providing quality care supported by evidence		5 Coordinating care across settings	
2 Caring for carers						
3 Working together to ensure people die in their place of choice						
4 Providing specialist care when and where it is needed						
7 Ensuring support from communities						

🟦 *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan* ***Priorities***

▢ *Strengthening palliative care: Policy and strategic directions 2011–2015* ***Strategic directions***

Vision

This policy aims to ensure that Victorians with a life-threatening illness and their families and carers have access to a high-quality palliative care service system that fosters innovation, promotes evidence-based practice and provides coordinated care and support that is responsive to their needs.

Challenges

This document responds to a range of challenges in meeting growing and changing demand for palliative care. It aims to provide palliative care for people with all types of life-threatening illnesses – not only cancer – and to ensure that people's wishes about how they are cared for and where they die are understood and met.

Specifically, our challenges are:

- Victoria's population is growing and ageing
- the way we live in old age, and the way we die, has changed
- meeting people's wishes to die at home
- addressing unmet need.

Responding to the challenges

In order to meet the changing requirements of people with a life-threatening illness, palliative care services should be clear about their role in caring for people across different illness trajectories at the end-of-life. Palliative care services need to work with generalist and other specialist health, community and aged care providers to provide integrated care that meets people's needs.

To ensure that people with a life-threatening illness and their families and carers are well supported, *Strengthening palliative care: Policy and strategic directions 2011–2015* aims to expand capacity and address gaps in the service system and to raise community awareness about death and dying.

This policy has been developed through:

- extensive consultation with the palliative care sector and other sectors likely to require the support of palliative care services in caring for clients
- expert advice and practice wisdom from the evaluation advisory group made up of leaders from palliative care and other related areas
- reviewing the evidence to ensure the actions in this policy are supported by research and best practice
- learning from the feedback and outcomes of the *Strengthening palliative care policy 2004–2009* (SPCP 2004–09) evaluation, including client and carer feedback on their experiences.

The government has committed $34.4 million new funding over four years for palliative care in the 2011–12 State Budget. This document outlines the policy and strategic directions for this increased support to the palliative care sector.

Expected policy outcomes

Strengthening palliative care: Policy and strategic directions 2011–2015 is expected to produce the following outcomes for all people with a life-threatening illness and their families and carers:

- access to appropriate services, wherever they live in Victoria
- seamless, quality care that is informed by evidence and research
- support from their communities.

The Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan will assist in budget and funding consideration through the term of the government when undertaking health service enhancement development and innovation. Implementation of palliative care priorities will be considered in that context.

The strategic directions for 2011–2015

Priorities for the strategic directions:

Strategic direction	Priorities
Informing and involving clients and carers	• Provide information about palliative care that is tailored to the needs of clients and carers • Actively involve clients and carers in the planning and delivery of their care • Ensure that advance care plans inform client care
Caring for carers	• Strengthen practical, psychological, social and spiritual support for carers of people with a life-threatening illness acknowledging that their needs may change over time • Strengthen support for families of children and young people with a life-threatening condition • Increase the availability of after-hours support to clients and carers in their homes, particularly in rural areas • Provide consistent support and training to carers that recognises they can have different needs and interests to clients • Ensure bereavement assessment and support is available to families and carers across Victoria • Provide support to carers from groups that are less likely to have access to palliative care, including Aboriginal and CALD groups
Working together to ensure people die in their place of choice	• Raise the awareness of palliative care by other health, community, and aged care providers about palliative care to ensure that people are cared for and die in their place of choice. • Assist aged care services to care for people at the end-of-life
Providing specialist palliative care when and where it is needed	• Ensure people who need access to specialist palliative care are receiving care appropriate to their needs at the right time, in the place of their choice • Provide a sustainable and equitable specialist bereavement support service for people experiencing complicated grief
Coordinating care across settings	• Integrate practices across health service and community settings to ensure access to coordinated and consistent care at the end-of-life • Strengthen the role of palliative care consortia in coordinating palliative care service provision and leading policy implementation in each region • Strengthen links between stakeholders in palliative care • Use technology to enhance service coordination for all palliative care services
Providing quality care supported by evidence	• Develop consistent clinical care protocols that are informed by research and evidence • Support and build future palliative care research capability across academic and clinical services and its translation into practice • Ensure all Victorian palliative care services provide quality care that is assessed against national standards and supported by a quality improvement culture • Continue to build and support the palliative care workforce to meet increasing demand for palliative care services • Ensure sustainability of the specialist paediatric palliative care workforce
Ensuring support from communities	• Strengthen Victorians' awareness, capacity and resilience in relation to dying, death, loss and bereavement, and their ability to support people with a life-threatening illness and their carers


EXIT
EXIT

Introduction

Vision

All Victorians with a life-threatening illness and their families and carers have access to a high-quality palliative care service system that fosters innovation, promotes evidence-based practice and provides coordinated care and support that is responsive to their needs.

Purpose

This document outlines how the Victorian Government will strengthen access to quality palliative care services between 2011 and 2015. It articulates the strategic directions and actions that will improve care for Victorians with a life-threatening illness, their families and carers. The strategic directions for 2011–2015 are:

1. informing and involving clients and carers
2. caring for carers
3. working together to ensure people die in their place of choice
4. providing specialist care when and where it is needed
5. coordinating care across settings
6. providing quality care supported by evidence
7. ensuring support from communities.

Audience

The primary audience for this policy is government-funded specialist palliative care services in Victoria. The directions and actions outlined in this policy are also relevant to a range of other health, community and aged care providers (including both public and private acute and primary healthcare providers, general practitioners (GPs), Primary Care Partnerships, Medicare Locals and other private health services) who seek to provide high-quality care for people with a life-threatening illness.

This policy is intended to be clear and easy to read for all people with an interest in palliative and end-of-life care, including people with a life-threatening illness and their carers and families. It is not, however, intended as an information guide for people with a life-threatening illness.

Context

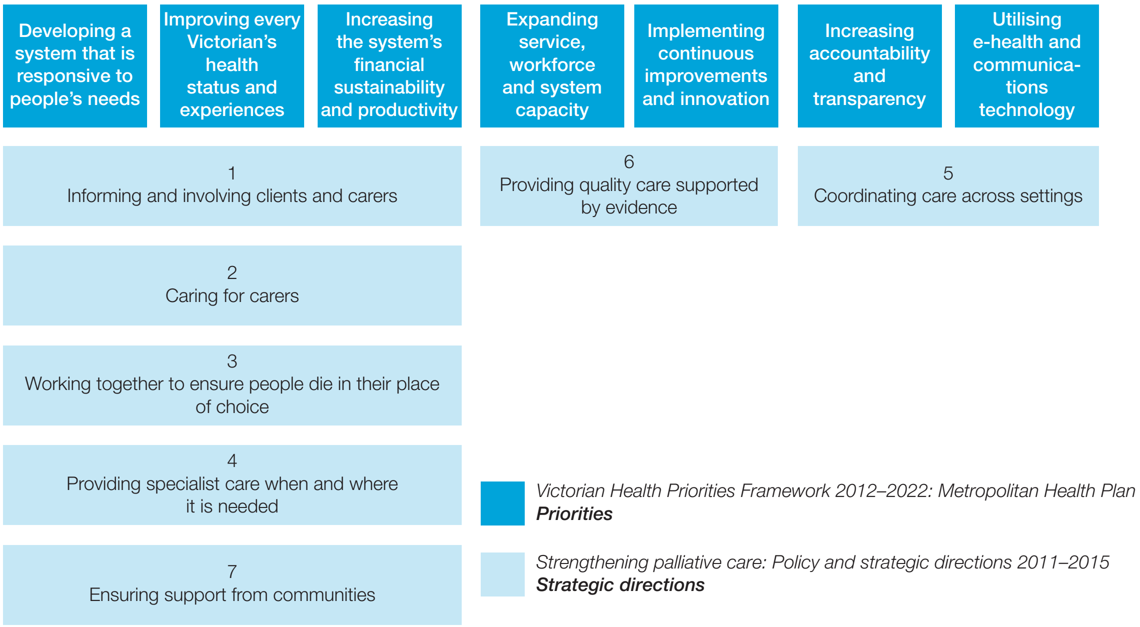
This policy will guide the work of Victoria's palliative care sector from 2011 to 2015. It will do this by building on the strengths of the sector, increasing the capacity of services to meet growing demand for palliative care and promoting coordination of care between public and private settings as appropriate.

This policy is consistent with the *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan* and is intended to outline in more detail the priorities and actions for palliative care. Figure 1 on page 12 demonstrates the primary relationships between the strategic directions in this policy and the *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan*.

This policy builds on the *National strategy for palliative care* (released in 2011), which commits Commonwealth, state and territory governments to developing consistent palliative care policies and services with the aim of making quality palliative care accessible to all people who are dying.

The government has committed $34.4 million new funding over four years for palliative care in the 2011–12 State Budget. This document outlines the policy and strategic directions for this increased support to the palliative care sector.

Figure 1: Primary relationship between strategic directions and the *Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan*



What is palliative care?

Victoria has adopted the World Health Organization (WHO) definition of palliative care. This definition articulates the particular skills and methods palliative care services bring to the care of dying people and their families and carers. The WHO (2010) defines palliative care as:

> *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. 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 patient's 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.*

Palliative care in Victoria

Palliative care in Victoria is delivered in a number of settings – from people's homes with primary health and GP support and with specialist palliative care support, through to public and private acute health services and highly specialised settings, and in public and private palliative care inpatient services. Palliative care is flexible to meet the needs of the client and their family.

The palliative care program in Victoria aims to achieve an integrated service across all aspects of care. This is supported by the following underlying principles:

- Care is holistic, multidisciplinary and client-centred.
- Care includes medical, nursing, allied health and volunteer services.
- Support is provided for carers, including grief and bereavement support.
- Clients can make informed choices about their care including the type of care and where the care is delivered.
- Service delivery is seamless between the locations where care is delivered, whether that be in the community or in a health service.

Services in Victoria funded by the state government to provide specialist palliative care comprise both health services and non-government organisations (NGOs). The state government funds palliative care service delivery, regional coordination and planning, as well as education and research.

A broad range of services, clinicians and individuals make up the primary treating team of people with a life-threatening illness and are involved in providing palliative care. This is represented diagrammatically in Figure 2 over the page.

Statewide clinical leadership

The Palliative Care Clinical Network (PCCN) provides clinical leadership in the implementation of policy directions and program initiatives in Victoria. The Palliative Care Clinical Lead and the members of the PCCN leadership group have a range of experience across palliative care and related sectors.

The PCCN oversees projects that further clinical service improvement and also convenes community-of-practice forums to provide an opportunity for workers to enhance their practice around key issues in palliative care. It addresses developing and evolving clinical needs and priorities in palliative care, and assists palliative care consortia and services to implement the service capability framework and related clinical frameworks.

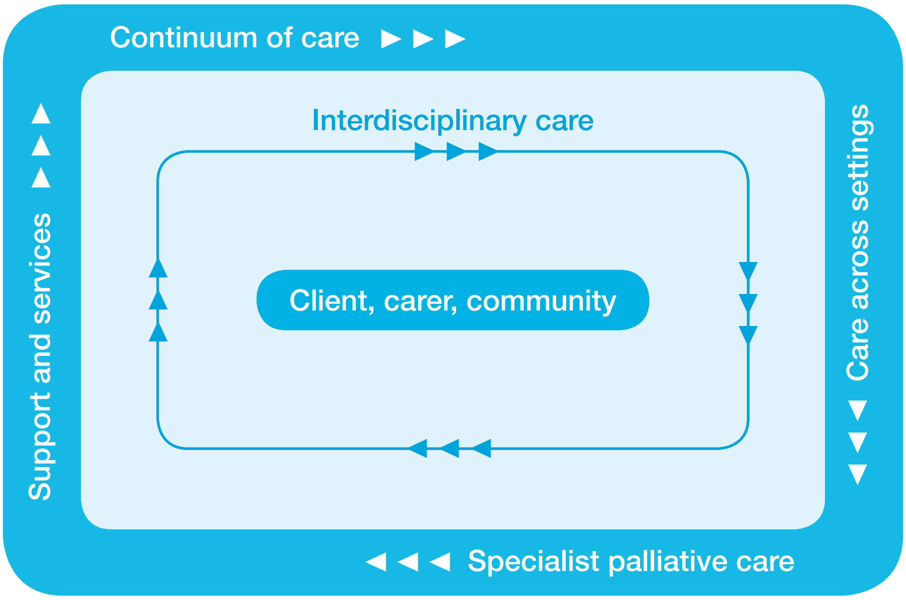
The PCCN maintains strong relationships with the regional clinical advisory groups established by each of the palliative care consortia, as well as links with other clinical networks and the Palliative Care Research Network.

Enabling people with a life-threatening illness to die at home

A man in his early 40s was diagnosed with cancer of the pancreas. He was being cared for at home by his mother who was in her late seventies. When he developed delirium it was thought he may have to be moved to hospital. This would not have been either his or his mother's wish.

After consultations with the palliative medicine specialist, his GP introduced an anti-psychotic drug, which was highly effective in addressing his delirium. He died peacefully at home with his mother.

Figure 2: Relationships underpinning palliative care



Suport and services may include representatives from:

- Aboriginal health services
- Aged care services (for example, Home and Community Care [HACC] program; Commonwealth-funded Community Aged Care Packages [CACPs] including Extended Aged Care at Home [EACH] and Extended Aged Care at Home Dementia [EACHD]; and residential services.)
- Allied health services (for example, social work, physiotherapy, occupational therapy, dietetics, speech therapy)
- Ambulance services
- Bereavement services
- Case management services
- Community support services
- Counselling services
- Disability services
- Equipment providers
- General practitioners
- Medical specialists (for example, geriatricians, oncologists)
- Nurses
- Pastoral care services
- Personal care attendants
- Pharmacy services
- Physicians
- Respite services
- Subacute services (for example, subacute ambulatory care)

Specialist palliative care (may include)

- Community palliative care services
- Inpatient palliative care services
- Consultancy palliative care services
- Day hospices
- Outpatient clinics
- Statewide palliative care services
- Academic services

Care across settings

- Family home
- Alternative home (for example, aged care)
- Inpatient hospice
- Hospital

Continuum of care

- Diagnosis
- Acute care – changes in care
  - – Crisis points
  - – Transition
  - – Terminal phase
- Bereavement

Adapted from Children's International Project on Palliative/Hospice Services 2001, *A call for change: recommendations to improve the care of children living with life-threatening conditions*, National Hospice and Palliative Care Organisation, Alexandria, Virginia

Regional leadership and coordination

Palliative care consortia were established in 2004 in all departmental regions. The role of the palliative care consortia is to:

- undertake regional planning in line with departmental directions
- coordinate palliative care service provision in each region
- advise the department about regional priorities for future service development and funding
- in conjunction with the PCCN:
  - implement the service delivery framework
  - undertake communication, capacity building and clinical service improvement initiatives.

Palliative care consortia comprise members from all funded palliative care services in each departmental region, as well as other stakeholders from health, community and aged care providers.

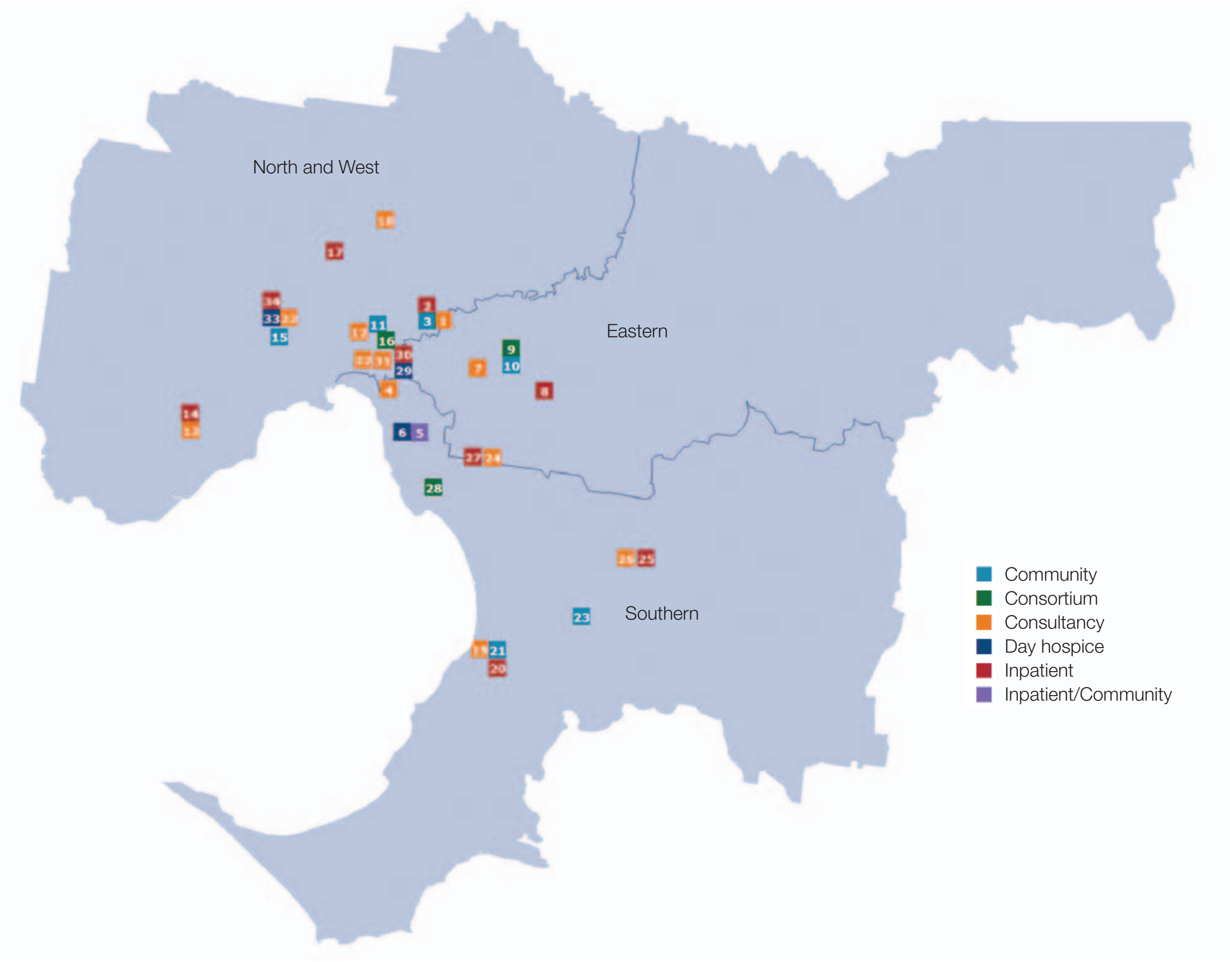
Community palliative care

Community palliative care services provide holistic care based on impeccable assessment of the needs of the client and their family and carers. Support can include nursing care, allied health, respite and practical support, as well as information, equipment, medications and access to medical review and assessment in peoples' homes. Volunteers also play a key role in providing practical and social support to clients and carers. Advice and assistance is available on request outside business hours.

These services also provide secondary consultation and liaison to generalist services caring for clients with a life-threatening illness. All community palliative care services have access to flexible funds to care for clients at home during the last days of life. Community palliative care services provide bereavement support for families of clients who have been in their care.

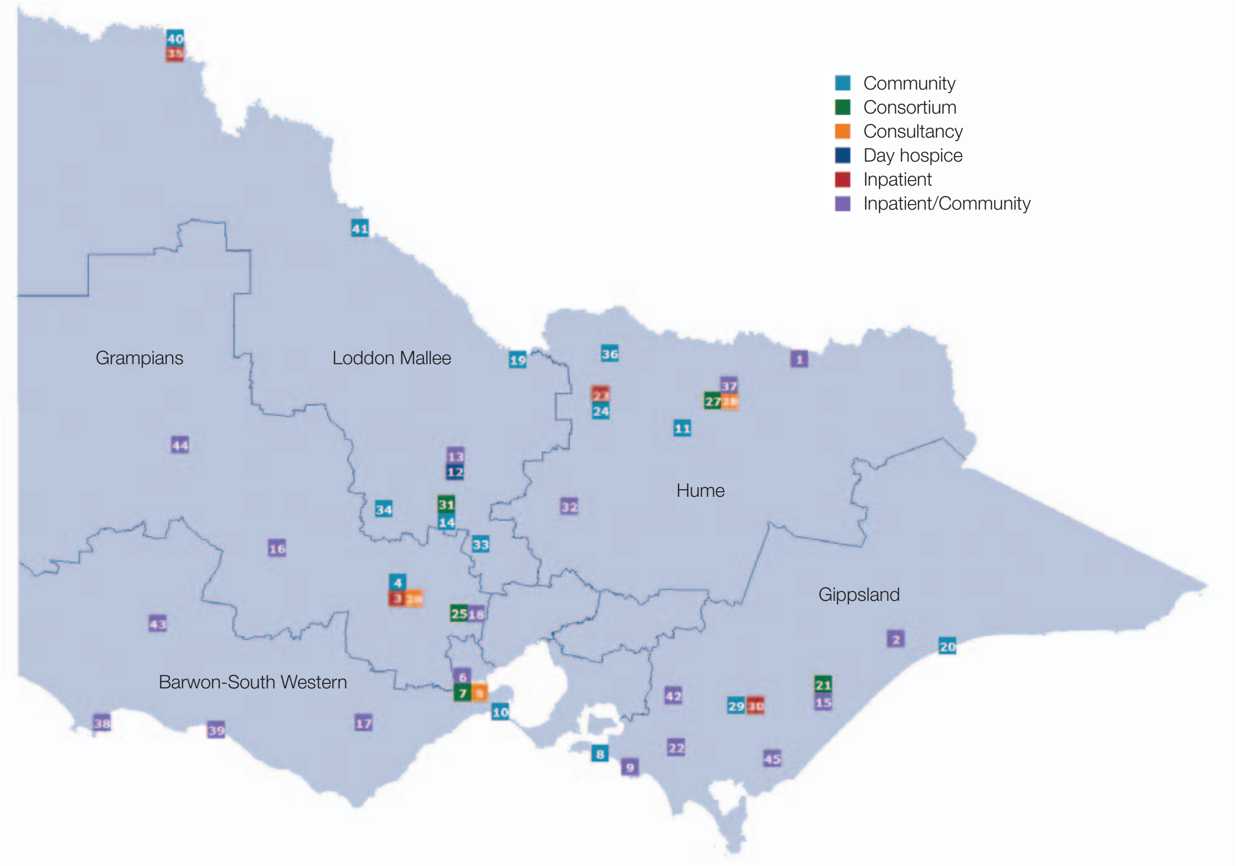
The maps below show the palliative care consortium boundaries and the funded specialist palliative care services within each consortium.

Figure 3a: Metropolitan palliative care services



1 Austin Health (Consultancy)
2 Austin Health – Austin and Repatriation Medical Centre (Inpatient)
3 Banksia Palliative Care Services (Community)
4 Bayside Health (Consultancy)
5 Calvary Health Care Bethlehem (Inpatient/Community)
6 Calvary Health Care Bethlehem – Day Centre (Day hospice)
7 Eastern Health (Consultancy)
8 Eastern Health – Wantirna Health (Inpatient)
9 Eastern Metropolitan Region Palliative Care Consortium (Consortium)
10 Eastern Palliative Care (Community)
11 Melbourne Citymission Palliative Care (Community)
12 Melbourne Health (Consultancy)
13 Mercy Health (Consultancy)
14 Mercy Health – Mercy Werribee Hospital (Inpatient)
15 Mercy Palliative Care (Community)
16 North and West Region Palliative Care Consortium (Consortium)
17 Northern Health – Broadmeadows Health Service (Inpatient)
18 Northern Health – The Northern Hospital (Consultancy)
19 Peninsula Health (Consultancy)
20 Peninsula Health (Inpatient)
21 Peninsula Home Hospice (Community)
22 Peter MacCallum Cancer Centre (Consultancy)
23 South East Palliative Care Ltd (Community)
24 Southern Health (Consultancy)
25 Southern Health – Casey Hospital (Inpatient)
26 Southern Health – Casey Hospital (Consultancy)
27 Southern Health – McCulloch House (Inpatient)
28 Southern Region Palliative Care Consortium (Consortium)
29 St Vincent’s Health – Caritas Christi Day Hospice (Day hospice)
30 St Vincent’s Health – Caritas Christi Hospice (Inpatient)
31 St Vincents Health (Consultancy)
32 Western Health (Consultancy)
33 Western Health- Day Hospice (Day hospice)
34 Western Health- Sunshine Hospital (Inpatient)

Figure 3b: Rural palliative care services



1 Albury Wodonga Health (Inpatient/Community)
2 Bairnsdale Palliative Care Service, Community Health Centre (Inpatient/Community)
3 Ballarat Health Services- Gandarra Palliative Care Unit (Inpatient)
4 Ballarat Hospice Care Inc (Community)
5 Barwon Health (Consultancy)
6 Barwon Health – McKellar Centre (Inpatient/Community)
7 Barwon South Western Palliative Care Consortium (Consortium)
8 Bass Coast Community Health Service (Community)
9 Bass Coast Regional Health (Inpatient/Community)
10 Bellarine Community Health (Community)
11 Benalla Palliative Care Service (Community)
12 Bendigo Health – Chum House Day Hospice (Day hospice)
13 Bendigo Health – Hospice and Evaluation Unit (Inpatient/Community)
14 Castlemaine Health – Palliative Care Service (Community)
15 Central Gippsland Health Service (Inpatient/Community)
16 Central Grampians Palliative Care Service (Inpatient/Community)
17 Colac Area Health (Inpatient/Community)
18 Djerriwarrh Palliative Care (Inpatient/Community)
19 Echuca Community Palliative Care Service (Community)
20 Gippsland Lakes Palliative Care (Community)
21 Gippsland Region Palliative Care Consortium (Consortium)
22 Gippsland Southern Health Service (Inpatient/Community)
23 Goulburn Valley Health- Shepparton (Inpatient)
24 Goulburn Valley Hospice Care Service Inc (Community)
25 Grampians Region Palliative Care Consortium (Consortium)
26 Grampians Regional Palliative Care Team (Consultancy)
27 Hume Region Palliative Care Consortium (Consortium)
28 Hume Regional Palliative Care Consultancy Team (Consultancy)
29 Latrobe Community Health (Community)
30 Latrobe Regional Hospital (Inpatient)
31 Loddon Mallee Region Palliative Care Consortium (Consortium)
32 Lower Hume Palliative Care (Inpatient/Community)
33 Macedon Ranges Palliative Care Service (Community)
34 Maryborough Community Palliative Care Service (Community)
35 Mildura Base Hospital (Inpatient)
36 Moira Palliative Care Service (Community)
37 North East Health Wangaratta (Inpatient/Community)
38 Portland District Health (Inpatient/Community)
39 South West Healthcare (Inpatient/Community)
40 Sunraysia Community Health Services Inc. (Community)
41 Swan Hill Palliative Care Service (Community)
42 West Gippsland Healthcare Group (Inpatient/Community)
43 Western District Health Service (Inpatient/Community)
44 Wimmera Hospice Care (Inpatient/Community)
45 Yarram and District Health Service (Inpatient/Community)

Inpatient palliative care

Inpatient palliative care services provide care to patients who require complex symptom and pain management or end-of-life care or respite.

Inpatient palliative care is provided in designated palliative care beds and by specialist consultancy services.

Palliative care beds in Victoria are located within acute hospitals, as part of purpose-built subacute units or services and as stand-alone services.

There are 264 designated palliative care beds in Victoria – 60 beds in rural regions and 204 beds in metropolitan regions. In 2009–10, 83,000 specialist palliative care bed days were provided in these beds. (Department of Health 2010[c]).

Palliative care beds can be used in a variety of ways in caring for people with a life-threatening illness who have complex needs. They can be used in coordination with community palliative care services to stabilise a client's symptoms and enable them to return home for ongoing care. Palliative care beds can also be accessed when families can no longer care for the client at home, particularly during the last days of life. In these instances, people are cared for in a palliative care bed until they die.

Other clinical specialties in acute hospitals may choose to admit a person to a designated palliative care bed when it has been identified that a patient is dying and requires the care of a specialist palliative care team.

A number of private hospitals and other services in Victoria provide specialist palliative care. Palliative care consortia and other palliative care services will promote and support the provision of appropriate and coordinated care with private hospitals and other private services for people with a life-threatening illness.

Consultancy services

Palliative care consultancy services are funded in all metropolitan health services and in all rural regions.

Consultancy services provide advice and support to treating teams in hospitals and in the community. Consultancy services also provide direct clinical care, assessment and advice for clients and carers with complex needs. This means the treating team can maintain care of the person with a life-threatening illness and address their pain, symptoms and psychological, social and spiritual concerns. Consultancy services work across acute and subacute services and have an increasing presence in outpatient clinics. Consultancy services assist in coordinating discharge planning with community palliative care services where patients wish to be cared for and/or die at home and transition to other specialist inpatient, subacute or residential locations.

Consultancy services provide specialist advice and support to services in the community, including community palliative care services and residential facilities, enabling them to meet very complex needs for clients that otherwise would necessitate admission to hospital.

Consultancy services also provide education and training about palliative care to other clinicians and provide palliative care input to cancer tumour streams and chronic disease management meetings.

Assisting clients and their families

A woman in her 40s, married with children, with advanced, metastatic cancer was in her local hospital under care of her GP. The palliative care consultancy team was asked by the GP and community palliative care service to assess the client for control of severe nausea and vomiting.

During the initial assessment, the palliative care team made changes to her medication, including introducing a syringe driver. A family meeting was convened by the palliative care consultancy team to discuss the terminal nature of the client's disease and to establish the goals of care.

The team supported her husband to tell their children of the terminal nature of her condition. A plan was developed based on the client's and family's wishes to discharge her home to die once her symptoms were controlled.

Symptom control was established and the client was discharged four days later. She died peacefully at home with her family five days after discharge, with good symptom control, supported by her GP and the local community palliative care service.

Outpatient clinics

Palliative care outpatient clinics provide interdisciplinary assessment, care planning and interventions early in the care pathway of a person diagnosed with a life-threatening illness, in conjunction with the client's GP. These services provide direct care and establish prospective care plans with other services, including community palliative care and inpatient services. Other outpatient clinics in areas such as pain or chronic disease management may also provide care to people with a life-threatening illness.

Day hospices

Day hospices provide psychological, social and spiritual support for people with a life-threatening illness and respite for their carer. There are four Victorian government-funded day hospices: three in metropolitan Melbourne (Sunshine, Caulfield and Kew) and one in Bendigo.

Attendance at a day hospice enables nursing, medical, allied health and pastoral care consultations to be provided and access to a range of programs including music therapy and fatigue management.

On average, 160 people per month attend one of Victoria's day hospices (Department of Health 2009[d]).

Peak body

Palliative Care Victoria (PCV) is the peak body for palliative care services in Victoria. Its activities include raising community awareness and capacity building, advocacy, strategic collaborative partnerships and projects, and member services. PCV is a member of Palliative Care Australia.

Statewide palliative care services

A range of statewide services are funded by the Victorian Government's palliative care program to provide specialist advice in relation to particular diagnoses or population groups.

- **Victorian Paediatric Palliative Care Consultancy Program (VPPCP)**

  An alliance between The Royal Children's Hospital, Monash Medical Centre and Very Special Kids, the VPPCP provides specialist paediatric palliative care advice to health professionals caring for children and young people with a life-threatening condition and their families, enabling them to receive optimal care in the setting of their choice. VPPCP is the lead agency in implementing the *Strengthening care for children with a life-threatening condition 2008–2015* policy. In 2009–10, the VPPCP cared for 150 children and young people and their families.

- **Very Special Kids (VSK)**

  VSK provides services to families who have a child with a life-threatening condition and to families whose child has died. VSK provides a range of services to more than 800 families across Victoria including needs-based counselling and emotional support, a sibling support program, trained volunteers, peer support, a bereavement support program, and planned and emergency respite and end-of-life care through Very Special Kids House (Victoria's only children's hospice).
- **HIV/AIDS Consultancy Service**

  The HIV/AIDS Consultancy Service is a multidisciplinary team based at Alfred Health comprising an infectious diseases physician, a clinical nurse consultant and a clinical nurse specialist in HIV. The consultancy ensures that all people living with and affected by HIV/AIDS in Victoria have access to optimal palliative care and support.
- **Motor Neurone Disease Association (MNDA) Victoria**

  MNDA provides family support including needs assessment and referral for approximately 300 clients each year, as well as support for generalist providers who are caring for people living with motor neurone disease. The association also provides equipment and a range of community and professional education activities.
- **Statewide Specialist Bereavement Service (SSBS)**

  Operated by the Australian Centre for Grief and Bereavement, the SSBS provides specialist bereavement counselling, builds the capacity of generalist health and community services, and facilitates leadership, quality and health promotion for the bereavement sector. In 2009–10, the service provided specialist counselling to 460 people, and over 500 people attended one of the support groups run by the service.

Linking people into bereavement support

A specialist bereavement counsellor received a referral from a man in his 30s whose father had died after suffering a stroke. The father had received inpatient palliative care from the time of his stroke until his death.

The counsellor met with the man who reported feeling depressed, unable to function at work and socially withdrawn. The counsellor listened to the man's story in detail, validated his distress and discussed how he may be affected by grief.

After several counselling sessions, the man ceased specialist bereavement support as he felt capable of moving forward equipped with the support and information provided by the counsellor about grieving, telephone help lines and local agencies who could provide support in the long term should his needs change.

Victorian Aboriginal palliative care – the beginning of our journey

Creating a culturally safe palliative care service system

The Victorian Aboriginal Palliative Care Program is a partnership between the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), PCV and the Department of Health. Its vision is to create a sustainable and culturally safe palliative care service system where Aboriginal people from all over Victoria can access palliative care services in the setting of their preference.

The aims of the program are to develop Aboriginal peoples' awareness of and access to palliative care services and enable palliative care services to provide culturally appropriate palliative care.

As a result of this program, Aboriginal palliative care regional forums have been held, and partnerships have been established between Aboriginal communities and palliative care services. Partnerships demonstrate a commitment to working together and are an important part of doing business in a culturally appropriate way.

Culturally appropriate clinical placements, workshops and resources (for example, Aboriginal art, music, storytelling, message stick and radio interviews) to upskill Aboriginal health workers in the palliative approach have been created, and a number of palliative care services have received cultural awareness education through the program.

The relationships between Aboriginal communities and palliative care services that have been created through this program will continue to grow. Aboriginal palliative care remains an important priority across Victoria.

The artwork on the following page has been developed as part of the program to represent Victorian Aboriginal palliative care. The artist is Kahli Luttrell, who is a Yorta Yorta descendent. Her description of the artwork is below:

As you twirl a piece of ribbon, you don't know which way it will go, and this of course applies to the paths and journeys we take in our lives, and how these paths can change as we go along in our life.

The road travelled together is easier than the road travelled alone and that's why the people in the art symbolise the support of our family, friends, community and services.

The circles also symbolise that many people have travelled in and out of our lives and these people are taking the same path into our Journey of the Dreaming, and the auras in the background are our ancestors and family members guiding us to the dreaming.


The Begining of our Journey
Kahli Luttrell

Academic centres

Palliative care research in Victoria is predominantly conducted through the following institutions, each of which undertakes research and education to help improve the quality of care for people with a life-threatening illness.

Many other services also conduct palliative care research. Palliative care academic centres in Victoria are members of the Victorian Palliative Care Research Network and are currently supported by the Victorian Cancer Agency to collaborate on research to benefit palliative care services, clients and carers.

Table 1: Academic centres

Academic centre	Auspiced by	Research focus
Centre for Palliative Care	A collaborative centre of The University of Melbourne and auspiced by St Vincent's Health	• family-centred palliative care • psychosocial care • symptom management • service delivery
Chair in Palliative Medicine	Monash University and Southern Health	• palliative care policy • service delivery • symptom management
Palliative Care Unit Research in Supportive Care (RISC) program	La Trobe University	• public health • pastoral care • sociological studies • supportive care
Vivian Bullwinkel Chair in Palliative Care Nursing	Financially supported by Monash University to continue Vivian Bullwinkel's vision that palliative care research improves quality of life for the sick and dying Clinical partners with Peninsula Hospice Service, Royal District Nursing Service and Peninsula Health	• service evaluation • palliative care policy • cultural issues • education
Department of Pain and Palliative Care Department of Nursing and Supportive Care	Peter MacCallum Cancer Centre	• supportive care • pain management

Why do we need to continue to strengthen palliative care? Challenges for the future

The WHO estimates that 56 million people die in the world each year. Approximately 60 per cent of those could have benefited from palliative care (Davies & Higginson 2004).

Developed countries have acknowledged the increasing demand for palliative care, and governments have responded by building integrated palliative care service systems and developing clear strategies and policy directions to guide future developments.

In the 1980s, the Victorian Government committed to funding and supporting a statewide palliative care service system. Since that time, the palliative care sector has expanded and become increasingly professional and integrated with other mainstream health, community and aged care providers.

Palliative care as a specialty vocation is a relatively new field. It was only in 1999 that the Royal Australasian College of Physicians (RACP) recognised palliative medicine as a specialty in its own right, establishing clear training and credentialing requirements for physicians entering this area (RACP 2010). A continued focus is required to ensure palliative care services continue to meet the needs of Victorians with a life-threatening illness into the future.

In Victoria, demand for palliative care is growing at 4.6 per cent per annum (Department of Health 2010). Government, health services and the palliative care sector are working in partnership to meet this demand. A number of challenges must be addressed in order to ensure that palliative care services remain responsive to the changing needs of our growing and ageing population.

Specifically, our challenges are:

- Victoria's population is growing and ageing
- the way we live in old age, and the way we die, has changed
- meeting people's wishes to die at home
- addressing unmet need.

Establishing end-of-life care pathways

The Pathway for Improving the Care of the Dying (PICD) was developed by the Supportive and Palliative Care Unit at Southern Health and is an adaptation of the Liverpool Care Pathway (authorisation in process). It aims to import the principles of palliative care into generalist health and aged care. The Gippsland Region Palliative Care Consortium and Southern Health are working together to introduce the PICD in health services across Gippsland (Jackson et al, 2009).

Some of the factors contributing to the success of the PICD rollout are the lectures and train-the-trainer workshops provided by senior Southern Health palliative care clinicians, the establishment of senior medical and nursing champions in Gippsland and resourcing for a part-time project officer in Gippsland.

To date, more than 400 patients at Southern Health and 250 patients in Gippsland have had their care managed through the PICD. PICD has been rolled out to the general medical, stroke and oncology units with other units planned to follow shortly. Medical and nursing staff say that using the PICD is straightforward and empowering, and helps them to meet patients' needs at the end-of-life.

For example, a junior doctor who had not cared for a dying person before was unsure of what medications and what doses to order. By using the PICD medication algorithms, the doctor was able to order appropriate medications and ensure the client's pain and symptoms were well managed.

Challenge 1: Victoria's population is growing and ageing

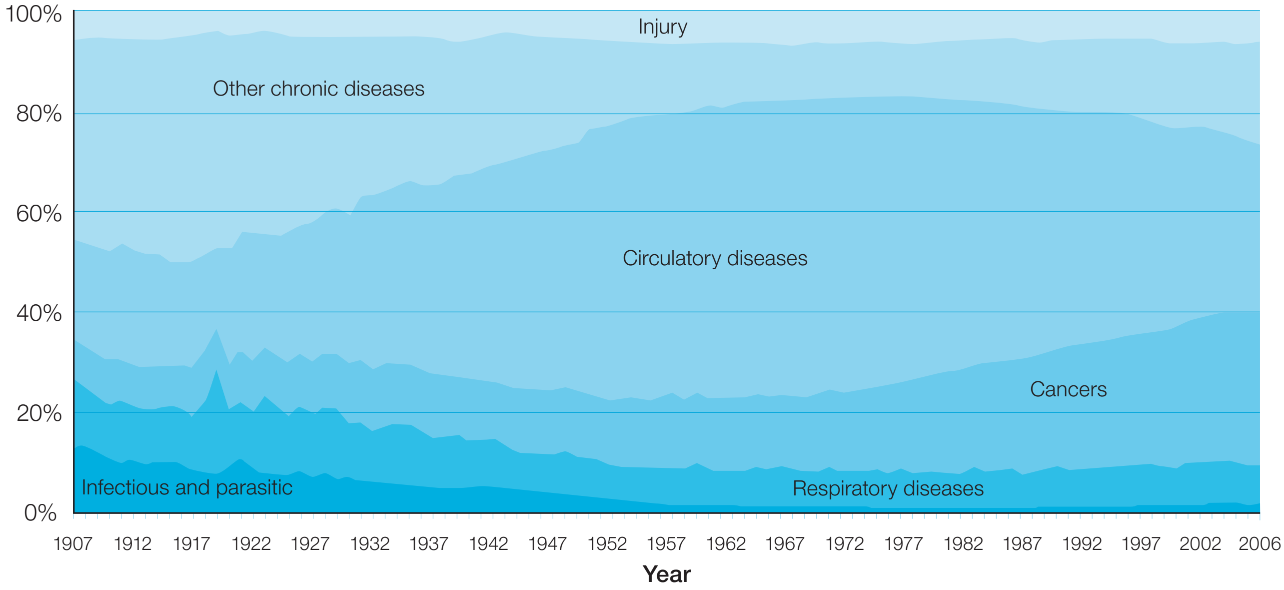
The population of Victoria is now over five and a half million. Between 2011 and 2022 it is predicted to increase to 6.45 million. The proportion of the population aged 60 years and over will be higher than has been experienced in the past 40 years, and the proportion of the population aged 70–84 will increase by 127 per cent. In particular, the proportion of the population aged 85 years or over is projected to increase by 236 per cent (Department of Planning and Community Development, 2009).

People aged over 70 are admitted to hospital more often, stay longer in hospital and use more healthcare bed days than younger age groups. It is likely that this group will have more complex needs and require more specialised care from a wider variety of specialists, including palliative care. The average age of referral to palliative care is 74 years (Department of Health 2011; Department of Health 2010[a]).

Challenge 2: The way we live in old age, and the way we die, has changed

The major causes of death for Victorians, like people in other developed countries, have changed. There is a clear trend in the increasing prevalence of chronic diseases, including cancer, as the main causes of death (AIHW 2010).

Figure 4: Changes in causes of death in Australia between 1907 and 2006



Source: Australian Institute of Health and Welfare (AIHW) 2010

Table 2 lists the current causes of mortality that result in the most years of life lost (YLLs) in Victoria.

Table 2: Top 10 causes of mortality burden by sex, Victoria, 2001

	Males	**Females**
1	Ischaemic heart disease	Ischaemic heart disease
2	Lung cancer	Stroke
3	Suicide	Breast cancer
4	Stroke	Lung cancer
5	Bowel cancer	Bowel cancer
6	Road traffic accidents	Chronic obstructive pulmonary disease
7	Chronic obstructive pulmonary disease	Diabetes
8	Prostate cancer	Alzheimer's and other dementias
9	Diabetes	Ovarian cancer
10	Pancreatic cancer	Suicide

Source: Department of Human Services 2005

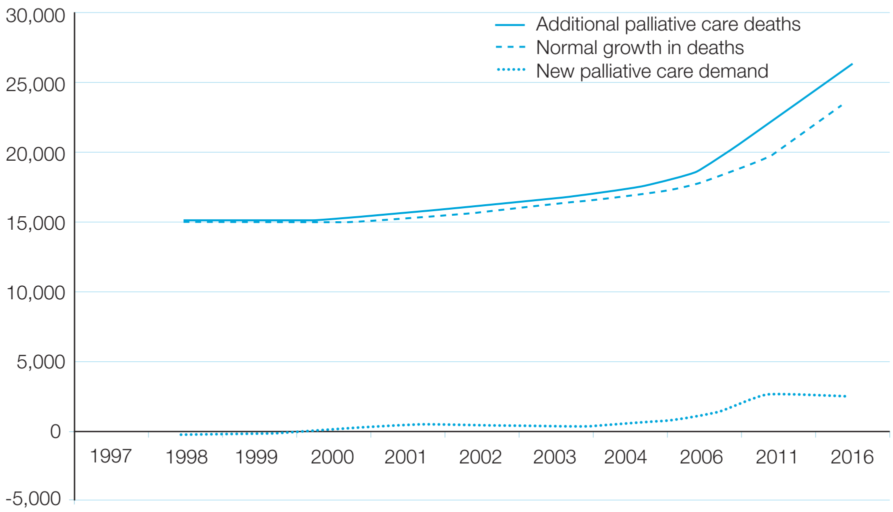
The Australian Bureau of Statistics (ABS) reports that 35,497 people died in Victoria in 2008 (ABS 2008). Of these people, 50 per cent had a chronic illness that would have benefited from palliative care. These illnesses include:

- cancer (all tumour streams)
- chronic respiratory disease
- neurological conditions, such as motor neurone disease, dementia, Huntington's disease and Parkinson's disease
- stroke
- organ failure, such as renal failure and heart disease.

Demand for palliative care is affected by two key trends. First, the incidence of cancer and other non-malignant chronic illnesses is increasing due to the ageing population, and will continue to grow into the foreseeable future (Department of Human Services 2003). Second, the number of people with a chronic illness (cancer and non-cancer) who would benefit from a referral to palliative care is growing at a faster rate than the total population.

Figure 5 shows projected new demand for palliative care services in the future over and above the growth in demand anticipated due to an ageing population (Department of Human Services 2006).

Figure 5: Projected new demand for palliative care



Source: Department of Human Services 2006

Of all the deaths in Victoria caused by chronic illness, approximately half are cancer related. The remaining 50 per cent are made up of the range of non-malignant illnesses listed in Table 2. By contrast, cancer makes up 85 per cent of all referrals to palliative care, and non-malignant conditions account for only 15 per cent of all palliative care referrals (Department of Health 2010[a]). It is anticipated that the prevalence of cancer and the prevalence of other chronic conditions will increase at about the same rate. Responding to this demand will present a substantial challenge to palliative care services (Department of Human Services 2006).

In addition to managing their chronic illnesses, many people have other conditions, such as dementia, that require more complex care. Nationally, the prevalence of dementia is projected to increase approximately fourfold from 2010 to 2050 (Access Economics 2010).

Challenge 3: Meeting people's wishes to be cared for and die at home

International research has found that up to 90 per cent of people with a life-threatening illness would prefer to die at home, or in a home-like environment. The research also found that, despite this preference, only 26.5 per cent of people died at home, while 56 per cent died in hospital (Higginson 2000). This figure is consistent with the proportion of Victorians who die in hospital.

A growing body of literature shows that involvement of palliative care can facilitate meeting people's wishes to be cared for and die at home or in a more home-like setting (Hatziandreu et al. 2008). This experience is borne out in Victoria, where a 2009 review of end-of-life care for palliative care clients found that 27 per cent of people who were receiving care from a community palliative care service died at home and 35 per cent died in a designated palliative care bed. A further 13 per cent of people registered with a community palliative care service died in a residential aged care facility (RACF). Only 25 per cent of people registered with a community palliative care service died in an acute hospital bed (Department of Health 2009[c]). Significant work is still required to enable palliative care services to better meet people's wishes to die at home.

This review also found that clients registered with community palliative care were five times more likely to be admitted directly to a designated palliative care bed than clients who were not receiving community palliative care. This reduces the number of presentations to the emergency department and reduces pressure on acute beds (Department of Health 2009^{c}).

As well, like most parts of the health system, primary health care is a mixture of public and private funding, with a mix of local government, public and private sector providers. Palliative care needs to achieve coordination of care between differently funded settings to enable care of individuals to be seamless, clinically appropriate and cost-efficient (Department of Health, 2011^{b}).

Helping to meet people's wishes to die at home makes economic sense. The 2009 Victorian review found it is about five times less expensive to care for a person with a life-threatening illness at home than it is to care for them in hospital. This is also confirmed by overseas studies that show palliative care can reduce costs by reducing hospital admissions and use of acute beds, length of stay and pharmacy costs. A Spanish study showed that appropriate community palliative care services improved health-system efficiency without compromising client care (Gómez-Batiste et al. 2006).

Understanding clients' wishes about where they wish to be cared for and where they wish to die is not straightforward. People's wishes are likely to change over time and people may have different preferences about where they wish to be cared for and where they wish to die (Gerrard et al 2010). Discerning these wishes requires clear and sensitive communication. It also necessitates regularly confirming clients' and carers' wishes to check whether they have changed.

Meeting people's wishes to die at home is important because it enables them to spend time with their family and friends and to maintain their own routines and preferences in a safe and familiar environment. While caring for someone with a life-threatening illness at home can be exhausting and stressful for family members, many people also say that helping their loved one to achieve their wish to die at home is very satisfying and can strengthen their relationship and sense of self (Hudson 2004).

Nevertheless, enabling people to be cared for at home and to die at home can be very challenging. The burden on family members can be immense, and supports and services must be in place to relieve this burden where necessary and to ensure that the needs of the client are met. Graphs 6a and 6b demonstrate the link between client phase of care and the level of stress reported by carers and families in both inpatient and community settings.

Figure 6a: Problem severity – inpatient setting

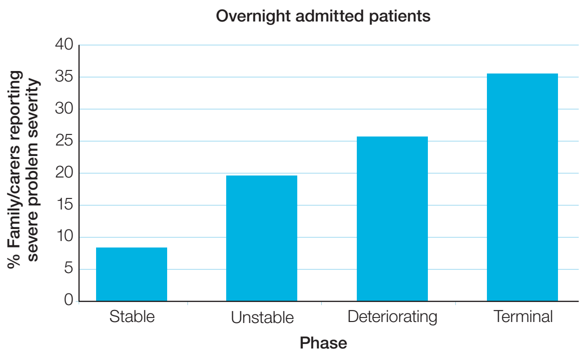
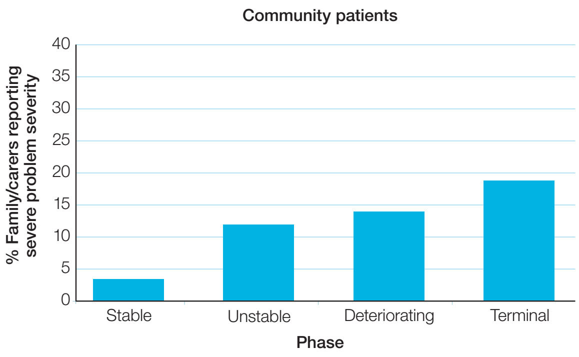


Figure 6b: Problem severity – community setting



Source: University of Wollongong 2009, *Palliative Care Outcomes Collaborative*, Victorian Reports July–December 2008

Challenge 4: Addressing unmet need

As part of providing equitable access to palliative care, the end-of-life care needs of all Victorians must be met, regardless of the diagnosis or the characteristics of particular population groups.

Significant progress has been made in improving access to palliative care, however, some groups are still underrepresented in palliative care service data, and projects such as the Aboriginal Palliative Care Program aim to improve access to palliative care services for underrepresented groups. People with non-malignant illnesses and conditions represent only 15 per cent of all referrals to palliative care. While this percentage has slowly increased over the last few years, approximately 7,500 people with chronic illness continue to miss out on palliative care each year (Department of Health 2010[a]).

Other groups, such as people from culturally and linguistically diverse (CALD) backgrounds, are also underrepresented in palliative care. Of the more than five million people living in Victoria, 14.8 per cent do not speak English well or do not speak it at all (Department of Health Information Centre 2010). However, only 6.93 per cent of the 435,475 contacts provided by community palliative care were provided to people who speak a language other than English.

There is evidence to suggest that a range of groups have unmet palliative care needs, including:

- people who live in an aged care facility or other institution (WHO 2004)
- people who have a non-malignant illness
- Aboriginal people (Sullivan et al. 2003)
- people who live in remote or rural areas (Girgis et al. 2006)
- people from CALD and other diverse backgrounds (Girgis et al. 2006; Smolinsky & Colon 2006)
- people from a low socioeconomic background, including people who are homeless or at risk of homelessness (Kushel & Miaskowski 2006)
- people who have a physical or intellectual disability and a life-threatening illness (Read & Thompson-Hill 2009).

Children and young people receiving palliative care require a different service response, often delivered by a range of services not required by adults receiving palliative care. In recognition of the particular needs of children and young people with a life-limiting condition and their families, the policy *Strengthening care for children with a life-threatening condition 2008–2015* has been developed. This policy is available from <www.health.vic.gov.au/palliativecare>.

Increasing access to bereavement services

The Victorian Statewide Specialist Bereavement Service (SSBS) is operated by the Australian Centre for Grief and Bereavement. The SSBS provides specialist consultancy, education and training to generalist services and specialist bereavement support for people assessed as experiencing complicated grief. Counselling is provided across Victoria and a range of support groups have been established.

The SSBS also provides two toll-free telephone services during business hours.
In 2009–10, 3,120 calls were received from the general public and health practitioners.

Meeting the challenges

In order to continue to meet the needs of Victorians with a life-threatening illness, future initiatives and actions must address the key challenges facing palliative care and the health service system more broadly. How we design and deliver high-quality palliative care services to meet these challenges will play an important role in providing access to responsive palliative care and building a service system to implement the strategic directions and actions. We will meet these challenges by:

- ensuring all Victorians, regardless of age, ethnicity and socioeconomic status, have equitable access to specialist palliative care
- providing integrated care to meet people's needs
- clarifying palliative care's role across illness trajectories and at the end-of-life
- developing and planning for flexible models of care for the future
- raising community awareness about death and dying.

Ensuring all Victorians have equitable access to specialist palliative care

All Victorians are entitled to receive high-quality palliative care, regardless of whether they live in inner-city Melbourne or the outer suburbs, in a major regional centre or a rural area. Variations in service delivery models and levels of funding across the state have made it difficult to achieve this equity of access.

In 2005, the Palliative Care Resource Allocation Model (PCRAM) was introduced as a more equitable way of allocating new funding to community palliative care services. The PCRAM allocates funding based on the needs of the population within defined geographical catchment areas. The PCRAM takes into account population growth, ageing, rurality and low socioeconomic status, and provides funding to support services to manage the impact these population characteristics have on service demand.

Further work has been undertaken to ensure equity of access to specialist palliative care for all Victorians through the development of a service delivery framework that articulates how services should be distributed across metropolitan and regional Victoria, and identifies clear service expectations.

The aim of the service delivery framework is to:

- provide a clear framework for assessing service capability
- reduce unexplained variation in services across the state
- articulate the roles and responsibilities of each service level to support client treatment and care, linkages, education and research in and across regions
- establish statewide structures that support best practice.

The service delivery framework forms an important part of the implementation of this policy over 2011–2015 to ensure consistent access to palliative care and clearly establish service delivery expectations. The service delivery framework will be supported by the phased implementation of a funding model that supports the equitable allocation of funds based on population needs and service activity. The service capability framework is in Appendix 1.

The implementation of activity-based funding (ABF) in hospital-auspiced palliative care will commence across the Australian health system from 1 July 2013. ABF will enable funding models to better reflect the costs and resources involved in delivering palliative care and to place resources where they will deliver the best outcome for clients.

Providing integrated care to meet people's needs

It is neither desirable nor feasible for specialist palliative care services to provide all end-of-life care. A high level of integration and coordination is required to ensure that people with a life-threatening illness receive care that is consistent across different settings and that can respond to rapid changes in client need. The need for this integration and coordination is demonstrated by research that shows extensive use of inpatient services and emergency department presentations in the last year of life (Rosenwax et al, 2011).

Effectively integrated care is more valuable than the sum of its parts. For example, it has been demonstrated that clients of community palliative care services who require an inpatient admission for pain and symptom management or end-of-life care are five times more likely to be admitted directly to an inpatient palliative care bed than those people with a life-threatening illness not registered with a community palliative care service (Department of Human Services 2009[c]). Models of care that support integration, such as region-wide services, service models that enable joint appointments, and models that ensure linkages between public and private services, are important components of meeting people's needs across service settings.

Most community palliative care services work with home nursing services to provide some of their clients' nursing care at home. Strong service coordination and communication between domiciliary and palliative care nurses is an important part of maintaining continuity of care for clients and their families. Formal shared care arrangements between palliative care services and other health services, as well as both public and private services, play an important part in ensuring service coordination for people with a life-threatening illness.

Developing relationships that benefit patients

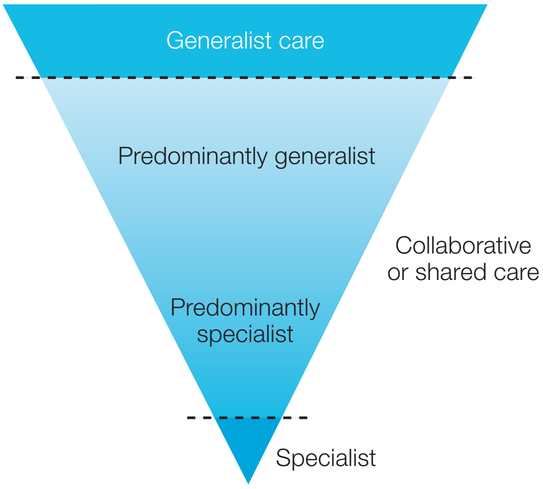
A woman living in rural Victoria in her early 70s with cancer of the stomach was being cared for at home by her family. She had expressed her wish to die at home and her family wanted to respect this. However, she became unconscious and developed symptoms that were difficult to manage and very distressing to her family.

Her nurse contacted a palliative medicine specialist in Melbourne, with whom the rural team had a long-standing service partnership. The specialist recommended an intervention that was only feasible because the specialist had previously consulted with the client and had a strong relationship with the nursing staff.

The client's symptoms were alleviated and the situation made more manageable for the family. She died peacefully and comfortably at home. Being able to fulfil their mother's wish to die at home was extremely helpful in the family's bereavement.

For these reasons, it is critical that specialist palliative care services coordinate care with a range of health, community and aged care providers. The figure below demonstrates the continuum of care from specialist to generalist services.

Figure 7: Generalist-specialist services continuum of care

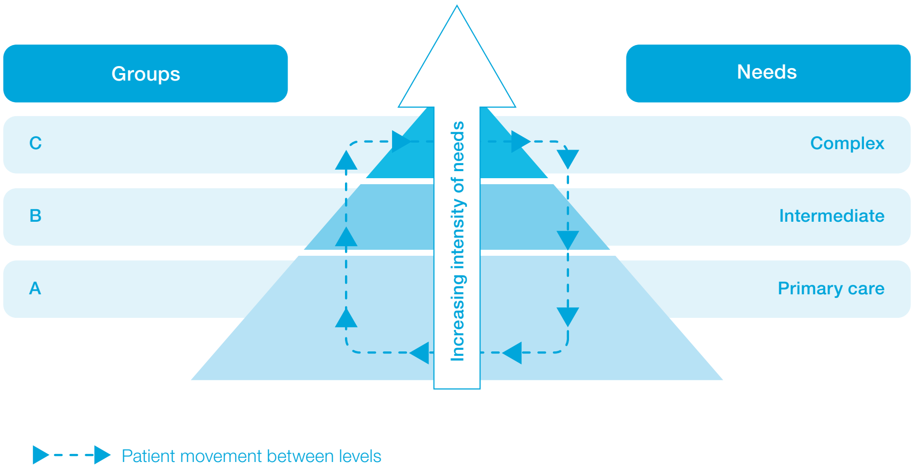


Source: Aspex Consulting 2010

There is often no clear point of transition between curative and palliative care, and clients may move between the different levels of care depending on the progression of their illness and associated needs.

The model developed by Palliative Care Australia describes how specialist palliative care services work with generalist services to provide care. The Palliative Care Australia model demonstrates how clients access various levels of care according to their needs and is represented diagrammatically in Figure 8, below.

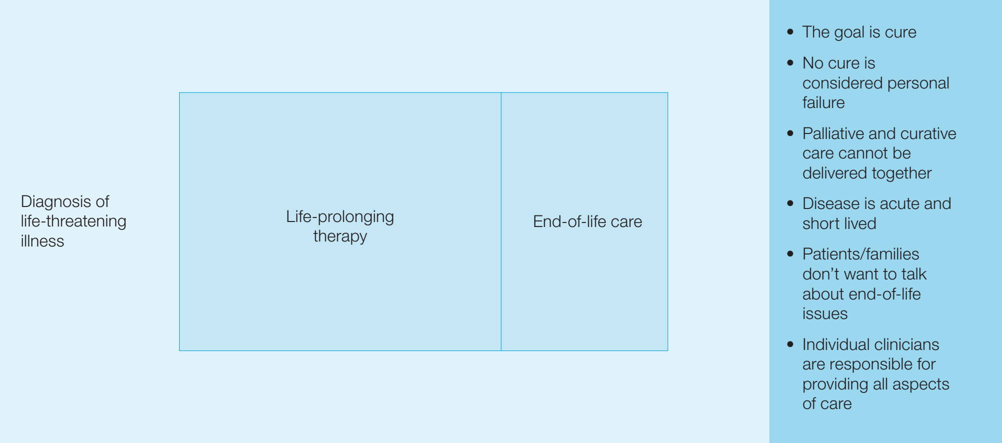
Figure 8: Changing needs of clients



Source: PCA 2005

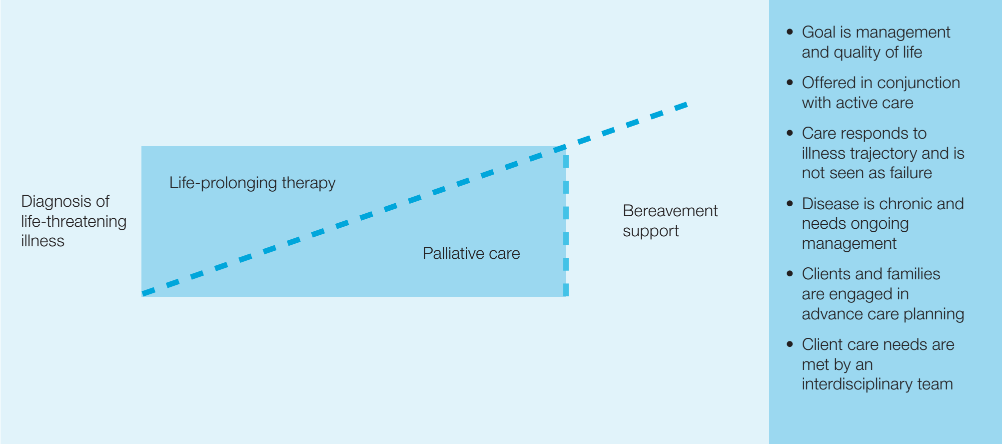
Changing the way providers view the place of palliative care in the treatment pathway can also influence the range of services offered and the goals of treatment. Traditionally, healthcare has focused on treatment aimed at eliminating disease. As disease patterns have changed, the goals of treatment must also change. This shift is depicted in Figures 9 and 10.

Figure 9: Traditional view of care and treatment



- The goal is cure
- No cure is considered personal failure
- Palliative and curative care cannot be delivered together
- Disease is acute and short lived
- Patients/families don't want to talk about end-of-life issues
- Individual clinicians are responsible for providing all aspects of care

Figure 10: Integrated palliative care



- Goal is management and quality of life
- Offered in conjunction with active care
- Care responds to illness trajectory and is not seen as failure
- Disease is chronic and needs ongoing management
- Clients and families are engaged in advance care planning
- Client care needs are met by an interdisciplinary team

Source: adapted from the *National Consensus Project for Quality Palliative Care* 2009

Clarifying palliative care's role across illness trajectories and at the end-of-life

The role of palliative care varies in different settings and different illness trajectories. In the future, it is likely that the role of palliative care will be more clearly defined by the diagnosis pathway to which it is applied.

In recent years, the importance of effectively meeting the needs of people with non-malignant illness has been strongly promoted and taken up by specialist services, generalist providers and clinical specialties. This focus continues to have implications for how palliative care is delivered, particularly in terms of care settings, workforce composition and skills, and developing care plans and pathways that take into account the nature of the illness. This change presents challenges and opportunities for how palliative care is promoted, the sectors that palliative care links with and the way in which palliative care is described and delivered.

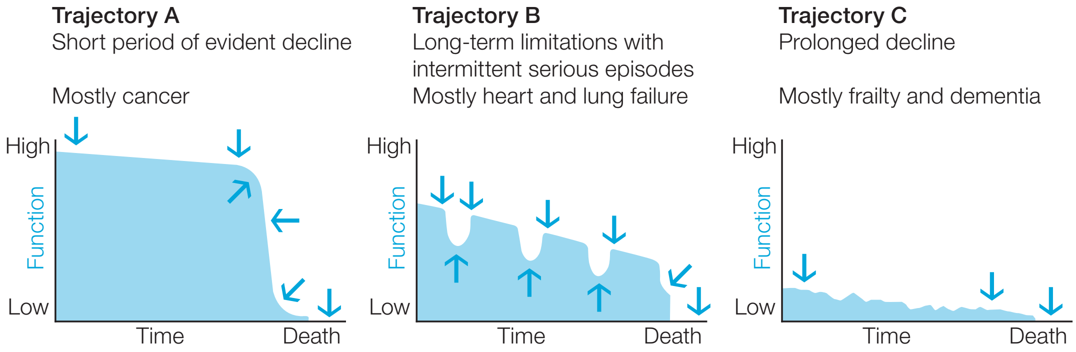
Palliative care services have initiated a number of projects aimed at improving the way palliative care is provided to people with a non-malignant, life-threatening illness. These projects include:

- implementation of the Motor Neurone Disease Palliative Care Pathways Project involving shared care workers in each region and community, and inpatient palliative care flexible top-up funding
- a Commonwealth Government-funded project that aims to establish a partnership model between palliative care and stroke services in order to ensure clients and their carers receive timely and appropriate palliative care
- establishment of a Renal Conservative Care Program to be incorporated into the existing chronic kidney disease pathway.

People with a life-threatening illness are likely to experience one of three end-of-life trajectories: care delivered over a short period of decline (such as cancer); long-term limitations with intermittent serious episodes of decline (such as heart and lung failure) and prolonged decline (such as frailty and dementia). These trajectories are illustrated in Figure 11. The arrows in this figure indicate triggers for palliative care involvement and therefore the types of palliative care response required for different end-of-life trajectories.

The strategic directions and actions outlined in this policy aim to better understand the role of palliative care across these trajectories and build appropriate service responses.

Figure 11: Palliative care trajectories



Trajectory A
Short period of evident decline

Mostly cancer

Trajectory B
Long-term limitations with intermittent serious episodes
Mostly heart and lung failure

Trajectory C
Prolonged decline

Mostly frailty and dementia

Source: Lynn & Adamson 2003

Providing specialist palliative care consultancy

The Eastern Health palliative care consultancy service aims to ensure that hospital patients with life-threatening illness are provided with optimal pain and symptom management, introduced to the palliative approach in a timely manner and linked with appropriate services on discharge.

The consultancy service assesses palliative care needs and assists teams, patients and families to define the goals of care. This results in prompt transfer to palliative care services, discharge back to residential care or home and a shorter acute length of stay.

Referrals to the Eastern Health palliative care consultancy service are steadily increasing. The team saw 1800 people in 2010. The increasing referral rate reflects the capacity-building work the consultancy service has done across the hospital. The consultancy service frequently receives referrals from cardiology, respiratory, neurology, renal and aged care units.

Developing and planning for flexible models of care for the future

The palliative care system is designed to deliver a service mix that provides options for how care is delivered to best meet the needs of the person with the life-threatening illness. Developing and planning for models of care that are proven to address the needs of different population groups is key to ensuring a flexible palliative care service system. In planning care for people with a life-threatening illness and their carers and families, the following principles should be taken into account:

- equitable access to a minimum level of palliative care across the state
- effective and efficient links between hospitals and community services
- clearly defined referral pathways
- appropriately trained specialist palliative care and generalist workforce
- appropriate mix of service models (including bed-based and community palliative care) to meet client needs.

Raising community awareness about death and dying

Paradoxically, demand for palliative care is increasing because modern medicine and healthcare has been successful in keeping more people alive, with illness, for longer. Sachs et al. (1995) observe that:

> *… the major success of modern medicine is creation of chronic illness. We rarely cure, but rescue from acute death to live a long time with progressive degenerative disease*.

Traditionally, the vast majority of people with a life-threatening illness died at home. Over time, death has become increasingly medicalised and institutionalised, and now only approximately 20 per cent of Australians with a life-threatening illness die at home. In contrast, 90 per cent of Australians spend most of their last year at home (Barbato 2003; Higginson & Sen-Gupta 2000; Hudson 2010; Kellehear 2001; Kissane 2000; McNamara et al. 1995), requiring care and support from family, friends, community members and local services.

The challenge for palliative care services is working within a culture and society that is increasingly removed from, and uncomfortable with, talking about death and dying. This makes it harder for palliative care services to communicate accurately with the broader community (including other health, community and aged care providers) about what palliative care can offer people with a life-threatening illness, and reduces people's willingness to refer to (or be referred to) palliative care. When there is cultural or linguistic incongruence between clinician and client, this increases the chance of referral to palliative care not occurring in a timely way.

Specialist palliative care services have an important role in supporting discussions in the community about death and dying to help create a culture that is more accepting of the need for palliative care services and more able to support people with a life-threatening illness and their families and carers.

Feedback from clients and carers clearly demonstrates that once people are receiving palliative care and have had clear and respectful conversations about their end-of-life wishes, they often regret that they were not referred to palliative care earlier. Similarly, clinicians who have undertaken Program of Experience in the Palliative Approach (PEPA) placements report that their views were challenged during the placement, which helped them to realise the value of referral to palliative care and the importance of initiating discussions about the end-of-life with their clients. PEPA is an initiative of the Australian Government funded through the National Palliative Care Program that provides a broad range of healthcare professionals with the opportunity to increase their experience, knowledge and skills in the delivery of the palliative approach.

Extending health professionals' experience of palliative care

In May 2009, an Aboriginal health worker attended a Program of Experience in the Palliative Approach (PEPA) workshop where she was introduced to the 'palliative approach to care'. A few months later she completed a clinical placement at her local community palliative care service and at an inpatient palliative care unit where she gained knowledge about specialist palliative care.

The Aboriginal Health Worker reported that the placement was a 'very positive experience' that increased her confidence in implementing the care required for people who have a life-threatening illness. She continues to use her palliative care knowledge in her work with community members.

People in rural areas receive specialist medical advice

Using the rural medical purchasing fund, the Loddon Mallee Regional Palliative Care Consortium funds a palliative medicine specialist from the Peter MacCallum Cancer Centre to provide palliative care services to the Mildura Specialist Palliative Care Clinic.

The palliative medicine specialist leads a palliative care outpatient clinic and provides teleconference support for a specialist palliative care nurse-led clinic, as well as undertaking education and liaising with GPs.

GP engagement with the palliative care clinic has been high. More than 50 per cent of Mildura GPs have referred patients to the clinic since it began. It has also been reported that access to new medications for Mildura patients has improved since the clinic was established.

End-of-life care pathways strengthen care in hospital

A 77-year-old woman was admitted to a stroke care unit following a middle cerebral artery stroke. She previously lived at home with her elderly partner and required assistance with some aspects of daily living. The day after her admission, the woman was referred to the Palliative Care Consultancy Service for assessment and was commenced on an end-of-life care pathway that afternoon. Several days later, she was transferred to the palliative care unit for terminal care.

During her admission, the multidisciplinary team met with the woman's husband to develop her care plan. Staff on the stroke care unit reported that developing an end-of-life care pathway prompted them to think of things they may not have thought of immediately, including spiritual aspects of care. It assisted with efficiency of care by setting out goals of care and helped staff to think about things they may not have when caring for a palliative stroke patient. Staff also reported that the end-of-life care pathway assisted with communicating with the family and carers.

Starting conversations about death, grief and living

Four funerals in one day is a play based on real people's stories and highlights many of the issues faced by dying people and the people who care for them. The play was written by renowned Australian actor and playwright Alan Hopgood in collaboration with Molly Carlile (former manager of the North and West Metropolitan Region Palliative Care Consortium). It has been performed many times throughout rural and metropolitan Victoria and continues to tour widely around the rest of Australia.

The play tells the story of Clarrie, who is dying and has had enough of being a burden on his family, and the nurses who are caring for him.

The play is followed by a conversation with the audience about death and grief, the concept of advance care planning and the need to build community capacity to support people with a life-threatening illness and their families. Questions are fielded by Alan and Molly in conjunction with a panel of local palliative care specialists. The audience is invited to continue the conversation over tea and scones.

Evaluations received after each performance have been overwhelmingly positive, with comments such as:

> 'A great way to broach a very difficult subject.'
>
> 'I wish I had had this night several years ago before my mother died.'
>
> 'I'm going home to talk to my Gran about her story'

Strategic directions

The strategic directions outlined in this policy will guide the work of palliative care services and consortia for the next four years.

These strategic directions have been informed by:

- extensive consultation with the palliative care sector and other sectors likely to require the support of palliative care services in caring for clients
- expert advice and practice wisdom from an advisory group made up of leaders from palliative care and other related areas
- reviewing the evidence to ensure the actions in this policy are supported by research and best practice
- learning from the feedback and outcomes of the SPCP 2004–09 evaluation, including client and carer feedback on their experiences.

These strategic directions respond to the challenges in meeting growing and changing demand for palliative care. The strategic directions for 2011–2015 are:

Strategic direction 1: Informing and involving clients and carers

Priorities

Provide information about palliative care that is tailored to the needs of clients and carers.

Actively involve clients and carers in the planning and delivery of their care.

Advance care plans inform client care.

Being actively involved leads to better outcomes

The evidence is clear that involving clients and their carers in agreeing and implementing their care (care planning) is instrumental in achieving the client's wishes about how they are cared for and where they die, as well as avoiding unwanted hospitalisation (Pooler et al. 2003). Effective care planning, particularly when multiple teams are involved in client care, maximises health outcomes and leads to better respect for the needs of the client and their family (Altilio et al. 2008; Woodhouse 2009). The relevance of care planning is not restricted by diagnosis – evidence demonstrates the value of care planning across a range of conditions including cancer, chronic heart failure, cardiopulmonary disease and in aged care facilities (Harding et al. 2008; Phillips, Davidson & Willcock 2009; Seamark, Seamark & Halpin 2007; Walling et al. 2008).

The value of seeking client and carer satisfaction data and acting on the findings

Assessing client and carer satisfaction has been shown to lead to improved compliance with medical regimes and maintenance of the relationship between the client, carer and service. It also provides useful evaluative and quality improvement data about whether a program is meeting its aims or a service is providing appropriate care (Brazil 2009).

Factors shown to influence client and carer satisfaction with palliative care include communication and access to information, perceived staff competence and accessibility, effective pain management, and case management (Grande et al. 2004; Lecouturier et al. 1999; Riegel et al. 2002; Ringdal, Jordhoy & Kaasa 2002).

Right information at the right time supports clients and their carers

Providing the right information – in the right format and at the right time – is an important part of meeting the needs of palliative care clients and their carers. Carers seek out information about the client's illness, prognosis, symptoms, treatment and care. Research in this area consistently identifies the importance of good-quality information as a central coping resource for carers of people with a life-threatening illness (Andershed 2006; Docherty et al. 2008; Kirk, Kirk & Kristjanson 2004).

In their study of what information people with a life-threatening illness and their carers want, Kirk, Kirk and Kristjanson (2004) found that information was most effective when targeted to individual needs and the stage of illness. Importantly, they found that the information provided needs to be honest and detailed because it helps clients to make realistic decisions about continuing to receive treatment (The et al. 2001; Weeks et al. 1998).

Anecdotally, clinicians sometimes say they are concerned that their clients will ‘lose hope’ if fully informed about their prognosis; however, several studies show that awareness of prognosis is in fact associated with greater satisfaction with care and lower levels of depression. The studies also found that people can maintain a sense of hope even once they know their prognosis is poor (Chochinov, Tataryn & Wilson 2000; Clayton et al. 2005; Schofield et al. 2003).

It is important that clinicians respond to clients’ individual needs about how much information they receive and in what form. These needs are influenced by a number of factors including personal choice and experience, as well as cultural and linguistic factors. Clients may also have a range of expectations of the role their family will play in receiving and disclosing information (Goldstein, Thewes & Botow 2002; Huang et al. 1999).

Advance care planning leads to better client outcomes

Advance care planning is the process of planning for future health and personal care whereby the person’s values, beliefs and preferences are made known so they can guide decision making at a future time when that person cannot make or communicate his or her decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-threatening illness has been diagnosed so they require the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting. (Australian Health Minister’s Advisory Council, 2011).

Advance care planning has been demonstrated to assist people to receive care in the place of their choice and minimise the chance of them receiving unnecessary treatment. Clients, carers and health professionals have indicated that undertaking a process of advance care planning improves quality of care, increases respect for client autonomy and minimises distress, anxiety and depression for families by avoiding the need for them to make urgent decisions at a time of crisis (Detering et al. 2010; Gutheil, Heyman & Stickland 2003; Meller et al. 2008; Tilden et al. 2004).

An evaluation of the implementation of the Respecting Patient Choices® program at Austin Health in 2003 found that 95 per cent of clients who had an advance care plan had their expression of treatment choices respected and their end-of-life wishes followed (Lee et al. 2003).

Advance care planning is different to an advance care directive, which is a legal document that is ‘intended to ensure a person’s preferences can be honoured during any period of temporary or permanent impaired decision-making capacity, and not only at the end of life’ (Australian Health Minister’s Advisory Council, 2011). A national framework for advance care directives has been developed. Advance care planning and advance care directives play an important role in ensuring that people’s wishes at end-of-life are discussed and documented.

Strategic direction 1: Informing and involving clients and carers

Priorities	Actions	Impacts
Provide information about palliative care that is tailored to the needs of clients and carers	1.1 Develop and implement an approach that provides accurate, consistent, timely and appropriate information about palliative care across Victoria and recognises that clients and carers may have different needs.	Clients and carers receive consistent information about palliative care that is timely and accurate and appropriate to their needs. Clients and carers receive information in a range of forms including web-based technologies. Information provided to clients and carers promotes health literacy and supports them to continue to ask questions about their care.
Actively involve clients and carers in the planning and delivery of their care	1.2 Ask clients and carers how they would like to be involved in the planning and delivery of their care. Work with clients, carers and other clinicians, particularly the client's GP, to develop an interdisciplinary care plan that reflects clients' and carers' wishes.	All clients have an up-to-date interdisciplinary care plan that reflects their wishes for how they would like to be involved in the planning and delivery of their care. Where appropriate, a copy of the completed care plan is provided to the client (and carer) and to other care providers, including the client's GP.
	1.3 Seek the views of clients and carers about their experience and satisfaction with palliative care services on an annual basis. 1.4 Take action to address issues identified.	Results of the survey are reported and action is taken to address issues identified.
Ensure that advance care plans inform client care	1.5 Palliative care services provide care in accordance with clients' advance care plans or wishes. 1.6 Palliative care services provide information and support for clients and carers to help them develop an advance care plan if they do not already have one.	All clients of palliative care services have an advance care plan. There is consistency between clients' advance care plans and the interdisciplinary palliative care plan.

Strategic direction 2: Caring for carers

Priorities

Strengthen practical and psychological, social and spiritual support for carers of people with a life-threatening illness, acknowledging that their needs may change over time.

Strengthen support for families of children and young people with a life-threatening condition.

Increase the availability of after-hours support to clients and carers in their homes, particularly in rural areas.

Provide consistent support and training to carers that recognises they can have different needs and interests compared to clients.

Ensure bereavement assessment and support is available to carers across Victoria.

Provide support to carers from groups that are less likely to have access to palliative care, including Aboriginal and CALD groups.

Why is it important to provide support to carers?

The Australian Bureau of Statistics estimates there are close to 2.6 million carers, and nearly 500,000 primary carers in Australia (ABS 2003), providing close to 1.2 billion hours of care annually (Access Economics 2005). It has been identified that carers experience stress associated with:

- uncertainty of their family member's illness trajectory
- questions about how best to care for their family member and ensure they have the services they need
- changes in paid employment
- a perceived lack of support from family and friends (Andershed 2006; Aouan et al. 2005; Edwards et al. 2009, Schulz & Beach 1999).

These stresses put carers at increased risk of experiencing a range of psychosocial problems, including fatigue, sleeping problems, depression, anxiety and burnout (Barg et al. 1998; Schulz & Martire 2004; Stajduhar & Davies 1998; Thomas, Morris & Harman 2002). With the ageing population, family and carers of people with a life-threatening illness may themselves be elderly or have conditions that make it difficult for them to care for someone with a life-threatening illness. Carers may find it difficult to prioritise their own needs over those of their family member, which can further exacerbate these physical, psychological and social problems.

Children and young people who are caring for a parent with a life-threatening condition have particular needs. In CALD families, they may be called on to assist with communication and translation. The potential effects on children and young people of caring for and losing a parent also need to be considered (Dearden & Becker, 2000).

In addition to these factors, carers of people with a life-threatening illness often experience significant financial costs. These costs can relate to reducing or giving up paid work. It is estimated that one-fifth of all family members of seriously ill people have to stop paid work to care for them. Carers often also bear increased out-of-pocket costs for medications, equipment, home modifications, respite and travel (Chen et al. 2010; Guerriere et al. 2010; Auon et al. 2005).

Family and informal carers provide the backbone of care to people who choose to spend most of their time at home during the terminal phase of their illness. Regardless of place of death, it is estimated that up to 90 per cent of people in the terminal phase of a life-threatening illness spend the majority of their time at home (Skilbeck et al. 2005). Having a live-in carer significantly improves the chances of a person with a life-threatening illness being able to die at home (Grande, Addington-Hall & Todd 1998; Higginson & Sen-Gupta 2000; Hudson & Payne 2009).

Carers tend to record higher satisfaction with palliative care when their family member dies at home (Brazil 2009).

Supporting carers can improve client and carer outcomes

Consultation with carers about their needs found that a range of services (such as information, education and support to care for their family member, access to self-help groups and after-hours support) all assist in helping them to care for a person with a life-threatening illness at home (Brazil et al. 2005; EAPC 2009; Remedios et al. 2008; Zapart et al. 2007). The following strategies have been shown to have positive impacts for carers and the people they are caring for.

Access to appropriate respite

Providing respite enables carers to have a break, and has been demonstrated to help carers undertake their role for longer periods (Stajduhar & Cohen 2009). Research has identified that a range of respite options need to be provided to meet the needs of carers, including planned and unplanned respite, in-home and out-of-home respite, day hospices, volunteer visiting programs and overnight nursing (Ingelton et al. 2003).

Access to after-hours support

Providing telephone information and support or a nurse visit if required after hours has been associated with easing client and carer anxiety, improving family support overall and enhancing clients' ability to stay in their own homes (Gomes & Higginson 2006; Wellman 2007).

The most likely reasons for carers and clients seeking advice from a palliative care service after hours relate to queries about medication, nursing advice, pain relief and anxiety (Aranda et al. 2001). It is estimated that specialised telephone triage on its own can solve between 30 and 97 per cent of after-hours requests for advice and support (Aranda et al. 2001; Elfrink et al. 2002).

Developing strategies to deal with issues that may arise after hours can help to avoid crises and unnecessary transfers to hospital outside of business hours (Ingelton et al. 2009). Carers have consistently indicated that knowing after-hours support is available from their specialist palliative care service increases their satisfaction with the service, even if they never have cause to access this support (Department of Human Services 2007).

Support and training for carers

Specialist palliative care services in the community play an important role in education and support for carers to enable them to carry out the day-to-day care for their family member, with backup and advice available from the service when required.

Andershed (2006) and Docherty et al. (2008) found that carers were empowered to undertake this often complex role through having adequate information and knowledge, particularly practical task-based education focused on the specific needs of the client, which is provided in a language they can understand. Carers' perceptions about how well they were supported to care for their family member have been demonstrated to improve their overall satisfaction with palliative care services (Department of Human Services 2007).

Appropriate bereavement support

Supporting families and carers in bereavement is a key component of providing best practice palliative care (Agnew et al. 2010; Kristjanson et al. 2006). Studies in grief and bereavement have confirmed the importance of providing a consistent approach to assessing bereavement needs for carers and families at risk of complicated grief, including the introduction of standardised practices for supporting and referring these people to appropriate services.

Complicated grief is defined as grief that involves the presentation of certain grief-related symptoms at a time beyond which is considered adaptive. These symptoms include separation distress, such as longing and searching for the deceased, loneliness, preoccupation with thoughts of the deceased; and symptoms of traumatic distress, such as feelings of disbelief, mistrust, anger, shock, detachment from others, and experiencing somatic symptoms of the deceased (Kristjanson et al. 2006). Complicated grief is associated with reduced quality of life, and there is rigorous evidence to demonstrate links between untreated complicated grief and an increased risk of physical health problems, hospitalisation and mortality from a range of causes, including suicide (Stroebe et al. 2008; Remedios et al. 2009; The Joanna Briggs Institute 2006).

Strategic direction 2: Caring for carers

Priorities	Actions	Impacts
Strengthen practical and psychological, social and spiritual support for carers of people with a life-threatening illness, acknowledging that their needs may change over time	2.1 Assist carers with the costs of caring, for example, respite, equipment, medication and home modifications needed to support them and help keep someone with a life-threatening illness at home.	Carers receive the support they need in a timely way and their out-of-pocket costs are minimised.
	2.2 The needs of carers are assessed using a consistent approach. Carers who are assessed as requiring practical and psychosocial support receive appropriate services.	Carers receive support that meets their needs.
	2.3 Ensure access to a range of respite options to meet the needs of clients and their carers by: • mapping available respite services • strengthening links between palliative care services and respite services • providing specialist consultation and advice to respite services about how to meet the needs of clients with a life-threatening illness • developing consistent statewide eligibility criteria for palliative care clients accessing respite.	Range of respite services is established. Respite services have increased knowledge about caring for people with a life-threatening illness. Clear and consistent eligibility criteria are developed and adopted by palliative care and respite providers.
Strengthen support for families of children and young people with a life-threatening condition	2.4 Ensure access to a range of respite options to meet the needs of children and young people receiving specialist palliative care and their families by: • providing access to a range of paediatric respite options (out of home and in home) • developing a centralised point of information on paediatric respite services, referral, equipment, case management and care planning • providing respite providers with information, education and clinical support to meet the needs and requirements of families with children with a life-threatening condition.	Children and young people have: • timely access to aids and equipment • an up-to-date care plan • timely access to respite that meets their needs. Respite services have increased knowledge about caring for children and young people with a life-threatening condition.
Increase the availability of after-hours support to clients and carers in their homes, particularly in rural areas	2.5 Implement after-hours models of care across Victoria.	More after-hours support, including telephone support and home visits where appropriate, is available to all clients and their carers.
Provide consistent support and training to carers	2.6 Palliative care services use an agreed approach to training carers.	Carers have increased knowledge about how to carry out the day-to-day care of their family member.
	2.7 All volunteers receive structured education and training in providing support and in-home respite to carers.	Volunteers have increased knowledge about how to support carers.

Ensure bereavement assessment and support is available to carers across Victoria	2.8 All carers are assessed for bereavement risk using a consistent approach. 2.9 Carers who are assessed as requiring bereavement support receive appropriate services.	Carers receive bereavement assessment, referral and support that is appropriate to their needs.
Provide support to carers from groups that are less likely to have access to palliative care, including Aboriginal and CALD groups	2.10 Models are developed that are based on research and evidence and address the needs of carers from groups less likely to have access to palliative care.	Carers from groups that are less likely to have access to palliative care receive support that is appropriate to their needs.

Strategic direction 3: Working together to ensure people die in their place of choice

Priorities

Raise the awareness of health, community and aged care providers about palliative care to ensure that people are cared for and die in their place of choice.

Assist aged care services to care for people at the end-of-life.

Strong links between palliative care and other healthcare services lead to better outcomes for clients

Most people receiving palliative care in Victoria are aged over 65. The needs of older people are complex, because they often have multiple medical problems that can lead to greater impairment and psychological impact, which means older people are more likely to need care that requires partnership and collaboration between different groups and across multiple settings (WHO 2004). Timely and coordinated communication and planning between services who care for people aged over 65 including aged care services, general practitioners, HACC services and palliative care services is required to ensure the needs of older people with a life-threatening illness and their families are met. This is particularly important for people who are socially isolated or are socioeconomically disadvantaged.

A number of health, community and aged care initiatives are increasingly focused on building clients' capacity and delivering services in a way that promotes clients' independence and autonomy, as well as participation in goal setting and decisions about their care. The HACC Active Service Model is an example of this way of working. These principles of care are consistent with the holistic approach that is part of providing palliative care and will be of benefit in forging stronger links between services that lead to better outcomes for clients (Department of Human Services 2008[d]).

Preference for place of death often varies according to carer burden, age, education and previous experience of health services, and can change significantly throughout the person's illness (Higginson & Sen-Gupta 2000, Gerrard et al 2011). Many people state a preference to die at home and acknowledge that this may not always be feasible if their needs become too complex to be managed at home. Services should aim to support people to be cared for in their place of choice for as long as possible.

A particular focus on end-of-life care for people in residential aged care facilities improves outcomes

On present projections, the number of Victorians aged over 80 (the primary users of residential aged care services) will increase by more than 37 per cent from 188,012 in 2006 to 257,806 in 2016 (Department of Health Information Centre 2010). At June 2008, 790 residential aged care services across Victoria provided care to 44,770 Victorians (Department of Human Services 2009[a]). Older people who die in residential aged care facilities are more likely to experience a prolonged period of disability before death than older people who die at home (WHO 2004). Studies have raised concerns about the number of people living in aged care facilities whose pain is not well managed due to lack of accurate assessment and treatment.

It has been demonstrated that when palliative care and end-of-life care models and approaches are implemented in aged care facilities, they can give staff greater confidence in communicating with residents and their families and in providing pain and symptom management. This leads to significant improvements in care for residents at the end-of-life. Specific improvements include an increased proportion of residents who die in aged care facilities with an advance care plan, as well as significant reductions in crisis admissions to hospital (Badger et al. 2009; Waldron et al. 2008).

In particular, the introduction and maintenance of end-of-life care pathways has been demonstrated to lead to better teamwork and to empower staff to initiate conversations with clients' families about end-of-life care (Duffy & Woodland 2006; Ellershaw et al. 2001). Clearer care goals and better communication with staff, clients and families have also been shown to lead to a reduction in crisis admissions to hospitals and a reduction in the proportion of client deaths that occur in hospital (Badger et al. 2009; Duffy & Woodland 2006).

Strategic direction 3: Working together to ensure people die in their place of choice

Priorities	Actions	Impacts
Raise the awareness of health, community and aged care providers about palliative care to ensure that people are cared for and die in their place of choice	3.1 Palliative care services provide consultation and support to health, community and aged care providers that are caring for clients with palliative care needs.	Public and private health, community and aged care providers have increased knowledge about how to care for people with a life-threatening illness and how to support someone with a life-threatening illness at home.
	3.2 The palliative care sector develops consistent and clear information for health, community and aged care providers about when and how to refer clients to palliative care. Information for GPs will be developed as a priority.	Clients receive timely and appropriate referral to palliative care. Information and referral processes promoted by the palliative care sector are consistent with referral and coordination strategies across health, community, and aged care providers.
	3.3 Clearly communicate palliative care clients' eligibility for HACC services.	Palliative care clients receive timely access to HACC services.
	3.4 Improve palliative care capacity in disability accommodation services.	People living in disability accommodation services who have a life-threatening illness are supported to be cared for and die in their place of choice.
Assist aged care services to care for people at the end-of-life	3.5 Undertake a statewide project to establish protocols and strengthen relationships between palliative care and aged care services, including residential, community and aged care assessment services.	Development of state and regional palliative/aged care action plans. Development of joint resources to support the provision of end-of-life care in aged care services.
	3.6 Establish an aged care palliative care link nurse in each region.	Implementation of end-of-life care pathways in residential aged care facilities. More aged care facility residents are supported to die in their place of choice.

Strategic direction 4: Providing specialist palliative care when and where it is needed

Priorities

Ensure people who need access to specialist palliative care are receiving care appropriate to their needs at the right time, in the place of their choice.

Provide sustainable and equitable specialist bereavement support.

Access to specialist palliative care consultancy services enables people with a life-threatening illness to remain in their place of choice for longer and improves their quality of life

Early referral to palliative care has been demonstrated to significantly improve clients' quality of life and mood and to improve their survival time (Temel et al. 2010). Specifically, international studies have demonstrated that palliative care consultancy services can identify previously undiagnosed problems, significantly improve management of clients' physical and psychological symptoms, reduce admissions to intensive care units, lower the costs of care and improve documentation of clients' goals (Casarett et al. 2008). Specialist palliative care consultancy services are also associated with more family-centred outcomes, particularly in relation to attending to family members' emotional and spiritual needs and giving them greater confidence in their own ability (Gelfman, Meier & Morrison 2008; Steinhauser, Christakis & Clipp 2001).

This is especially important when providing specialist advice and consultation for children with a life-threatening condition, due to the unpredictable illness trajectories experienced by this group. These trajectories are often characterised by a series of health crises, rather than a steady decline, which can make it more difficult to accurately assess prognosis (Steele 2000).

Unpredictable trajectories are also associated with non-malignant conditions in adults and as more people with non-malignant conditions receive palliative care, it is likely that people will increasingly be discharged from specialist palliative care services when their condition stabilises and readmitted when they require specialist palliative care input (Rosenwax et al. 2011).

Providing specialist bereavement support for carers and families leads to better health and psychological and social outcomes

There is extensive evidence to demonstrate that people who experience complicated grief are more likely to experience poor health, psychological and social outcomes (Center for the Advancement of Health 2003; Stroebe et al. 1999; Stroebe et al. 2007; The Nucleus Group 2004). For people who have been assessed as experiencing complicated grief, specialist interventions have been demonstrated to be of value (Jacobs & Prigerson 2000; Zisook & Schucter 2001).

Strategic direction 4: Providing specialist palliative care when and where it is needed

Priorities	Actions	Impacts
Ensure people who need access to specialist palliative care are receiving care appropriate to their needs at the right time, in the place of their choice	4.1 Support community and consultancy palliative care services to increase activity to meet growing demand.	Improved equity of access to community, inpatient and consultancy palliative care services for all Victorians.
	4.2 Implement the palliative care *Service delivery framework* (SDF) across Victoria, with advice from the PCCN. As part of this implementation: • services will undertake self-assessment against the service capabilities detailed in the framework • the service delivery framework will be used by palliative care consortia in regional service planning.	Clients have access to an appropriate level of specialist palliative care in their region. There is clear information about the palliative care services that are available across regions and the capabilities of these services.
	4.3 Work in partnership with Aboriginal health workers and their employing agencies to promote access to culturally appropriate palliative care services.	More Aboriginal people have access to culturally appropriate palliative care.
	4.4 Work with palliative care services and multicultural organisations to develop approaches that improve access for people from a CALD background. Monitor access to palliative care by CALD groups.	More people from a CALD background access culturally appropriate palliative care services.
Provide a sustainable and equitable specialist bereavement support service for people experiencing complicated grief	4.5 Implement a consistent approach to bereavement risk assessment, referral and support by palliative care and specialist bereavement services across Victoria.	People assessed as experiencing complicated grief have access to specialist counselling from qualified counsellors.
	4.6 Enhance the capacity of the statewide specialist bereavement service to provide training, consultancy and advice to palliative care and other services that provide support for people experiencing complicated grief.	
	4.7 Enhance the capacity of the statewide specialist bereavement service to provide additional specialist bereavement counselling in metropolitan and rural areas.	

Strategic direction 5: Coordinating care across settings

Priorities

Strengthen the role of the palliative care consortia in leading service coordination and policy implementation in each region.

Integrate practices across health service and community settings to ensure access to coordinated and consistent care at the end-of-life.

Use technology to enhance service coordination for all palliative care services.

Effective service coordination leads to better outcomes for clients and carers and more efficient use of service resources

Effective service coordination is important for palliative care clients and their carers whose time-critical and rapidly changing needs are best met by multiple services working together. Brockbank (2002, p. 164) describes a responsive and effective palliative care system as one in which 'care responds to changing needs and care settings, clinicians work across organisational and professional boundaries, and care packages are organised so that clients can receive services as and when they need them'.

Work undertaken with health services in Victoria has demonstrated that working in partnership leads to shorter intake and assessment times, better waiting list management, reduced administrative duplication and clearer staff understanding of their roles. Improvement in electronic communication between agencies has also supported better coordinated services, resulting in improved outcomes for consumers (Department of Human Services 2008[a]; 2009[a]).

End-of-life care pathways facilitate meeting client and carer needs

There is increasing evidence that using an integrated care pathway to manage care at the end-of-life is a good way to implement and monitor best practice, and to standardise care in a variety of settings. Using pathways to manage the care of dying people has gained considerable support from the clinical teams who have used them and there is evidence that pathways improve the quality of care in the last days and hours of life (Department of Health 2009[a]).

End-of-life care pathways are a key way of facilitating integrated and consistent care for people with end-of-life care needs. There is a substantial body of evidence to demonstrate that effective use of end-of-life care pathways leads to better documentation of care goals, improved symptom assessment and management, and decreased unnecessary intervention at the end-of-life (Ellershaw et al. 2001; Luhrs et al. 2005).

International research has demonstrated a reduction in total symptom burden for palliative care clients following implementation of an end-of-life care pathway, particularly in relation to pain control (Luhrs et al. 2005). It has also been demonstrated that when aged care facilities introduce end-of-life care pathways, there is a reduction in crisis hospital admissions for their residents, and the residents' wishes to die at home are more likely to be achieved (Badger et al. 2009).

In order to meet the needs of the significant proportion of people who have an expected death outside of a specialist palliative care service, a recent pilot study recommended that end-of-life care pathways be established across all health services and services like aged care facilities (WA Department of Health 2009).

Strategic direction 5: Coordinating care across settings

Priorities	Actions	Impacts
Integrate practices across hospital and community settings to ensure access to coordinated and consistent care at the end-of-life	5.1 Promote the integration of end-of-life care pathways across hospitals and community settings, prioritising people with non-malignant illnesses who may not otherwise have access to specialist palliative care when required.	Health, community and aged care providers seek palliative care services' input into end-of-life care planning.
Strengthen the role of the palliative care consortia in coordinating palliative care service provision and leading policy implementation in each region	5.2 Develop stronger links between palliative care consortia, the PCCN and all other relevant stakeholders.	Broadened number and type of partnerships between palliative care consortia and other health, community, aged care and other providers and structures per region, including Primary Care Partnerships and Medicare Locals.
	5.3 Strengthen consortia governance and accountability processes and document them consistently.	Palliative care consortia have documented governance and accountability processes in place that are understood by consortia members. See Appendix 2: Palliative Care Consortia reporting proforma
Use technology to enhance service coordination for all palliative care services	5.4 Encourage consistent and equitable IT solutions that facilitate coordination and consultation across all palliative care services.	IT solutions are in place to support quality initiatives and connectivity.

Strategic direction 6: Providing quality care supported by evidence

Priorities

Develop consistent clinical care protocols that are informed by research and evidence.

Support and build future palliative care research capability across academic and clinical services and its translation into practice.

Ensure all Victorian palliative care services provide care that is assessed against national standards and supported by a quality improvement culture.

Continue to build and support the palliative care workforce to meet increasing demand for palliative care services.

Ensure sustainability of the specialist paediatric palliative care workforce.

Evidence

Applying consistent clinical care standards leads to better physical, psychological, social and spiritual outcomes for clients

There is evidence that implementing clinical guidelines, protocols and tools facilitates improvements in client care, for example, timely referrals to palliative care, reduced admissions to the emergency department, decreased length of stay in hospital and an increase in the proportion of deaths at home or in a non-acute care facility (Dudgeon et al. 2009; Gould et al. 2007; Hanson et al. 2010; Waller et al. 2008). A recent review of literature related to clinical service improvement in palliative care found that a focus on routine assessment of symptoms and active engagement in discussions to prepare for the end-of-life facilitates improved client and caregiver outcomes (Department of Health 2010[b]).

Factors that are likely to lead to good outcomes from clinical service improvement initiatives include strong upper-level administrative and clinical leadership from palliative care organisations, dedicated project coordination, continuity and buy-in from services (Dudgeon et al. 2009).

Pain represents one of the major issues reported by people with a life-threatening illness and their carers. The management of pain remains inconsistent throughout the developed world and there is significant evidence to demonstrate that the introduction of standard pain assessment and measurement tools can improve people's experience of pain (Department of Human Services 2008[c]).

Translation of research into clinical practice leads to better outcomes for clients and carers

Reporting, analysing and acting on clinical outcome data has been demonstrated to lead to significant improvements in client outcomes, including advance care planning, pain management, family support and care coordination. The experience of health services in New York involved in annual reporting of cardiac surgery outcomes since 1989 is that enduring improvements in client care can be achieved by integrating outcomes reporting into routine processes, publishing the results in scientific journals and involving leading clinicians in overseeing the improvements (Chassin 2002; Gould et al. 2007).

Internationally and in Australia, concern is being expressed that the growth of palliative care programs is not matched by growth in the evidence base for palliative care. In particular, there is concern that little is known about the structures or processes of care that result in quality outcomes, and how best to measure these outcomes (Kutner 2008).

Key areas that have been identified as requiring more research include the types of practical support, education and information and services that may improve the wellbeing of carers (Harding & Higginson 2003), caring for people with a non-malignant condition, and the needs of carer groups such as male caregivers, children and young people, new immigrants and people from CALD backgrounds (Payne & Hudson 2008). In order to effect improvements in client care, palliative care services also need to be able to translate research findings into clinical practice (Abernethy et al. 2007).

A workforce skilled at caring for people at the end-of-life leads to better outcomes for clients and carers

Discussing prognosis and end-of-life issues is an important part of meeting the needs of people with a life-threatening illness and their families (Steinhauser et al. 2000; Wenrich et al. 2001). However, many healthcare professionals find it difficult to discuss these topics, citing lack of training, stress, insufficient time and a fear of upsetting the client and their family (Baile 2002; Christiakis & Iwashyna 1998; Chochinov et al. 1995; Clayton et al. 2005; Morita et al. 2004; Mueller 2002; VandeKieft 2001). The palliative care workforce requires ongoing education and support to enable them to undertake this role effectively. Clinical practice guidelines can assist clinicians to be prepared for these discussions with evidence-based information and suggestions about how to deliver the information in a sensitive way (Clayton et al. 2007).

Initiatives to encourage palliative care clinicians to stay in the workforce also lead to better outcomes for clients and carers. A study of a nurse-led community case management program for clients with heart failure found that expert multidisciplinary care and the long-term therapeutic relationship between the community nurse and the client and carer led to fewer emergency admissions, fewer unplanned hospitalisations, reduced costs of care and high client satisfaction and quality of life (Anderson 2007).

Strategic direction 6: Providing quality care supported by evidence

Priorities	Actions	Impacts
Develop consistent clinical care protocols that are informed by research and evidence	6.1 Implement a program of work for the PCCN including: 6.1.1 providing clinical advice to the department on the implementation of the SPCP 2011–2015 and the SDF 6.1.2 reviewing quality indicators and identifying quality improvement opportunities as part of monitoring quality data collection 6.1.3 endorsing and adopting evidence-based clinical guidelines and protocols 6.1.4 implementing evidence-based clinical tools at a service level 6.1.5 identifying service delivery research priorities.	Established statewide program of work for the uptake of evidence into clinical practice. Palliative care service delivery is more consistent and evidence based.
Support and build future palliative care research capability across academic and clinical services and its translation into practice	6.2 Enable clinicians to participate in research as part of their clinical work. 6.3 Develop strategies to ensure current evidence is published and communicated and is translated into practice and action. 6.4 Undertake research that includes a focus on how to improve access to palliative care services for Aboriginal and CALD communities.	Increased research capacity in clinical and academic settings. Palliative care research is published and communicated through means such as CareSearch. Research and evidence is translated into clinical practice and builds community awareness and capacity. Development of evidence that demonstrates how to improve access to palliative care services for Aboriginal and CALD communities.
Ensure all Victorian palliative care services provide quality care that is assessed against national standards and supported by a quality improvement culture	6.5 Palliative care services will maintain accreditation and participate in national palliative care outcomes and standards assessment processes.	All palliative care services are accredited with a recognised provider. Palliative care data contributes to monitoring and measuring quality care. All palliative care services are encouraged to participate in the National Standards Assessment Process (NSAP) and the Palliative Care Outcomes Collaborative (PCOC). All palliative care services participate in the Victorian Palliative Care Satisfaction Survey.

	6.6 Provide ongoing support to palliative care consortia and their member services to develop region-wide clinical service improvement programs that link with the work of the PCCN.	Rigorous and ongoing clinical service improvement is undertaken by palliative care consortia and their member services.
Continue to build and support the palliative care workforce to meet increasing demand for palliative care services	6.7 Work with the Commonwealth Government, Health Workforce Australia and the Workforce Unit in the Department of Health to develop innovative strategies to educate, train and recruit more specialist palliative care clinicians (medical, nursing and allied health) and to build the capacity of the general health, community, aged care and disability workforce.	The palliative care workforce grows sufficiently to meet demand. The capacity of the health, community, aged care and disability services workforce to care for people with a life-threatening illness is enhanced.
	6.8 Work with the Nurse Policy Unit in the Department of Health to support the palliative care nurse practitioner program.	Nurse practitioners are available across Victoria to meet the complex needs of people with a life-threatening illness and to provide leadership for other palliative care clinicians. Career pathways for nurses in palliative care are strengthened.
	6.9 Evaluate, maintain and expand the palliative care scholarship program.	The palliative care workforce is appropriately skilled to meet the needs of clients, and high levels of staff retention are maintained.
	6.10 Build on existing resources to strengthen the capacity of palliative care services to recruit, train and support volunteers.	There is a more sustainable foundation for the ongoing contribution of volunteers in palliative care. Volunteers receive consistent recruitment, training and support.
	6.11 Encourage workplace-based rotations through chronic disease specialties (for example, renal, cardiac and neurological specialties) and settings. Agree and implement joint appointments between services and settings.	Palliative care clinicians extend their clinical skills and knowledge in relation to palliative care and associated chronic diseases.
Ensure sustainability of the specialist paediatric palliative care workforce	6.12 Establish a paediatric palliative care training-in-place program across medicine and other disciplines, including: • increasing the number of junior medical officer rotations to three per year • training an additional paediatric palliative care medical specialist.	Paediatric palliative care specialist consultancy and advice is consistently available.

Strategic direction 7: Ensuring support from communities

Priorities

Strengthen Victorians' awareness, capacity and resilience in relation to dying, death, loss and bereavement, and their ability to support people with a life-threatening illness and their carers.

Strengthening peoples' awareness of death, dying and loss enables better referral to palliative care when it is needed

People with a life-threatening illness spend the majority of their time with friends, family, colleagues and acquaintances, not healthcare professionals. These networks play a key role in helping the family and carers cope during the caring phase and in bereavement (WHO 2007). Determinants of health, such as personal resilience, autonomy and social connectedness are just as relevant when people approach the end-of-life (Rumbold & Salau 2009).

A range of individual, communal and societal benefits can result from strengthening the community's awareness and understanding of death, dying, loss and palliative care. Benefits include greater willingness to explore issues of death and dying, and an increased capacity in the community to initiate or take part in conversations that relate to death and dying. This in turn raises the possibility of people in the community being able to support each other in a variety of ways and consider timely access to palliative care services (Gardner, Rumbold & Salau 2009; Kellehear 2005; Nutbeam 2009).

Building the capacity of the community enables them to better support people with a life-threatening illness and their families

In order for communities to better support people with a life-threatening illness, specific strategies to build the capacity of the community need to be implemented. Community capacity-building strategies have been demonstrated to lead to positive outcomes; for example, Australian and international research has demonstrated that involving communities in the planning and provision of services improves clinical palliative care (Gardner, Rumbold & Salau 2009; Department of Health UK 2009) and a stronger understanding of what palliative care is improves the timeliness of referrals to palliative care (Remedios et al. 2009).

International evidence shows that advance care planning (ACP) can help ensure an individual's preferences for end-of-life treatment are met and can act as a catalyst for promoting group and community discussions about end-of-life care (Green & Levi 2008; Tilden et al. 2004; United States Department of Health and Human Services 2009; Royal College of Surgeons 2009; Department of Health UK 2008).

Strategic direction 7: Ensuring support from communities

Priorities	Actions	Impacts
Strengthen Victorians' awareness, capacity and resilience in relation to dying, death, loss and bereavement and their ability to support people with a life-threatening illness and their carers	7.1 Develop and implement a strategy that helps to build awareness and understanding of death, dying and loss across Victorian communities through: • communications • partnerships • practical methods, tools and education strategies targeted to meet the needs of specific communities • strategies to enhance opportunities for palliative care service volunteers to engage with their communities • strategies to ensure that people who are referred to palliative care are more prepared and are supported by their communities • links and communication mechanisms at a statewide level between palliative care stakeholders across health, community and aged care.	Victorians are better able to support people with a life-threatening illness and their carers.

Appendix 1:
Palliative Care Service Capability Framework

This document is an excerpt from the *Final interim service delivery framework report—Executive summary,* 2010.

Further development of the framework will be undertaken by the Palliative Care Clinical Network in consultation with the sector.

The full copy of the framework can be downloaded from: <www.health.vic.gov.au/palliativecare>.

Capability framework
The framework comprises:

- three types of services (inpatient, community and consultancy)
- three levels of inpatient categories, two levels of community-based services and one level of consultancy

across seven dimensions of measuring and describing capability.

Inpatient palliative care services – Level 1	
Role description and range of services	• provides management of palliative care patients with generally anticipated problems and outcomes • range of services will include physical and psychological, social and spiritual care • discharge planning and effective liaison with community-based palliative and generalist providers • provides or facilitates access to psychological, social and spiritual care, bereavement support and respite care • assessment of patient care needs and exploration of patient goals, expectations and choices for place of care, including knowledge of advance care planning and end-of-life issues • volunteer program (and coordination) either specific to palliative care or through an organisation-wide program
Catchment	• local and sub-regional
Staffing profile	• nursing and medical staff with knowledge of palliative care and/or qualifications in palliative care with access to a consultancy service • access to allied health, psychological, social and spiritual staff • coordination of volunteers specific to palliative care or through an organisation-wide program
Education, training and research	• information to other staff who work in generalist services in the local and sub-regional area about the palliative approach • support and education for palliative care patients, carers and families • provide a health-promoting palliative care approach to build communities' capacity to respond to death, dying, loss and care
Quality framework	• participation in the Department of Health's Clinical Services Improvement Program, including self-assessment against PCA's National Standards Assessment Program • quality activities are supported through formal links with Levels 2 & 3 inpatient services, palliative care consortia and consortia clinical groups • routine collection of palliative care patient and carer satisfaction • participation in health service system-wide quality improvement and assurance activities
Service integration and linkages	• protocols with Levels 2 and 3 inpatient services and consultancy service or other arrangements to obtain advice and coordinate referral for more complex palliative care patients • referrals and protocols to access bereavement support, psychological and spiritual care and respite for palliative care patients, carers and families • protocols to access allied health, psychological, social and spiritual staff • formal links and referral arrangements with a range of medical specialty services • formal links and referral arrangements with primary and specialist community providers • understanding of services offered by statewide palliative care services • participation and involvement in coordination activities through the palliative care consortia
Infrastructure, facilities and supporting services	• access to designated palliative care beds (Levels 2 or 3) and/or acute inpatient beds • capacity to provide access to accommodation for family and carers if required • access to a facility that will support family meetings • tele-health facilities • access to equipment loan and other services to support return to home for palliative care patients

Inpatient palliative care services – Level 2	
Role description and range of services	• as for Level 1 plus • provides a broad spectrum of care and has the capacity to manage most palliative care patients, including physical and psychological, social and spritual needs • interdisciplinary approach • experience and provision of advance care planning and end-of-life care with clear protocols for timely referral to community services • a patient management pathway that is inclusive of interdisciplinary assessment, liaison with community-based service providers, discharge planning and provision of discharge information to primary care providers • formal linkages to support Level 1 services
Catchment	• sub-regional
Staffing profile	• as for Level 1 plus • interdisciplinary team made up of medical and nursing staff with specialist qualifications in palliative care, and allied health, psychological, social and spiritual staff with experience and/or specialist qualifications in palliative care • substantial presence/involvement of medical practitioner with specialist qualifications in palliative medicine who may work across other health services • provision of on-call or other after-hours support by medical staff with experience in palliative care • access to other allied health, psychological, social and spiritual and clinical staff supporting psychological, social and spiritual care needs of palliative care patients, carers and families
Education, training and research	• as for Level 1 plus • undergraduate and postgraduate teaching (registrars, trainees, students) • provide education and support in specialist palliative care within the health service • some outreach education and support to generalist and community-based services • participation in palliative care research and quality improvement projects
Quality framework	• as for Level 1 plus • contributes data to a state/national system that monitors and measures palliative care outcomes • use of validated assessment tools and evidence-based care pathways and protocols
Service integration and linkages	• as for Level 1 plus • protocols with Level 3 inpatient service or other arrangements to provide advice and receive referral for more complex patients • protocols and liaison with other services and clinical support units within/external to the health service • formal link with a palliative care consultancy service • relationship and information sharing with statewide palliative care services • formal links with specialist community services for joint postgraduate registrar and training programs
Infrastructure, facilities and supporting services	• as for Level 1

Inpatient palliative care services – Level 3	
Role description and range of services	• as for Level 2 Plus • provides comprehensive care and has capacity to manage the full range of palliative care patients, including clinical and/or psychological, social and spiritual complexities • complex symptom and pain management • provision of interdisciplinary care including psychological, social and spiritual care for palliative care patients, carers and families by qualified providers • availability of liaison psychiatry and/or psycho-oncology and/or appropriate mental health services • provides advisory/consultation services to generalist providers • after-hours on-call provision for specialist palliative care advice and patient/carer support • formal linkages with Levels 1 and 2 inpatient services to provide advice and consultation • provides a palliative care volunteer program
Catchment	• regional (and potentially statewide role for some services)
Staffing profile	• as for Level 2 Plus • comprehensive interdisciplinary team, including medical practitioner with specialist qualifications in palliative medicine, specialist nursing (may include nurse practitioner) and allied health, psychological, social and spiritual staff with qualifications and experience in palliative care • staff with joint appointments across settings and/or universities • coordinator of volunteers
Education, training and research	• as for Level 2 Plus • formal education programs in the palliative approach available to other hospital staff and on an outreach basis to external health professionals • collaborative arrangements with community palliative care for formal education programs for family carers and patients • staff with joint appointments with universities • origination, leadership and active participation in palliative care research, knowledge integration and quality improvement activities
Quality framework	• as for Level 2 Plus • meets all or some of the requirements for Royal Australasian College of Physicians (RACP) accreditation in relation to palliative medicine • offers a leadership role, including provision and training support of peer reviewers and supports their training for PCA's National Standards Assessment Program • contributes to a statewide data system • monitors/reports palliative care clinical indicators and participates in benchmarking activities • provides clinical leadership in the use of resources that promote consistency and good clinical practice, such as validated assessment tools and evidence-based care pathways and protocols

Inpatient palliative care services – Level 3	
Service integration and linkages	• as for Level 2 Plus • protocols and liaison with other services and clinical support units within/external to the health service (including acute care, subacute care, emergency departments, medical and radiation oncology, intensive care and diagnostic imaging) • Substantive involvement of other clinical practitioners (including, but not limited to, general practitioners, other generalist and specialist medical practitioners, clinical nurse consultants and nurse educators from other clinical fields, Aged Care Assessment Service (ACAS) teams, bereavement specialists and aged care services) • leadership in service and care coordination through mechanisms such as interdisciplinary team meetings and case conferencing involving providers across settings • leadership in activities such as consortia clinical advisory groups • formal links and referral arrangements with a range of specialist palliative care services
Infrastructure, facilities and supporting services	• as for Level 2 Plus • access to high-end diagnostic management and treatment facilities

Community Palliative Care Services – Level 1	
Role description and range of services	• provides management of palliative care clients with generally anticipated problems and outcomes through one or more specific services (not full range of comprehensive care) to support clients in the community • range of services will include physical and psychological, social and spiritual care • participates in discharge planning and liaison with inpatient palliative care and acute hospital services • provides or facilitates access to psychological, social and spiritual care, bereavement support and respite care • assessment of client care needs and exploration of client goals, expectations and choices for place of care, including knowledge of advance care planning and end-of-life issues • after-hours support • volunteer program (and coordination) either specific to palliative care or through a link into a volunteer network
Catchment	• local and sub-regional
Staffing profile	• nursing and other staff with knowledge of palliative care and/or qualifications in palliative care with access to a palliative care consultancy service • may involve palliative medicine specialists through a palliative care consultancy service on an advisory basis • coordinator of volunteers specific to palliative care or links to a volunteer network • may include generalist medical staff and/or nurse practitioner in palliative care
Education, training and research	• information to other staff who work in generalist services in the local and sub-regional area on the palliative approach • support and education for palliative care clients, carers and families • provide a health-promoting palliative care approach to build communities' capacity to respond to death, dying, loss and care

Community Palliative Care Services – Level 1	
Quality framework	• participation in the Department of Health's Clinical Services Improvement Program, including self-assessment against PCA's National Standards Assessment Program • quality activities are supported through formal links with Level 2 community services, palliative care consortia and consortia clinical groups • routine collection of client and carer satisfaction data • participation in health service system-wide quality improvement and assurance activities
Service integration and linkages	• protocols with Level 2 community services and consultancy service or other arrangements to obtain advice and coordinate referral for more complex palliative care clients • collaborative relationships with generalist and specialist health providers to support joint management and shared care of palliative care clients in the community • referrals and protocols to access bereavement support, psychological, social and spiritual care, and respite for palliative care clients, carers and families • protocols to access allied health, psychological, social and spiritual staff • formal links and referral arrangements with a range of specialist palliative care services • understanding of services offered by statewide palliative care services • participation and involvement in coordination activities through the palliative care consortia
Infrastructure, facilities and supporting services	• access to designated appropriate-level palliative care beds and/or acute inpatient beds and respite facilities • access to tele-health facilities • access or referral to equipment loan and other services to support palliative care clients at home

Community Palliative Care Services – Level 2	
Role description and range of services	• as for Level 1 Plus • provides comprehensive clinical care (including complex symptom and pain management) and psychological, social and spiritual care, bereavement support and access to respite care • arrangements for 24-hour coverage to meet needs of community palliative care clients and their families and carers • provision of interdisciplinary care by qualified providers • protocols for access to psychiatry and/or psycho-oncology and/or appropriate mental health services • experience and provision of advance care planning and end-of-life care with clear protocols for timely referral to inpatient services • interdisciplinary assessment of client care needs and exploration of client goals, expectations and choices for place of care-liaison with inpatient services, and provision of information to other providers • provides advisory/consultation services to generalist providers • formal protocols to support Level 1 community services • provides a palliative care volunteer program
Catchment	• sub-regional and regional

Community Palliative Care Services – Level 2	
Staffing profile	• as for Level 1 Plus • comprehensive interdisciplinary team, including medical practitioner with specialist qualifications in palliative medicine, specialist nursing (may include nurse practitioner) and allied health, psychological, social and spiritual support staff with qualifications and experience in palliative care • staff may have joint appointments across settings and/or universities • coordinator of volunteers
Education, training and research	• as for Level 1 Plus • teaching and training for nursing, medical staff and primary care staff in specialist palliative care • collaborative arrangements with inpatient services for formal education programs for carers and palliative care clients • staff with capacity to provide mentoring and education in undergraduate and postgraduate studies • leadership and participation in palliative care research, knowledge integration and quality improvement activities
Quality framework	• as for Level 1 Plus • meets all or some of the requirements for RACP accreditation in relation to palliative medicine • offers a leadership role, including providing peer reviewers and supports their training for PCA's National Standards Assessment Program • undertakes routine collection of client and carer satisfaction and employs other mechanisms to support consumer feedback • contributes data to a state/national system that monitors and measures palliative care outcomes • monitors/reports palliative care clinical indicators and participates in benchmarking activities • provides clinical leadership in the use of resources that promote consistency and good clinical practice, such as validated assessment tools and evidence-based care pathways and protocols
Service integration and linkages	• as for Level 1 Plus • substantive involvement of other clinical practitioners (including, but not limited to, GP's, other generalist and specialist medical practitioners, clinical nurse consultants and nurse educators from other clinical fields, ACAS teams, bereavement specialists and aged care services) • staff to provide advice and consultation to Level 1 services • leadership in activities such as consortia clinical advisory groups • formal links and referral arrangements with a range of specialist palliative care services • participation and involvement in coordinating activities through the regional palliative care consortia
Infrastructure, facilities and supporting services	• as for Level 1 Plus • facilities for the provision of psychological and social support/counselling services away from the home

Consultancy Palliative Care Services	
Role description and range of services	• ‘in-reach’ consultancy advice and support to hospital-based staff • ‘outreach’ consultancy advice and support to generalist community-based healthcare professionals and community palliative care services • assessment and symptom management, clinical decision-making, advance care planning, patient and family communication, end-of-life care • approximately 40 per cent direct clinical care and 60 per cent consultancy service, including but not limited to the following elements – coordinating access and service provision for palliative care patients, carers and their families through referral and liaison with acute services, inpatient palliative care units, ambulatory care clinics and community palliative care services – capacity building, education and advocacy on the palliative approach – may include provision of specialist palliative care ambulatory clinics – may include participation in regional and/or sub-regional interdisciplinary meetings – may include participation in interdisciplinary cancer team meetings
Catchment	• statewide, regional and/or sub-regional
Staffing profile	• interdisciplinary team, including medical practitioner with specialist qualifications in palliative medicine, and nursing staff with qualifications and experience in palliative care (may include a nurse practitioner in palliative care and other staff with specialist qualifications in palliative care) • facilitates access to other required services, including allied health, psychological, social and spiritual care
Education, training and research	• undergraduate and postgraduate training of nursing and medical staff, and other disciplines, as defined by the consultancy staffing profile • extensive role in provision of education about palliative care for health professionals across all settings and on a regional basis • staff with joint appointments at universities • leadership and participation in palliative care research and knowledge integration • provide a health-promoting palliative care approach to build communities’ capacity to respond to death, dying, loss and care
Quality framework	• employing agency meets requirements for RACP accreditation in relation to palliative medicine • participation in the Department of Health’s Clinical Services Improvement Program, including self-assessment against PCA’s National Standards Assessment Program • offers a leadership role, including providing peer reviewers and supports their training in the National Standards Assessment Program • contributes to a statewide data system • provides clinical leadership in the use of resources that promote consistency and good clinical practice, such as validated assessment tools and evidence-based care pathways and protocols • quality activities are supported through formal links with inpatient and community services, palliative care consortia and consortia clinical groups

Consultancy Palliative Care Services	
Service integration and linkages	• collaborative relationships with generalist and specialist health providers to support joint management and shared care of palliative care patients requiring palliative care • leadership role in standardising referral protocols and communication channels with other health providers to support improved access to palliative care services on a geographic basis • formal links and referral arrangements with a range of specialist palliative care services • leadership in activities such as consortia clinical advisory groups • participation and involvement in coordinating activities through the regional palliative care consortia
Infrastructure, facilities and supporting services	• access and referral to acute and non-acute inpatient beds • access and referral to community facilities, including respite and aged care • tele-health facilities

Appendix 2: Palliative Care Consortia reporting proforma

Department of Health Palliative Care Consortia

Reporting requirements for the strategic directions 2011–2015

Area	Key performance indicator	Due
Role statements audit tool	To report ongoing compliance against the consortia decision-making groups role statements. To report on the audit tool outcomes and action plan and completion of tasks against agreed timelines. *Reporting*: electronic copy of audit tool and action plan	Annually – 30 September
Regional governance structure	To provide a copy of a signed memorandum of understanding that includes: • primary signatories (palliative care funded services) and affiliates, for example, PCPs and GP divisions • CEO delegations in writing • evidence of palliative care being included in individual members' strategic plans • evidence of a specific palliative care plan for each member organisation. To provide a copy of the palliative care consortium terms of reference. *Reporting*: electronic copy	Annually – 30 September
Regional planning	To facilitate attendance by Department of Health representatives at regional planning forums. To ensure the regional strategic plan aligns with the Department of Health palliative care policy and other relevant government policy. To ensure the regional strategic plan addresses the service access expectations for the region, ensuring equitable distribution of the required types of service and designated levels of capability, as detailed within the service delivery framework and service capability framework. To provide a copy of the updated regional strategic plan (when available). To provide a report on the implementation and progress of the regional strategic plan within the annual report. *Reporting*: electronic copy	Annually

Area	Key performance indicator	Due
Annual report	To develop and submit an annual report describing the activities, challenges and initiatives introduced in the region in the preceding financial year. Suggested structural features appear below as first-order headings; however, subheadings may be used to assist clarity of reporting (a template will be provided): 1. Content/Index 2. Overview 3. About us • regional population and demographics • consortium organisational structure and profile • consortium member agency profile, staffing and key initiatives, for example, joint appointments 4. Year highlights • major projects, for example, nurse practitioner projects • report on quality activities – Consortium Clinical Advisory Group 5. Reports • consortium chair, executive and manager report • listing of delegated consortium members and attendance at meetings • identified portfolios for consortium members and participation in other decision-making groups • accreditation status and accrediting agency for each consortium member agency • training, education, research and workforce development activities • regional plan implementation and progress 6. Consortia roles • regional planning – *Aboriginal palliative care* – *PEPA post-placement support activities* – *health-promoting palliative care* – *rural palliative care medical purchasing fund (rural consortia only)* • Coordinating care – *after-hours palliative care* – *culturally and linguistically diverse palliative care* – *motor neurone disease regional workers/activities* • determining priorities for future service development and funding in conjunction with departmental staff 7. Future directions 8. Financial statement • consortium fundholder budget acquittal (financialaccountability statement) including: – other project funding – rural medical purchasing fund Copies of the annual report are to be distributed to key stakeholders. Palliative care consortium annual reports (short or full version) will be loaded to the Victorian Palliative Care Program website. *Reporting*: electronic copy (hard copy if available)	Annually 30 September

Area	Key performance indicator	Due
Consortium regional visit	To facilitate and participate in an annual regional site visit with representatives of the Depatment of Health's palliative care team and regional office. Minimum one-hour allocation during consortium meeting. Location and date to be negotiated. Attendance by the Department of Health at Consortium Clinical Advisory Group, as negotiated.	Annually Annually
Statewide meetings	To provide a written report on consortium activities for the palliative care statewide meetings held twice per annum (as per statewide meeting reporting template). *Reporting*: electronic copy To provide a presentation aligned with the submitted report where requested. Attendance at statewide meetings as per role statements.	Bi-annually

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