

Strengthening palliative care:
a policy for health and community
care providers 2004–09



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2004–09

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Ministerial foreword

The management of people with life-threatening illness and their families and carers has changed significantly over the past two decades. As a result, more people are being cured of their disease and people who cannot be cured are living much longer.

With the increase in the length of time people live with life-threatening illnesses, the focus of health care changes. It moves gradually from a focus on cure to one of symptom control and to improving the individual's quality of life until death.

Palliative care plays a crucial role in improving quality of life through the control of symptoms as well as providing psychosocial and spiritual care from diagnosis to the end of life and bereavement.

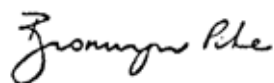
The challenge for the Victorian Government as well as for health services is to build on the achievements in palliative care provision over the past decade to ensure all Victorians, wherever they live and whatever their circumstances, have access to quality palliative care in a way that meets their individual needs.

This policy document, *Strengthening palliative care: a policy for health and community care providers 2004-09*, articulates the principles that underpin an integrated service system across Victoria and provides the framework to meet this challenge. These principles include integrating the palliative approach into the practice of all health and community care services, as well as strengthening access to specialist palliative care providers.

To achieve the improved care for all Victorians with life-threatening illness, we need to strengthen the way in which Victorian palliative care services work together. The establishment of regional palliative care consortia brings together key stakeholders to facilitate consistent and timely care of people with life-threatening illness and their families across the service system. The palliative care consortia will enable local providers to assess the needs of their community, to identify priorities to meet current service gaps and to strengthen the capacity of all local providers. In addition, the consortia will strengthen links between specialist palliative care services and general health and community care providers.

This policy, developed in conjunction with the Palliative Care Strategic Framework Working Party, was released as a consultation paper in May 2004. The very positive responses and endorsement for the policy directions from more than 70 organisations and individuals across Victoria has been very gratifying.

The Victorian Government is committed to ensuring the principles and framework identified here are implemented over the next five years. We look forward to working with you towards achieving the vision that all Victorians with a progressive life-threatening illness and their families and carers will have access to a high quality service which fosters innovation and provides coordinated care and support that is responsive to their needs.



Hon. Bronwyn Pike, MP
Minister for Health

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The Department of Human Services also thanks all the stakeholders who supported the development of this document through their participation in regional consultation workshops and their feedback on the public consultation report of the draft policy (May 2004).

We also acknowledge the following services that provided us with examples of good practice in palliative care. These are a small example of the many innovative and quality practices that exist in palliative care in Victoria:

- Barwon Health/Barwon South Western Region Community Based Palliative Care
- Mercy Western Palliative Care
- Mornington Division of General Practice
- Motor Neurone Disease Association of Victoria
- South East Palliative Care Ltd
- Victorian Paediatric Palliative Care Program
- Wimmera Hospice Care
- Hume Regional Palliative Care.

Following community consultation, Sheila Hirst, in conjunction with other members of the department's Metropolitan Health and Aged Care Division, revised this policy document.



Executive summary

With improvements in medical technology and the focus on early identification and control of disease, the management of people with a life-threatening illness and their carers and families has changed significantly over the past two decades. As a result, people with a life-threatening illness are living longer. This has changed the focus of health care from cure to control of symptoms and to improving the person's quality of life until death.

In Victoria, care of people with a life-threatening illness occurs in a variety of settings, including acute and sub-acute inpatient care facilities, residential care facilities and the home. A variety of generalist and specialist service providers provide care.

The policy directions in this document are aimed at strengthening service delivery for people with life-threatening illness and their carers and family through:

- improving the equity of access to specialist palliative care services for people with life-threatening illness
- building effective and efficient links between hospitals and specialist palliative care services
- building effective and efficient links between specialist palliative care services and other relevant community, health and allied health providers, including disability services and residential aged care.

The vision underpinning this policy is:

All Victorians with a progressive life-threatening illness and their families and carers will have access to a high quality service system which fosters innovation and provides coordinated care and support that is responsive to their needs.

The palliative approach

The palliative approach that improves the quality of life of patients facing life-threatening illness and their families is becoming increasingly important. This approach improves quality of life by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement (adapted from World Health Organization 2004a).

All health care providers need to incorporate the palliative approach into their clinical practice and draw on additional specialist palliative care knowledge, attitudes and skills when required. Non-specialist palliative care providers, including general practitioners, community- and hospital-based doctors, nurses and allied health staff, as well as other specialist service providers, such as oncologists and geriatricians, use the palliative approach (Palliative Care Australia 2004).

Specialist palliative care

Specialist palliative care builds on the palliative approach and reflects a higher level of expertise in complex symptom control, loss, grief and bereavement. Specialist palliative care providers work in two key ways: first, by providing direct care to individuals and their families; second, by providing a consultancy service to other generalist service providers, supporting their care of the patient and family.

The needs of people with a life-threatening illness

People with a life-threatening illness want freedom from pain and control of symptoms; access to appropriate care regardless of where they live; options for care both now and in the future and real choice about treatments and services; someone who is in charge of their care and who can answer their questions; support to discuss their concerns and feelings; and dignity and respect for culture, lifestyles and beliefs (National Health Priority Action Council 2004; National Institute of Clinical Excellence 2003). At the same time, carers want help for their practical needs, such as financial advice, home care and respite, and access to information specific to their needs; support to discuss their concerns and feelings; and knowledge that the best possible care and advice is being provided (National Health Priority Action Council 2004).

In planning care for people with a life-threatening illness and their carers and families, the ideal service system needs to ensure:

- the health and residential care workforce practises the palliative approach
- there is equitable access to a level of specialist palliative care across the state
- the mix of bed-based and community-based specialist palliative care services is appropriate
- care and referral pathways are clearly defined and options are identified. Communication strategies ensure general practitioners, community care providers and other health providers are fully informed of, and able to participate in, the care plan for patients under their care
- effective and efficient links exist between hospitals and community services
- sufficient numbers of appropriately trained specialist palliative care providers are available to provide care across a region.

Developing an integrated service system

An integrated service system is fundamental to achieving the ideal service system.

A key platform of this document is the establishment of regional consortia of specialist palliative care providers to facilitate the integration of care for people with a life-threatening illness and their carers and families across the service system. The palliative care consortia ('the consortia') will have four major roles within their geographic area of responsibility:

- regional planning: planning services for people with a life-threatening illness and implementing planned service development priorities following approval by the Department of Human Services
- designating hospital roles within the region: designating clearly defined roles for hospitals which will ensure consistent access to specialist palliative care services
- coordinating care: developing and implementing processes and systems for coordinated and integrated care for people with a life-threatening illness
- determining priorities for future service development and funding in conjunction with departmental staff to support the further implementation of the regional plans.

This document represents the policy direction informing how future funding will be allocated. The consortia and the department will agree on priorities for new funding initiatives within each region.

Expected policy outcomes

Implementing the directions of this policy is expected to produce these outcomes:

- All patients with a life-threatening illness and their families and carers will have access to care appropriate to their needs, wherever they live in Victoria, through regional integrated palliative care service systems.
- People with life-threatening illness and their carers and families will be provided with seamless, quality care by care providers using common protocols, service tools and policies within each integrated palliative care service system.
- People with life-threatening illnesses and complex needs will have appropriate and timely access to specialist palliative care services through direct care or in-reach and consultancy services no matter where they live in Victoria.

Guiding principles

The following principles underpin the directions outlined in this policy document. They form the basis of practices and processes which will guide health and community care providers in achieving the expected outcomes in caring for people with a life-threatening illness and their carers and families.

Principle one

People with a life-threatening illness and their carers and families have information about options for their future care and are actively involved in those decisions in the way that they wish.

Expected outcomes

- All care plans are developed and implemented based on the informed decisions and needs of the person with a life-threatening illness and their families and carers.
- People with life-threatening illness will be encouraged and supported in developing an advanced care plan to meet their future needs.

Principle two

Carers of people with a life-threatening illness are supported by health and community care providers.

Expected outcomes

- The health and wellbeing of the carer is enhanced by improved access to appropriate respite care and support services.
- Carers are adequately supported so they can provide care to the person with life-threatening illness in line with the patient's and carer's wishes.
- Carers' ability to navigate the system will be strengthened through the provision of information about available services and supports.

Principle three

People with a life-threatening illness and their carers and families have care that is underpinned by the palliative approach.

Expected outcomes

- People with life-threatening illness, their carers and families receive optimal care through the adoption of the palliative approach by all health, community, residential aged and disability care services.
- The unique needs of the individual with a life-threatening illness and their carers and families will be addressed by developing and implementing an agreed care plan.

Principle four

People with a life-threatening illness and their carers and families have access to specialist palliative care services when required.

Expected outcomes

- Patients with life-threatening illness and complex needs have appropriate and timely access to specialist palliative care through an integrated service system.
- All carers and family members assessed with complex grief and bereavement are provided with information about and access to appropriate counselling and support.

Principle five

People with a life-threatening illness and their carers and families have treatment and care that is coordinated and integrated across all settings.

Expected outcomes

- Services are coordinated in the best way to meet the needs of people with life-threatening illness and their carers and families.
- People with life-threatening illness will be able to clearly identify the key professional contact in the provision of their care.

Principle six

People with a life-threatening illness and their carers and families have access to quality services and skilled staff to meet their needs.

Expected outcomes

- People with life-threatening illness and their carers and families receive care and support from suitably qualified service providers and trained volunteers.
- All staff and volunteers involved in the care of people with life-threatening illness and their carers and families practice the palliative approach.
- People with life-threatening illness and their carers and families receive the best care available based on current research evidence.

Principle seven

People with a life-threatening illness and their carers and families are supported by their communities.

Expected outcomes

- Communities are able to actively support friends, family, neighbours, work and social contacts who have life-threatening illness and their carers and families.
- Community awareness of the needs of and supports for people with life-threatening illness and their carers and families is enhanced through community promotion and education.



Introduction

With improvements in the understanding of disease processes, advances in medical technology and the focus on early identification and control of disease, the management of people with a life-threatening illness and their carers and families has changed significantly over the past two decades. As a result, survival from cancer has increased, with more people being cured and those who are not cured living longer (Giles & Thursfield 2002). The same trend is evident for organ failure, cardiovascular disease, diabetes and a range of other illnesses. While there has been an emphasis for some time on quality of life for end-of-life care, the increasing length of life from disease diagnosis to death has changed the focus of health care from cure to symptom control and to improving the person's quality of life until death.

For this reason, the palliative approach that improves the quality of life of patients facing life-threatening illness and their families is becoming increasingly important. This approach improves quality of life by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement (adapted from World Health Organization 2004a). (See Appendix 1 for the World Health Organization definition.)

All health care providers need to practise the elements of the palliative approach and draw on additional palliative care knowledge, attitudes and skills. Non-specialist palliative care providers, including general practitioners, community- and hospital- based doctors, nurses and allied health staff, as well as other specialist service providers, such as oncologists and geriatricians, generally provide the palliative approach (Palliative Care Australia 2004).

Specialist palliative care services reflect a higher level of expertise in complex symptom control, loss, grief and bereavement. Specialist palliative care providers 'may accept prime responsibility for care, or work indirectly through advising patients' professional carers' (Kristjanson, Toye & Dawson 2003).

Background

In Victoria, people with a life-threatening illness and their carers and families have a strong system of support which was founded at the beginning of the twentieth century when groups such as Melbourne Citymission and the Sisters of Charity provided care in various ways for the sick and dying (Smith 2001). This base was expanded over the years with dedicated state funding for palliative care services in the 1980s. In 1987, the Australian Government introduced the Medicare Incentives Package, which gave the states monies to fund community palliative care services. By 1991, Victoria had 23 community palliative care agencies.

Care of people with a life-threatening illness in Victoria occurs in a variety of settings, including acute inpatient care facilities, sub-acute inpatient care facilities, residential care facilities and the home. A variety of service providers provide this care, including generalist health care providers (such as general practitioners, district nurses and home care providers), specialist health care providers (such as oncologists and haematologists) and specialist palliative care service providers.

The Department of Human Services' Palliative Care Program funds palliative care providers in 30 inpatient settings across Victoria and through 34 community programs in the eight departmental regions of the state to provide care in all communities. In addition, four consultancy services are funded through this program (see Appendix 2). Finally, a number of other public providers have established palliative care services funded through their core funding from the Department of Human Services (for example, the Peter MacCallum Cancer Institute, Melbourne Health).

Use of palliative care services

Of all people admitted to public hospitals for more than one day in 2002–03, only one per cent died in the hospital (Department of Human Services 2003a). Of these deaths, only 3,071 patients (0.26 per cent of all separations) died in a designated palliative care unit in a hospital. The average length of stay for patients in a designated palliative care unit was 17.1 days in a metropolitan hospital and 13.7 days in a rural hospital. Of all patients admitted to a designated palliative care unit, 66.7 per cent died in the unit.

Data do not support anecdotal suggestions that patients are often admitted to a palliative care unit shortly before they die because the family and carers face an increased burden at the end of the patient's life. Rather, the average length of stay was 19 days for people who were admitted to and died in a palliative care unit and 17 days for people who were admitted to but did not die in a palliative care unit during that admission. Of patients admitted to a designated palliative care unit, 83.3 per cent were over the age of 60 years.

In 2002–03, 7,228 patients accessed community palliative care services (Department of Human Services 2003b). Of these, 52.9 per cent were male and 76.4 per cent were over the age of 60 years. The average length of stay was 97.7 days. Malignancy was the reported diagnosis in 87 per cent of the cases. Clinical consultancy or care was provided in 23.6 per cent of contacts, and spiritual or emotional support or counselling was provided in 20 per cent of contacts. Nurses provided 74.4 per cent of services. Fifty-one per cent of patients cared for through community palliative care services died in hospital.

Strengthening the system

The existing service system has significant strengths built on the expertise developed in community and inpatient settings and on collaborative models of care among specialist palliative care providers. A number of initiatives in the development of palliative care in Victoria have evolved over the last decade. These initiatives include:

- the appointment of a ministerial taskforce on palliative care to advise on the development of a comprehensive and integrated palliative care system within the general health system. The taskforce reported in *Palliative care services in Victoria: a vision* (Department of Human Services 1995)
- the publication of planning and resource guidelines in *Palliative care in Victoria: the way forward* (Department of Human Services 1996). These guidelines set parameters for a restructure of community services and an expansion of inpatient hospice services across the state

- a tender process in 1998 for community palliative care services across the state based on the report, *Victorian palliative care services: service integration – directions* (Department of Human Services 1997).
- funding in 2002 of several innovative community initiatives, including projects addressing the needs of the multicultural and Indigenous populations and strengthening links between specialist palliative care providers and general practitioners
- funding and establishment of three pilot day hospices in 2003. These hospices will be evaluated to determine the value to patients and their families and carers and whether there are any cost efficiencies for services.

In addition to the Victorian initiatives, a number of projects are underway, funded through the Caring Communities Grant of the National Palliative Care Program. These initiatives include developing comprehensive user-friendly evidence-based online information service, building rural capacity through volunteering, an experiential palliative care program for general practitioners, and the statewide implementation of the Program for Experience in the Palliative Approach (www.palliativecare.gov.au/program.htm).

What has been achieved?

The significant achievements in providing Victorian palliative care services over the past five years include:

- enhanced profile of palliative care in the community
- improved access and equity to palliative care services across the state
- development of integrated models of care which have strengthened the collaboration and integration of care to community palliative care recipients
- development of innovative projects to optimise care, including initiatives to enhance access to afterhours medication and to address the needs of special groups
- flexible funding models which have helped to tailor services to meet local needs
- the accreditation of a number of services in accordance with the Australian Council on Healthcare Standards
- development of new academic chairs which has increased the scope of palliative care research and added additional rigor to the field.

While the current system has particular strengths as demonstrated, the statewide consultation in 2003 identified areas of the system that require further enhancement. Key areas for improvement are service availability, integration of care, education of generalist health and community providers in the palliative approach, and workforce issues.

Further, there are increasing demands on the current system as a result of:

- community expectations of flexible care that is easily accessed and responsive to needs
- the increasing length of survival time from diagnosis of a life-threatening illness to death.

For these reasons, the system must achieve further improvements in coordinating and integrating services, which was the intention of the policy work in the 1990s. This work progressed the integration of the service system across many community settings, but was less effective in achieving this integration **consistently** across the acute–community interface in both metropolitan and rural areas.

Developing the plan for the future

This paper, *Strengthening palliative care: a policy for health and community care providers 2004–09*, provides the framework for the improved delivery of palliative care services for the next five years. The Palliative Care Strategic Framework Working Party, established in 2003, guided this policy and the findings of the 2003 statewide consultation informed its framework. In May 2004, the draft policy was forwarded to key stakeholders for further consultation. Submissions were received from 70 stakeholders (see Appendix 3) and the paper was modified in response to the submissions.

Strengthening palliative care – report outline

The next section discusses the way forward and provides the vision and the organisational framework required for the policy. It also articulates expected outcomes and the key actions for implementing this framework.

The seven principles for strengthening palliative care services in Victoria are then articulated. Within each principle, the key objectives, expected outcomes and action areas are outlined for the Department of Human Services, for health and community services and, where needed, for specialist palliative care services.

Good practice examples are included to demonstrate achievements within the field.

The final section outlines the implementation plan.

While this document addresses many issues, the following key points are highlighted and underpin the overall policy:

- A **regional** approach is the critical policy platform, with services working together to optimise the community's access to quality palliative services. This approach complements the directions of Palliative Care Australia (2004).
- Palliative care services are provided to **individuals**, their families and carers, each of whom come with their **unique life experiences**. Service providers offer care that takes into consideration the individual's specific needs, based on their age, life stage, ability, social relationships, culture, other life experiences and influences, as well as the nature and impact of the life-threatening illness.



Given the scope of the key action areas, further prioritisation will take place within the initial implementation phase.

A number of key points underpin this policy.

- The focus of palliative care is not limited to people with cancer, but can be beneficial to all people with a life-threatening disease. This includes people with neurodegenerative diseases, such as motor neurone disease and Huntington's disease, as well as people with advanced organ failure, HIV/AIDS and other life-threatening illnesses.
- The provision of palliative care services to children with life-threatening illnesses, their families and carers is included in this policy document. It is clearly acknowledged that services for children and their families need to consider the different developmental stages of the child and the unique implications of this for care, communication and decision making processes. Specialist paediatric palliative care services play an important role in supporting and advising generalist services in this care.
- The increasing overlap between acute treatment and palliative care services compounds the complexity of palliative care. For many patients, the transition from curative treatment to palliative care is gradual. Where active treatment continues to be offered, its goal gradually changes from cure or control of the disease to the control of symptoms (National Breast Cancer Centre and National Cancer Control Initiative 2003). For other people, for instance those with HIV/AIDS, there is a moving in and out of palliative care because active treatment enables the individual to return to relatively good health for periods of time (Foley et al. 1995). Finally, for people with advanced organ failure, palliative care might be essential at the same time as the individual awaits the potential 'cure' through the availability of an organ transplant.
- General practitioners, with their established relationships with people with a life-threatening illness, are frontline providers of care and need to be an integral part of the care of individuals within the community setting and part of the team within inpatient services.
- The palliative approach and specialist services should be accessible wherever the individual with a life-threatening illness is based—in the home, in residential aged care services, in community residential units or within the acute care sector.
- Palliative care teams are interdisciplinary teams, composed of a range of medical, nursing, allied health staff, chaplains and volunteers, all of whom contribute to the physical, functional, emotional, psychological, social and spiritual aspects of care and wellbeing. Allied health team members include social workers, physiotherapists, occupational therapists and a multitude of other therapists (Crawford & Price 2003).
- This policy informs the provision of all public palliative care services in Victoria, regardless of whether the service is funded through the Department of Human Services' palliative care funding program or other funding sources.
- The important role of the private sector in providing care for people with life-threatening illnesses is acknowledged and strengthening links across the public and private sectors is encouraged.



A plan for the future

This document represents the policy direction underpinning how future funding will be allocated. The key directions of this policy are to:

- improve the equity of access to specialist palliative care services for people with life-threatening illness
- build effective and efficient links between hospitals and specialist palliative care services
- build effective and efficient links between specialist palliative care services and other relevant community, health and allied health providers, including disability services and residential aged care.

The vision is:

All Victorians with a progressive life-threatening illness and their families and carers will have access to a high quality service system which fosters innovation and provides coordinated care and support that is responsive to their needs.

Expected policy outcomes

- All people with a life-threatening illness and their families and carers will have access to care appropriate to their needs, wherever they live in Victoria, through regional integrated palliative care service systems.
- People with life-threatening illness and their carers and families will be provided with seamless, quality care by care providers using common protocols, service tools and policies within each integrated palliative care service system.
- People with life-threatening illnesses and complex needs will have appropriate and timely access to specialist palliative care services no matter where they live in Victoria.

In planning care for people with a life-threatening illness and their carers and families, the ideal service system needs to ensure:

- there is equitable access to a level of specialist palliative care across the state
- the mix of inpatient and community specialist palliative care services is appropriate
- effective and efficient links exist between hospitals and community services
- the palliative approach is strengthened and integrated into the care of all generalist health, community and residential care services
- care and referral pathways are clearly defined and options are identified
- communication strategies ensure general practitioners, community care providers and other health providers are fully informed of, and able to participate in, the care plan for patients under their care
- sufficient numbers of appropriately trained specialist palliative care providers are available to provide care across a region.

‘This initiative provides an exciting opportunity for people to work together to progress work in order to strengthen palliative care services.’

Respondent to consultation paper

The following discussion outlines the establishment of the palliative care consortia and their role in supporting the achievement of this vision and expected outcomes.

At the end of this section, the key objectives, action areas and responsibilities are outlined.

Palliative care consortia

An integrated service system is fundamental to achieving the ideal service system. To ensure there is consistent access to specialist palliative care services and to enable continuity of care across the care continuum, specialist palliative care providers (community, inpatient and consultancy services) and other relevant palliative care providers will form regional palliative care consortia ('the consortia').

The consortia will enable a more efficient and cooperative use of resources while supporting an integrated approach to care for the patient. This approach is consistent with the geographic approach to planning for services that is being adopted in cancer services and the primary care partnerships. The consortia will adopt the department's regional boundaries. Each regional consortium will operate as a partnership with memorandum of understanding between members. All specialist palliative care providers funded under the department's Palliative Care Program will be required to participate. Other publicly funded palliative care services are encouraged to participate in the consortia.

An integrated service system is fundamental to achieving the ideal service system.

The consortia will have four major roles:

- regional planning: planning services for people with a life-threatening illness and implementing service delivery priorities following approval by the Department of Human Services
- designating hospital roles within the region: designating clearly defined roles for hospitals which will ensure consistent access to specialist palliative care services
- coordinating care: developing and implementing processes and systems for coordinated and integrated care for people with a life-threatening illness
- determining priorities for future service development and funding in conjunction with departmental staff to support the further implementation of the regional plans.

The consortia will be informed by the work of regional advisory committees which have representation from the Divisions of General Practice, hospitals, district nursing, consumers, volunteers, other relevant health and community providers, such as local government and community health services, and the local integrated cancer services committees that are being developed.

The consortia will be responsible for developing regional plans for how palliative care services are to be delivered across their regions, addressing the principles of care described within this framework. The consortia will have a major role, therefore, in assessing the needs of people with a life-threatening illness in their geographic area of responsibility and in implementing initiatives to meet these needs. This role provides the opportunity for local flexibility in planning initiatives because local services will determine need and priorities for further action. The consortia will review and build on service strengths and current links between specialist palliative care services and other health and community services. The consortia will also play an important role in capacity building of all services and will provide local leadership and advocacy.

'The proposal to develop regional palliative care consortia represents a logical step in strengthening relationships between palliative care providers to improve care for patients. Through the efforts of palliative care providers and supported by the Department, we anticipate major improvements in service delivery in the years to come'

Respondent to consultation paper

Funding will be made available to support the work of the consortia in service planning and implementing priority initiatives to achieve an integrated service delivery system.

Supporting the consortia

Funding will be made available to support the work of the consortia in service planning and implementing priority initiatives to achieve an integrated service delivery system. Other resources, such as guidelines, draft terms of reference and planning templates, are being developed to support the work of the consortia.

Specialist palliative care services providers should consider the possibility that local primary care partnerships might provide a platform for facilitating the consortia. In particular, the advisory committee might be established from primary care partnerships in a region. Primary care partnerships increasingly work together at a regional level and a number of palliative care providers are members of the partnerships. Rural consortia might wish to link in with and possibly share the resources of the advisory committees of the local integrated cancer services. However, any links with local integrated cancer services must not be to the detriment of links to and involvement with other relevant non-cancer services.

Development and implementation of regional plans

The palliative care consortia will develop a plan for how specialist palliative care services are to be delivered across their regions and how they will work together with other health and community care providers. The plan must be consistent with the principles in this document to achieve the expected outcomes for people with life-threatening illness and their families and carers. The plans must include the following elements:

- arrangements between hospitals and specialist palliative care services to ensure all hospitals have access to the full range of specialist palliative care services required for people with a life-threatening illness and their carers and families
- community palliative care services that are available across the region
- facilitation of the appropriate hospital role designations in accordance with the agreed criteria (see below)
- arrangements to link all specialist hospital and community palliative care services with an acute care facility that can respond to the acute medical care needs of the patient (such as, a bowel obstruction, a bone fracture or a cord compression)
- arrangements to link all specialist hospital and community palliative care services with a facility that can respond to significant psychological or psychiatric needs of the patient
- the identification of gaps in service provision and strategies to address these
- mechanisms to facilitate the integration and efficiency of service delivery
- mechanisms to help coordinate patient care across care settings.

Some regions might require subregional planning, depending on the geography of the region, the location of services and hospitals, and the existing relationships between providers and their community. However, it must be clearly demonstrated how these sub-regional plans link together into the regional plan.

Role designation for public hospitals

All hospitals are responsible for providing palliative care in accordance with evidence-based best practice standards. To this end, all hospitals or services must have a palliative care policy which guides care from admission to discharge for both acute and respite care. This policy must demonstrate how specialist palliative care education and advice is accessed and used. In addition, inpatient services must clearly demonstrate their links and referral patterns with specialist community palliative care services and with primary care and generalist community services.

The level of generalist or specialist palliative care service provided depends on the overall capacity of the individual hospital, their geographic location and the population which they serve. The consortia will have a major role in ensuring there is consistent access to specialist palliative care services across a region.

Based on the final agreed criteria for each level, each consortium will assign a role designation that defines the ability of hospitals in that region to respond to the needs of people with a life-threatening illness and their carers and families. The role designation will be based on:

- the palliative care skill level available within the hospital
- the ability of the hospital to provide out-of-hours consultancy advice
- the ability of the hospital to provide inpatient respite and stabilisation of symptoms.

Three levels of service designation for palliative care services are proposed, each with their own criteria (See Table 1).

Further consultation with key stakeholders and the department is required to finalise this role designation framework.

Across a region, the consortium will determine formal links between hospitals and health services to ensure all health services have access to the full range of palliative care services required for people with a life-threatening illness and their carers and families. These services include pain and symptom management, complex psychosocial care, terminal care and respite.

In this proposed structure, a hospital that does not have a designated palliative care unit will be supported by a specialist palliative care team. The support might be provided by a community or hospital service (an in-reach consultancy) or a designated palliative care unit, depending on the level of support required, the location of the hospital and the needs of the patient. Further, each hospital will be linked with an acute care facility that can respond to the acute medical care needs of the patient (such as a bowel obstruction or a bone fracture) and any significant psychological or psychiatric needs.

Table 1: Draft role designation for palliative care services

Designated service level	Draft descriptors and criteria
Level one	Level one services can include smaller community hospitals accessing specialist community-based palliative care services on an as-needed basis.
	Level one services might have specific beds that are identified as being appropriate for palliative care patients.
	A specialist palliative care in-reach service includes, at a minimum, a palliative care nurse who has access to guidance from a palliative care physician or a sufficiently trained medical practitioner who has formal links with a palliative care physician.
	There is access to staff experienced in providing grief and bereavement services.
Level two	An onsite specialist palliative care service includes, at a minimum, a palliative care physician or sufficiently skilled medical practitioner who has formal links with a palliative care physician and a palliative care trained nurse.
	There is onsite availability of staff experienced in providing grief and bereavement services.
	Secondary specialist palliative care consultation is available Monday to Friday within usual business hours.
Level three	Designated palliative care beds are available and where possible meet the requirements of the Hospice unit generic brief (Department of Human Services 2000); for example, metropolitan and regional hospitals with large dedicated palliative care inpatient units. Staff are employed onsite (not in-reach) and are available on a 24-hour basis.
	A palliative care team includes a palliative care physician or sufficiently skilled medical practitioner who has formal links with a palliative care physician, palliative care trained nurse, staff experienced in providing grief and bereavement services.
	There is a 24-hour secondary consultation service.
	There is direct acceptance of patients from community-based specialist palliative care providers.

In each region, at least one hospital must be designated with a level three role, at least one must be designated with a level two role, and all must be able to provide a level one palliative care service. Hospital services with significant cancer services will be required to provide specialist palliative care services onsite as set out in the Victorian Cancer Services Framework (Barton et al. 2003).

In addition, each region must have at least one community palliative care service that has, at a minimum, a palliative care physician or sufficiently skilled medical practitioner who has formal links with a palliative care physician, palliative care trained nurses, staff experienced in providing grief and bereavement services, and an interdisciplinary approach. Specialist palliative care services must ensure adequate resourcing of a palliative care physician as a critical member of the specialist palliative care team.

While this might be the ideal service configuration within each region, there might be gaps in the current service level. Some designation levels might not be readily available in all regions and current services might meet some, but not all, the criteria within any specific designated level. These gaps will be a focus for service development through this policy's implementation.

Coordination of care

The consortia will foster a climate of partnership by working across administrative boundaries to achieve consistency of care and equity of access in providing specialist palliative care services (National Council for Hospice and Specialist Palliative Care Services 1999). However, achieving equitable access to specialist palliative services in part depends on the quality of generalist services and the extent to which the palliative approach has been integrated into these services.

A key element of the regional plans will be to facilitate the integration and efficiency of service delivery and care coordination. The plans need to address:

- developing common standards and protocols for access to specialist palliative care services
- identifying and developing opportunities for joint appointments across settings and across the palliative and cancer care services
- developing formalised partnerships, links and networks with health and community care providers
- supporting the generalist health and community providers to adopt or strengthen their palliative approach
- developing protocols that ensure 24-hour secondary specialist palliative care support and access to medications after hours
- developing and implementing mechanisms to assist service and care coordination
- links with the local primary care partnerships
- links with the integrated cancer services (Barton et al. 2003)
- a coordinated approach to community awareness-raising about palliative care
- a strategy to respond to people with culturally and linguistically diverse needs
- developing links with statewide services, including the Motor Neurone Disease Association of Victoria, Very Special Kids, the Victorian HIV Consultancy and the Victorian Paediatric Palliative Care Program.

Funding

The funding to support specialist palliative care services is provided through bed day funding for designated palliative care beds and population-based funding for community palliative care services. While there will always be a need for both community and inpatient specialist palliative care services, the interdependence of both settings of care influences the demand for each type of service.

A lack of appropriate community services might prevent patients from remaining at home, thus increasing the demand for inpatient care and crisis care through emergency departments. Likewise, the unavailability of inpatient care when it is needed prevents patients from being stabilised quickly so they can return home or prevents carers from accessing respite when they are most in need.

There is some evidence that the majority of people prefer to die at home (Charlton 1991) and that expanding specialist palliative care community services results in an increase in the proportion of people who die at home (Constantini et al. 1993). Strengthening the palliative approach through generalist health and community services might further contribute to this outcome. Regional planning will determine the local priority for community palliative care services and inpatient services, depending on the current service mix and demand.

The Department of Human Services will review funding arrangements to ensure equity of a notional regional budget for specialist palliative care services based on:

- population needs in a geographic location
- the mix of inpatient palliative care services and community palliative care services available in the region.

Additional funds will be allocated to regions on an equitable basis. The consortia will determine how future funds will be used in accordance with the regional plans.

The Department of Human Services will require that it approves all regional plans before it allocates additional funds. The consortia will also develop key performance indicators to monitor the implementation of the regional plans and the department will review the achievement of the objectives set out in this document.

Achieving the plan

Key objectives

- To facilitate the development of regional integrated service systems to strengthen the provision of palliative care across Victoria
- To achieve consistency of care and equity of access to the provision of specialist palliative care services

Action areas for the department

- To work with and support specialist palliative care providers to establish consortia that will facilitate the development and implementation of the integrated regional approach to palliative care service delivery
- To support the development and implementation of the role designation framework by finalising the criteria in consultation with the field, supporting its implementation and working with consortia or specialist palliative care services to address gaps in levels of specialist service or to strengthen the capacity of services to meet the criteria
- To work with consortia and specialist palliative care providers and associated stakeholders to address gaps in service delivery

- To work with the Cancer Coordination Unit (Department of Human Services) to ensure all role designation levels of cancer services have access to specialist palliative care services and specialist palliative care services have formal links with the metropolitan and regional integrated cancer services
- To develop an evaluation framework that will be used to monitor the implementation of the regional plans and the objectives set out in this document

Action areas for palliative care consortia

- To develop the organisational structures, processes and agreements to facilitate the work of the consortia
- To develop and support the implementation of the regional plans which reflect the principles and objectives of this policy document and progress the achievement of a regional integrated service system for palliative care
- To work with services in designating roles to hospitals and formally link hospitals and health services together to ensure specialist palliative care services are available at all hospitals across the region
- To strengthen the coordination between specialist services and generalist health and community care providers
- To provide advice to the Department of Human Services about unmet service delivery needs and future service planning
- To develop links with the metropolitan and rural integrated cancer services
- To develop formal links with statewide services, such as the Motor Neurone Disease Association of Victoria, Very Special Kids, the Victorian HIV Consultancy and the Victorian Paediatric Palliative Care Program

Principles

The following principles underpin the direction outlined in the previous section and form the basis of practices and processes that will guide health and community care providers in the care of people with a life-threatening illness and their carers and families.

Within each principle the expected outcomes are highlighted. The discussion of each principle identifies:

- key objectives
- action areas for the Department of Human Services
- action areas for health and community care providers, which include, but are not limited to, hospitals, general practitioners, community health centres, Home and Community Care program providers, and specialist palliative care providers
- where appropriate, additional action areas for specialist palliative care services or consortia.

'The seven principles encourage best practice along the continuum of care and across organisational boundaries, and they are respectful of patients and carers. They also provide a public health infrastructure in palliative care.'
Respondent to consultation paper

Principle one

People with a life-threatening illness and their carers and families have information about options for their future care and are actively involved in those decisions in the way that they wish

Principle one: expected outcomes

- All care plans are developed and implemented based on the informed decisions and needs of the person with a life-threatening illness and their families and carers.
- People with life-threatening illness will be encouraged and supported in developing an advanced care plan to meet their future needs.

Patients and carers want some level of information at different stages during the patient's illness. This information helps to alleviate anxiety, enables informed decisions about the care they want, and assists them prepare for their future.

Patients and carers should be involved in discussions about their care and agree with the care plan developed. In particular, their response to their illness and the management of their symptoms might influence future decisions about their care. For this reason, they should have regular opportunities to be involved in reviewing and adjusting their care plan as their circumstances change.

While many patients will want significant levels of information to support their decision making, this is not the case for all patients. It is also unrealistic to expect all people will always be able to make the decisions when they are very sick or when the individual's and family's perspectives are conflicting. In addition, the individual or family's values might be informed by the specific cultural context within which they live their lives and this might conflict with the service provider's cultural values (Kanitsaki 1998; Lickess 1993). (See principle three.)



Palliative care providers need to negotiate, guide and assist the decision making of individuals and families in a way that respects the individual's and family's values, beliefs and needs however divergent or conflicting these might be (Aranda 1998). The level and type of information required therefore depends on the evolving needs of the patient and carers.

Providers should assess the needs and preferences of individual patients and carers on an ongoing basis to ensure appropriate information is available in a variety of formats (National Institute of Clinical Excellence 2003). Without this, patients might be limited in how they can participate in the decisions about the treatment and care they do and do not want. Alternatively, from their perspective, patients might feel overburdened by the constant and inappropriate need to make decisions (Street 1998).

For many patients or families who want continuing information and involvement in decision making about care, the myriad of services, systems and supports that are available in the community can be very confusing. Information alone might do little to enable them to access the services they need. One provider (for example, a general practitioner, community nurse, specialist palliative care provider) acting in a case manager or coordinator role is needed to not only facilitate access to information but to assist clients to identify what options are available to them in their specific circumstances.

If a person with a disability has a legally appointed health guardian or a 'person responsible' (as determined in the *Guardianship and Administration (Amended) Act 2002*) who makes medical decisions on behalf of the person, then particular attention must be paid to ensuring legal requirements are met. Health guardians and persons responsible need to be provided with information and involved in developing and reviewing the care plan.

Finally, there are specific issues about the autonomy and guardianship for children and young adolescents with life-threatening illness, which are independent of legal considerations. Influenced by their age, developmental stage, and life and illness experience, children might require information and want to be actively involved in the decision making about their treatment and care.

'I don't want to be constantly bothered having to talk through what to do next. I am dying... it is too much...I don't want all these choices...when my son died, I wanted to be involved in all the decision-making.. this time, I have made the big decision not to have any more treatment. That is enough.'

Patient comment quoted in Street 1998

Good practice example: Living Well project (statewide specialist organisation)

The Living Well project was developed for people living with motor neurone disease and their carers in response to identified needs. The eight-week program is professionally facilitated and provides the opportunity for patients and their carers to meet with others with a similar life experience to explore issues around life changes, death and dying, and practical and legal matters. The program offers participants a greater understanding of themselves and others, less fear, more positive attitudes and an increased ability to make informed choices.

The Living Well facilitators' kit offers a range of print and electronic resources for health professionals to offer this program throughout Australia and overseas.

Advanced care planning

Advanced care planning is an interactive process of communication between a person and the health care provider to determine the person's wishes for their treatment, and often, their death (Department of Health and Ageing 2004). Ongoing discussion with and feedback to the patient and the people most important to the patient appears to be the most successful approach to determining the patient's preferences for care (Prendergast 2001). There is some evidence that people want to know whether they are dying and that they want their families to know too (Charlton 1991). However, cross-cultural research in this area is more limited (Kanitsaki 1998). There are wide variations in care of the dying and in bereavement practices and beliefs about death both between and within different cultural groups (Lickiss 2003). It is likely this variation is also reflected in the practices of disclosing the impending death to the patient and family members.

A systematic method to implement advanced care planning is the Respecting Patient Choices[®] project, which Austin Health has implemented. Preliminary project results indicate patients wanted to discuss their current health condition and future medical treatment options and valued the discussions and the information presented to them (Lee et al. 2003). Additional projects funded by the Australian and Victorian governments are underway in Victoria to implement advanced care planning.

Evaluating these projects and disseminating their findings is important for the ongoing development of advanced care planning initiatives. Of particular interest will be the experience of addressing advanced care planning with people from different cultural backgrounds.

Good practice example: Advanced care planning with a child and his family (specialist palliative care consultancy service)

A young child with a life-threatening, non-malignant condition and his family living in semi-rural Victoria were referred by the child's local medical practitioner for specialist support. The family was keen to discuss end-of-life issues, but was reluctant to link in with local palliative care services.

A home visit was held to discuss the family situation and the parents' wishes. In agreement with the parents, a letter was sent to all relevant hospital, school and community carers, and the ambulance service. One key worker was nominated as a point of reference for the parents and ensured regular verbal and written communication was maintained between carers and service providers. The child, the family and other carers are now well supported to achieve the family's wishes.

Achieving principle one

Key objectives

- To have patients and their carers and families actively participating in planning their care
- To have health care providers paying specific attention to advanced care planning in the care of people with a life-threatening illness and their carers and families

1.1 Action areas for the department

1.1.1 To promote and facilitate the use of advanced care planning by both generalist and specialist service providers, including palliative care services

1.2 Action areas for health and community care providers

1.2.1 To provide information resources for patients and carers which are responsive to their needs and reflect their learning style and cultural needs

1.2.2 To ensure local service providers have information about palliative care and community support services readily available

1.2.3 To regularly assess and respond to the individual needs of patients and their carers and families to ensure their appropriate involvement in case planning

1.2.4 To facilitate access to interpreters which will enable patients and carers who have limited English fluency to actively participate in discussions about care options

Principle two

Carers of people with a life-threatening illness are supported by health and community care providers.

Principle two: expected outcomes

- The health and wellbeing of the carer is enhanced by improved access to appropriate respite care and support services.
- Carers are adequately supported so they can provide care to the person with life-threatening illness in line with the patient's and carer's wishes.
- Carers' ability to navigate the system will be strengthened through the provision of information about available services and supports.

Carers and families make a vital contribution to care for people with a life-threatening illness and carer participation in care planning is critical to ensuring the best outcome for the patient. The Australian Bureau of Statistics (1998) found more than 100,000 Victorians (2.27 per cent) were primary carers for people with a disability or long term condition or elderly people.

Carers experience significant burden as a result of their responsibilities (National Council for Hospice and Specialist Palliative Care Services 1993) and the ageing population and smaller size of families further contribute to carers' physical, economic and emotional burden. In particular, carers of younger people with a life-threatening illness might also be responsible for young children and face the economic necessity of continuing paid employment.

Carers require service providers to recognise their needs and to pay particular attention to good communication and to providing practical support (such as home care and respite), service coordination, referral for financial advice, and emotional support. Service providers should regularly assess carers' needs and preferences, particularly concerning their ability and willingness to provide different aspects of care. Carers Victoria has developed a discharge checklist to assist health care professionals in including carers in transition planning. This checklist provides useful reminders that could be used during any stage of the patient's care (see www.carersvic.org.au for more information).

While working towards achieving this policy document's vision, carers need realistic information about their eligibility for and access to current support services, which might be limited in some areas (see principle one). Although accessing support services might be challenging for some carers, in other situations the burden on carers is compounded by the lack of coordination resulting in multiple carers visiting the home.

Therefore, a careful balance is needed between strengthening coordination of care, improving consistency in service delivery and ensuring care coordination empowers clients and families and does not impose unwanted service levels.

'In one week alone, I had 52 different people coming in from eight different agencies. It was overwhelming.'
Carer of motor neurone disease client

The Victorian State Government's key initiative for carers, the Support for Carers Program established in 1996, recognises the importance of supporting carers in their critical role of assisting people who require care to remain in their homes. A program evaluation in 2001, along with additional reviews of the program's components, concluded the program, while innovative for its time, is now underdeveloped as a conceptual framework for supporting carers and unable to provide sufficient coordination across participating programs. To this end, the Department of Human Services has endorsed the development of a strategic policy framework to promote a coordinated approach to meeting carers' needs.

Respite

Respite is an important element of care for the carers and families of people with a life-threatening illness. Carers and families need to know they have the opportunity for a break from their primary care role when needed and the person they care for will continue to receive the best possible care in their absence. Respite is required for many reasons,



such as short periods so the carer can maintain other social contacts and commitments or longer periods to give the carer a complete physical rest. Timely access to a diverse range of respite options (such as in-home, inpatient, out-of-home, residential and overnight respite) is a vital component of care that should be available when required. These diverse options should include an appropriate range of respite care to meet the specific needs of children and young adults.

The National Respite for Carers Program is an Australian Government initiative to support and assist relatives and friends caring at home for people who cannot care for themselves as a result of chronic illness, disability or frailty. In 2003, Commonwealth Carer Respite Centres received palliative care funding under the program to support them in providing respite for carers of people with a terminal illness. The Home and Community Care program also provides in-home respite.

Monitoring respite needs and ensuring access to a diverse range of options are important stages in planning services for adults and children with a life-threatening illness and their carers and families.

Home and Community Care program

The increasing disability of people with a life-threatening illness during the disease progression requires a need for home and personal care. The Home and Community Care program provides these services to assist with basic maintenance and support and thus enable individuals to continue living independently within the community (Department of Human Services 2003c). Regardless of age, people with a life-threatening illness are eligible for Home and Community Care program services. While palliative care services are part of the 'no growth' Home and Community Care program services, these relate only to providing specialist palliative care not basic maintenance and support. Eligibility is determined by an assessment of need and priority of access, as determined by the individual service provider and is informed by the Charter of Public Services in a Culturally Diverse Society (Department of Human Services 2003). This charter also supports the approach underpinning this palliative care policy of providing culturally sensitive services to special needs groups within the community (See principles five and six).

People with a life-threatening illness and their carers and families might have an urgent need for a service depending on their individual support needs, the complexity of their symptoms and the stage of their disease. It is important that specialist palliative care providers develop stronger partnerships with health and community care services so a shared understanding of the needs of people with a life-threatening illness and their carers is incorporated into service mechanisms to ensure a timely response to urgent requests.



Achieving principle two

Key objectives

- To have available a range of supports to meet the individual needs of carers, including information, respite, counselling and practical supports
- To have available responsive home care services

2.1 Action areas for the department

2.1.1 To work with the Australian Government to:

- ensure the National Respite Program for Carers meets the needs of carers of people with a life-threatening illness
- explore ways to improve access to appropriate residential care options for people who require respite care and for those who cannot remain at home but do not require inpatient care

2.1.2 To ensure the Department of Human Services' Carer Policy reflects the specific needs of carers of people with a life-threatening illness

2.1.3 To work with the Home and Community Care program to ensure a timely response to the needs of people with a life-threatening illness and their carers and families by:

- ensuring eligibility criteria are appropriately and consistently interpreted across the state
- developing guidelines for the appropriate prioritisation of palliative care referrals against other Home and Community Care referrals
- developing clearly defined criteria for shared care with palliative care services

2.1.4 To explore providing flexible funding packages to support the small number of paediatric patients who have intensive care needs and are not currently able to access appropriate support and equipment services

2.2 Action areas for health and community care providers

2.2.1 To regularly assess and respond in a timely manner to the individual needs of people with life-threatening illness and their carers and families. This might include:

- facilitating links to patient or carer support groups to reduce social isolation
- supporting the development of relevant carer support groups if needed.

2.2.2 To provide relevant information for carers about respite, counselling and practical supports as soon as possible after contact has been made with the person with the life-threatening illness. This should include information on access to specialist respite services as required.

2.3 Additional action areas for specialist palliative care services or consortia

2.3.1 To work in partnership with the Australian Carer Respite Centres to ensure carers of people with a life-threatening illness have access to the support and information they need

2.3.2 To ensure local services have established links with specialist statewide services, such as the Motor Neurone Disease Association of Victoria and the Victorian Paediatric Palliative Care Service

2.3.3 To facilitate regional negotiations to maximise access to responsive home services

2.3.4 To ensure regional plans identify how the consortia will meet the respite needs of the community and report service gaps to the department

Principle three

People with a life-threatening illness and their carers and families have care that is underpinned by the palliative approach.

Principle three: expected outcomes

- People with life-threatening illness, their carers and families receive optimal care through the adoption of the palliative approach by all health, community, residential aged and disability care services .
- The unique needs of the individual with a life-threatening illness and their carers and families will be addressed through developing and implementing an agreed care plan.

The palliative approach

The focus of the palliative approach is on improving the quality of life of people with a life-threatening illness and their carers and families through providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement (World Health Organization 2004a).

The needs of people with a life-threatening illness and their carers and families vary over time, depending on the development of symptoms, disability and burden (Lynn & Adamson 2003). These needs might include managing:

- pain and symptom distress
- emotional or spiritual concerns
- nutritional, speech or swallowing related issues
- practical difficulties (such as with transport or financial advice)
- problems with accessing information or psychiatric problems (Fitch 2000).

As such, palliative care is relevant to people at any stage of their illness and not confined to the final days and weeks of their life. Palliative care is also not limited to people with cancer; people with life-threatening illnesses such as neurodegenerative disease and advanced organ failure might also benefit from the palliative approach (Kristjanson, Toye & Dawson 2003).

Many patients with a life-threatening illness, however, do not require direct access to specialist palliative care, rather their additional needs can be met through the support of their general practitioner or other existing primary and community service providers who in turn have access to specialist services (Palliative Care Australia 2004). However, the palliative approach is required to achieve high quality care.

Good practice example: In-reach to small hospitals with no palliative care beds (rural palliative care service)

Rural hospitals that do not have designated palliative care beds need access to specialist palliative care services and expertise. The palliative care medical consultant provides primary and secondary consultation across the region, with emphasis on ensuring all regional hospitals have access to the consultant. The medical consultant visits all hospitals within the region on a rostered basis and according to identified need. At the same time, the community-based palliative care nurses attend hospitals and provide input into assessments and care plans for palliative care patients. General practitioners and nurses are also able to contact the medical consultant or palliative care nurse specialist by telephone with their queries about patient care.



Both these in-reach activities provide people receiving palliative care services with a coordinated and integrated approach to their care. Importantly, those hospitals that do not have designated palliative care beds have ongoing access to specialist palliative care services and expertise.

The palliative approach that focuses on quality of life for the patient is good medical, nursing and allied health practice and is not just the role of specialist palliative care providers (National Council for Hospice and Specialist Palliative Care Services 1993). While the palliative approach should be a part of the treatment repertoire of all care providers in managing people with a life-threatening illness and their carers and families, these skills cannot be assumed. The palliative approach extends beyond 'usual' primary care and incorporates specific palliative care knowledge, attitudes and skills, including communication skills and 'breaking bad news'.

Further education and skills development for all generalist care providers is essential to ensure continuing skills development and quality of care (Palliative Care Australia 2004). In addition, specialist palliative care providers need to share their expertise with the generalist health care providers to ensure the most appropriate care provider meets the patient's needs (Glare & Virik 2001).

Generalist health and community care services should ensure all staff receive regular education in the palliative approach (Kristjanson, Toye & Dawson, 2003). To assist this, the Australian Government is providing funds to each state and territory to enable primary health practitioners to gain professional exposure to and experience in palliative care. This project, the Program of Experience in the Palliative Approach, was established to provide primary health practitioners with an opportunity to develop knowledge by undertaking a workforce placement with a specialist palliative care service.

It is important that health and community care services recognise the needs of people with a life-threatening illness and their carers and families and ensure the service's policies and protocols reflect the palliative approach. This approach involves providing an appropriate environment for patients who require terminal care, psychological and emotional support for those patients, and support for their families and carers. The Liverpool Integrated Care Pathway for the Dying Patient (Ellershaw & Wilkinson 2003) was developed

to improve the care of the dying patient, particularly in the last week of life. This pathway assists general health care providers in adopting a palliative approach and following best practice in pain and symptom management. This pathway might provide a framework that can be modified, extended and trialled to suit the hospital, community and residential care environment.

Including the palliative approach in undergraduate and postgraduate education programs for a wide range of service providers will further support the continuing adoption of the palliative approach (see principle six).

Residential care (including supported residential services)

The recognition that palliative care is relevant not only to terminal care but also to progressive debilitating diseases highlights its relevance to the residents of aged care facilities who grow increasingly more frail and disabled and who can suffer from multiple co-morbidities. However, the values, commitment and interest of residential care providers might influence access to the palliative approach and services.

Strengthening palliative care in residential aged care facilities was the focus of an Australian Department of Health and Ageing project (2004). The project's Guidelines for a Palliative Approach in Residential Aged Care support this approach as an opportunity to reduce distress for residents and families and to support residents in their wishes for their future care.

As with other generalist services, it is important that residential aged care providers have access to appropriate support from generalist and specialist palliative care services and service providers to enable them to support residents with their palliative care needs.

Cultural issues

The focus of palliative care on enhancing quality of life demands an understanding of a person's values and the meaning attached to those values. Values are influenced by the cultural experiences and beliefs of the person and are important in the care of someone who has a life-threatening illness. Culture, which includes elements of attitudes, behaviour, customs, language, types of dwelling and clothing, art and social institutions (Lickiss 2003), is particularly relevant to the issues people with a life-threatening illness face.

For carers of people with a life-threatening illness, cultural sensitivity, competence and responsiveness are required in a range of areas, including communication (language, disclosure and dissent), modes of decision making, an understanding of disease, pain and other symptoms, concepts of death and dying in relation to the rest of life, customs surrounding death, and spiritual and religious issues (Lickiss 2003).

For those from culturally and linguistically diverse backgrounds, past experiences of loss and grief associated with migration, disenfranchisement and dislocation (Kanitsaki 1998) might result in more complex responses to the experiences of a life-threatening illness and death.

The Cultural Diversity Framework (Department of Human Services 2003d) provides a structure for planning and delivering culturally responsive services across the broader human services sector. This framework highlights the need for systematic processes in understanding the multicultural characteristics of the service population, developing partnerships with multicultural stakeholders, and creating a culturally diverse workforce. It can guide service providers in planning a systematic approach to diversity.

Good practice example: Working with the Vietnamese community (metropolitan palliative care service)

After recruiting a Vietnamese-speaking project officer, this specialist palliative care service undertook a needs analysis to ensure its services were accessible and appropriate to the large Vietnamese-speaking community in the region. As a result, the service recruited, trained and supported Vietnamese-speaking palliative volunteers to work with people with palliative care needs. The service made language-specific information available and extensively publicised in local newspapers information on palliative care supports in the region. At the same time, agency staff undertook cultural awareness training in the Vietnamese community's specific palliative care needs. The main outcome of these initiatives is a more effective and culturally sensitive service using Vietnamese-speaking volunteers and staff.



The Multicultural Palliative Care Guidelines (Taylor & Box 1999), developed by Palliative Care Australia, provide practical advice for health care professionals caring for people with a life-threatening illness and their carers and families. The guidelines also include cultural information about 20 language groups, which can assist staff when they approach someone from that culture.

The Department of Human Services' web site www.health.vic.gov.au/palliativecare contains the results of several Victorian projects that aimed to promote awareness of and access to services for people from culturally and linguistically diverse backgrounds and to foster culturally sensitive palliative care services through staff training and support. Key learnings from these projects can assist providers to develop policies, protocols and practices that reflect a culturally responsive service.

A particular priority for the Australian Government has been to improve palliative care services for Aboriginal and Torres Strait Islander people. A study of national Indigenous palliative care needs (Sullivan et al. 2003) was undertaken to provide an understanding of Aboriginal and Torres Strait Islander people's needs, how well current services meet those needs, and how the national palliative care strategy can achieve its aims for Indigenous people. The study results identified elements of good practice and key targets for future service development. Information from this project provides a sound basis for health care providers to develop appropriate and accessible services for Aboriginal and Torres Strait Islander people.

A resource kit, Providing culturally appropriate palliative care to Indigenous Australians, has recently been developed as part of the National Palliative Care Program.

Good practice example: Indigenous Palliative Care Project (metropolitan palliative care service)

A metropolitan palliative care service conducted a pilot project, which brought together the community palliative care service, a local Aboriginal health service and an Aboriginal cooperative. The project's aim was to look at how to provide best practice palliative care to the Indigenous community in a way that is culturally respectful and best meets the needs of the Indigenous community.

The project facilitated a meaningful two-way cultural exchange, with palliative care professionals and volunteers receiving training in working with the Indigenous community. Four Aboriginal community representatives successfully completed a modified version of the Palliative Care Volunteer Program, while other Indigenous community members learnt about palliative care and bereavement support, drawing on relevant language and concepts.

This initial pilot project has strengthened links between palliative care providers and the Indigenous community.

People with a disability

People with a disability can have special needs related to their disability. Those with cognitive disabilities or severe communication needs, for example, might be unable to express their needs concerning pain management or the side effects of medication.

Specialist palliative care providers need to be aware of the specific needs of people with a disability and those who care for and support them. For people who live in community residential units, the units are their home, and as such, the residents might require the advice and support of specialist palliative care providers for grief and bereavement counselling. Further, the staff supporting residents in community residential units might not be familiar with the palliative approach and might require specific training and support to ensure people with a disability receive optimal palliative care.

Children with life-threatening illness

Children with life-threatening illness and their families have particular and varying needs depending on the child's developmental stage, the nature of the life-threatening illness, and the significant uncertainty that might accompany the prognosis and medical treatment.

The developmental differences of children can not only influence treatment strategies but make communication and decision making processes more complex. As a result, the issue of discussing their impending death might be a challenge for the child, the parents, extended family and service providers (Noone 1998).

While the general principles of palliative care apply to both adults and children, as with other special needs groups, there are specific needs and care approaches in which generalist or specialist service providers might have limited experience. Specialist paediatric services, such as the Victorian Paediatric Palliative Care Program and Very Special Kids, play a critical role in supporting generalist services (see principle four).



Achieving principle three

Key objectives

- To have health, community and residential aged and disability care services integrate the palliative approach into their practice
- To have cultural sensitivity, competence and responsiveness evident in the practice of health, community and residential care services

3.1 Action areas for the department

3.1.1 To work with the Australian Government to facilitate the implementation of the Guidelines for a Palliative Approach in Residential Aged Care, including:

- the provision of additional and appropriately skilled resources
- the trialling of innovative models of care in residential facilities
- the incorporation of evidence of the palliative approach in the accreditation and standards for aged care services

3.1.2 To develop a strategy to meet the needs of Indigenous people who have a life-threatening illness and their families and carers. This will include working with the Australian Government to implement the recommendations of the National Indigenous Palliative Care Needs Study (Sullivan et al. 2003) and with the Victorian Aboriginal Community Controlled Association to implement Indigenous palliative care projects.

3.1.3 To work with department's Disability Services Division to facilitate the implementation of the palliative approach into the care of people with a disability

3.1.4 To investigate adapting the Guidelines for a Palliative Approach in Residential Aged Care for health and community care providers (links with principle six)

3.2 Action areas for health and community care providers

3.2.1 To ensure the palliative approach is incorporated into generalist services, including residential aged care and disability services. This will include developing and modifying care pathways and implementing staff orientation and ongoing in-service programs.

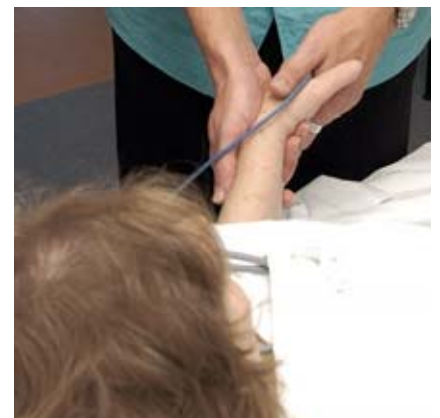
3.2.2 To respond sensitively to the needs of the individual and family from diverse cultural backgrounds by:

- providing ongoing cross-cultural training for staff which specifically addresses the cultural influences on palliative care, death, loss and grief
- encouraging the employment of bilingual staff or staff from a culturally and linguistically diverse background
- developing and implementing protocols for the formal early and ongoing assessment of needs for and the routine provision of interpreter services

3.2.3 To ensure links are made with specialist paediatric palliative care services to facilitate optimal care for children with life-threatening illness and their families

3.3 Additional action areas for specialist palliative care providers

3.3.1 To work in partnership with local residential aged and disability care services to provide ongoing in-service training in the palliative approach, including the health-promoting palliative care approach (links with principle seven)



Principle four

People with a life-threatening illness and their carers and families have access to specialist palliative care services when required.

Principle four: expected outcomes

- Patients with life-threatening illness and complex needs have appropriate and timely access to specialist palliative care through an integrated service system.
- All carers and family members assessed with complex grief and bereavement are provided with information about and access to appropriate counselling and support.

While all health and community care providers have responsibility for adopting a palliative approach for people with a life-threatening illness and their carers and families, specialist palliative care providers have a principal role in supporting the care provided by primary and tertiary care providers, assessing complex symptoms and providing options for care (Maddocks 2003). They can undertake this role by providing direct care for the small number of complex patients and secondary consultation for the majority of people. While all patients might need information and many patients need emotional or psychological support, only some patients need complex symptom management (Fitch 2000).

Role designation

As indicated in the section, 'A plan of the future', role designation provides an important framework for improving access to appropriate specialist palliative care services for people with life-threatening illness across Victoria.

Timeliness

The increasing length of life from cancer diagnosis to death and the variable trajectory of some illnesses have changed the need for palliative care at the end of life. Care is now needed earlier in the course of the disease (Glare & Virik 2003). Access to specialist palliative care should be based on the need for complex symptom management and complex grief and bereavement issues and not on the estimated time to death.

Palliative Care Australia (2004) further defined this complexity of need in a recent draft paper. As a guide, this paper identifies the patient features that require specialist consultancy and direct specialist care. They are outlined here.

Specialist palliative care consultancy	Required there is an exacerbation of a previously stable symptom or there are identified needs (physical, social, emotional or spiritual) that exceed the capacity (knowledge, resources facilities) of the primary palliative care service or provider
Direct care from a specialist palliative care service on an ongoing basis	Required when one or more of the following is present: <ul style="list-style-type: none"> • complex pain or symptoms not responsive to established management protocols • complex psychological or social needs • increased risk of complicated bereavement for family or carers

Increasing health and community care providers' knowledge and skills of the palliative approach (as outlined in principle three) will assist in timely and appropriate referral. However, services need to consider a more structured approach to ensuring timely access to specialist palliative care services. This approach might include appropriate triggers for specialist palliative care services in care pathways, developing joint clinics or joint ward rounds with selected specialty areas (such as oncology), participating in multidisciplinary meetings, and assessing and screening people with a life-threatening illness and their carers and families to identify the need for specialist palliative care services.

Effective communication between specialist palliative care providers and the general practitioner might enhance the care of the client and carers. In addition, shared care agreements with General Practice Divisions might strengthen the interface between generalist and specialist services and reduce the need for referral for direct specialist care.

Assessment and screening that evaluates pain and symptoms, complex grief and bereavement risk, and spiritual care needs will help to determine the need for specialist palliative care services. Triggers might be uncontrolled pain or symptoms, or features associated with complex grief, such as lack of social supports, the age of the bereaved person, whether cumulative loss has occurred, and whether the illness is lengthy (Centre for Palliative Care 2000).

A validated screening tool would assist general service providers in ensuring the standard for accessing specialist palliative care across the state is uniform and not based on the palliative care experience or variable knowledge of the general provider.

Assessment and screening that evaluates pain and symptoms, complex grief and bereavement risk, and spiritual care needs will help to determine the need for specialist palliative care services.

Availability

Currently, a variety of both community and hospital providers provide specialist palliative care services; however, access to specialist palliative care is variable across the state. There is inconsistent access to consultancy or in-reach consultancy services in non-designated palliative care beds across health services. Further, the range of specialist palliative care services provided is variable, as is the availability of appropriately qualified staff for designated palliative care beds in hospitals. This variation is particularly evident in facilities with only one or two designated palliative care beds.

Variation in the models of community specialist palliative care has resulted in the provision of a variable quality of care. Some specialist palliative care services use generalist staff to provide the care because skilled staff are not available. Further, the individual contract arrangements of providers might result in inconsistency in the skill level of those providing specialist palliative care services. For this reason, the costs to patients vary depending on the provider who has been contracted to provide the care.

Good care planning involving the patient and carer can minimise the need for out-of-hours service.

Out-of-hours services

Good care planning involving the patient and carer can minimise the need for out-of-hours service. However, during the progression of the illness, people with a life-threatening illness and their carers and families might require direct care on a daily basis. While general medical and nursing services can provide this care, they might need up-to-date information on the patient's condition, as well as secondary advice from specialist palliative care providers. Regional (and if necessary, sub-regional) planning is necessary to ensure direct care and secondary specialist palliative care consultation are available when required for people with a life-threatening illness.

Medication

Clear protocols across a region or sub-region are necessary to ensure there is access to medications as required. In rural areas, some specialist palliative care services have developed arrangements with local hospitals to provide specific medications after hours while other services anticipate patient need for medication and ensure these medications are placed in the patient's home.

Good practice example: Emergency use of palliative care drugs (rural palliative care service)

This project's purpose was to ensure patients who unexpectedly require medication for symptom control are able to promptly access this medication. It established a protocol between the local hospital pharmacy and the commercial pharmacies in the region, in conjunction with the Division of General Practice. The palliative care staff listed the medications patients in home and residential care most commonly require and negotiated after-hours access to them through the local hospital pharmacy. The palliative care service held an information evening with the general practitioners and pharmacists to inform them of this service.

Costs for these medications are covered through the Unassigned Bed Fund. While staff successfully anticipate the medication requirements of most patients, the protocol provides an important adjunct to pharmacy services when unanticipated emergencies arise.

Special needs groups

In addition to specialist palliative care, special needs services might be required. These statewide services provide education and support to palliative care service providers and the community in relation to specific issues, such as human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), motor neurone disease, multiple sclerosis, and children's needs.

These and other specialist patient groups are identified as having specific needs and care approaches that might not be familiar to care providers who have not previously worked with such groups. Links with the organisations that provide special needs services, such as the Motor Neurone Disease Association of Victoria, the Victorian Paediatric Palliative Care Program, and the Victorian HIV Consultancy, are an expectation of all specialist palliative care providers.

Good practice example: Caring for John (specialist palliative care consultancy service)

John was 15 and required palliative care at home. He lived in a remote rural area with no general practitioner or hospital services within 100 kilometres. The local bush nursing service provided support for John.

The specialist care services provided information to the bush nurses about symptom management and purchasing and using a syringe driver, and telephone counselling to family members. The bush nurse liaised daily with the paediatric oncologist, including at weekends as necessary. Through this communication, John's escalating symptoms were controlled using Morphine and Dexamethasone. The nurse was able to stay with John and his family throughout his final day and John died peacefully at home.

Day hospices

In Victoria, there has been a strong interest in developing day hospice services. A day hospice is a specific day care service that supports patients with a life-threatening illness to remain in their own homes. It can provide:

- the opportunity to monitor and control physical symptoms, thereby preventing admission to hospital
- relief from social isolation
- respite for the carer.

This service provision is consistent with the Victorian State Government's objectives to maintain people in their own homes, to prevent avoidable admission to acute care, and to support carers and families.

While day hospices are prevalent in the United Kingdom (Goodwin et al. 2003), they have been less prevalent in Australia and there has been little evaluation of day hospices to determine their effectiveness (Spencer & Daniels 1998).

In Victoria, a day hospice has been operating at Caritas Christi for the past three years. To evaluate the day hospice model of service delivery in the Victorian context, three day hospice pilots are underway. The results will reveal their value to patients and cost-effectiveness to inform the future development of day hospices in Victoria.

Grief and bereavement

Psychological and spiritual support is an integral component of palliative care and should be a routine part of care for people with a life-threatening illness and their carers and families. Direct clinical staff provide most of the general psychological support and play an important role in identifying distress, anxiety and depression (National Institute of Clinical Excellence 2003).

While grieving is a normal response to loss and not everyone needs expertise to manage their grief (Maddocks 2003), some people are at risk of a complicated grief or bereavement response. The factors that might put carers and family of people with a life-threatening illness at risk of complicated bereavement include the characteristics of the bereaved, the characteristics of the dying person, the character of the interpersonal relationships, and the characteristics of the illness and nature of death (Centre for Palliative Care 2000). These factors take account of:

- the age of the bereaved
- whether the bereaved has a history of mental illness
- whether the bereaved has experienced cumulative multiple loss
- whether the bereaved has few adequate coping mechanisms
- whether the dying person is a child or the parent of a young person
- whether the bereaved lacks social support
- whether the dying is from an inherited disorder or a stigmatised disease
- whether the illness before death is lengthy.





Palliative Care Australia (1998) outlined principles for providing a bereavement support program which is part of a specialist palliative care service. These principles highlight the need for a structured approach to bereavement support, including an assessment for risk of complex bereavement, specialist counselling for those who are at risk or have a complicated grief reaction, and education and training for staff and volunteers. The Centre for Grief Education (2001) has developed minimum standards for bereavement support programs in palliative care services in Victoria. These standards are compatible with the principles developed by Palliative Care Australia and are provided with clear guidance on how to achieve the standards.

The Department of Human Services (2004a) has undertaken a review of specific grief and bereavement services to explore how to optimise the specialist grief and bereavement services funded by the department to strengthen the community's resilience in dealing with loss, grief and bereavement and to clarify the services' respective roles within the wider service system.

The review focused on:

- determining the priorities and opportunities for loss, grief and bereavement services (including clinical services, training, education research and consultancy) within the broader service system
- clarifying the respective roles, responsibilities, strengths and weaknesses of the specific funded services
- identifying the synergies and opportunities that might be promoted across the services to maximise client outcomes
- ascertaining the services' accessibility by those in the community who require grief and bereavement services, along with how existing services can best meet those needs.

Achieving principle four

To achieve this principle and to support the overall policy directions, a regional approach to service planning and development through establishing palliative care consortia and implementing role designation is clearly identified and articulated in earlier in the section 'A plan for the future'. The objectives and action areas identified here build on this framework and address more specific issues.

Key objectives

- To have specialist palliative care services available when required
- To give people with life-threatening illness, and their families and carers access to general direct care services, appropriate medication and specialist consultation or care on a 24-hour, seven-day-a-week basis
- To have a systematic approach and access to the provision of grief and bereavement services across the continuum of care

4.1 Action areas for the department

4.1.1 To work with service providers to develop validated screening and assessment tools for people with a life-threatening illness and their carers and families to facilitate referral to specialist palliative care services

4.1.2 To work with Palliative Care Victoria to develop a statewide communication and information strategy which will develop or disseminate a range of palliative care information materials to meet identified gaps and to be available to various target audiences, such as general practitioners, community providers and specialist medical consultants

4.1.3 To review funding arrangements to ensure equity of a notional regional budget (inpatient and community) for specialist palliative care services, based on a population needs-based funding formula

4.1.4 To review the evaluation outcomes of the day hospice program and determine the future directions

4.1.5 To work with the palliative care field to develop clinical indicators for specialist palliative care services

4.1.6 To work with services to address unmet needs in accessing 24-hour care on a seven-day-a-week basis. This includes investigating different models of 24-hour, seven-day services and improved access to medication

4.1.7 To improve access to specialised grief and bereavement services

4.2 Action areas for health and community care providers

4.2.1 To ensure all relevant care pathways include triggers for specialist palliative care

4.2.2 To educate staff in identifying the factors that might contribute to complex grief and bereavement

4.3 Additional action areas for specialist palliative care providers or consortia

4.3.1 To develop links with specialist treating teams, such as oncology and haematology, local disability specialists and so on

4.3.2 To develop mechanisms to ensure people have access to appropriate services on a 24-hour, seven-day-a-week basis. This includes access to direct services, specialist palliative care consultation services and after-hours medication.

4.3.3 to provide quality bereavement support services for palliative care service clients by:

- Providing skilled and trained staff to assess and counsel clients with potential or actual complex grief and bereavement
- Having services comply with the minimum standards for bereavement support programs in palliative care services in Victoria (Centre for Grief Education 2001).

Principle five

People with a life-threatening illness and their carers and families have treatment and care that are coordinated and integrated across all settings.

Principle five: expected outcomes

- Services are coordinated in the best way to meet the needs of people with life-threatening illness and their carers and families.
- People with life-threatening illness will be able to clearly identify the key contact in the provision of their care.

People with a life-threatening illness and their carers and families need to access varying levels of support, treatment and care across the term of their illness. To achieve integrated service delivery across a range of settings, all service providers need to work together to ensure care and support is provided as a continuum of care. However, coordinating care for people with a life-threatening illness and their carers and families might be difficult in the health care and community services system, with people being treated in different geographic locations and by a variety of providers that have different reporting arrangements with state and local government organisations.

Primary care partnerships

The goal of the Primary Care Partnership Strategy is a health system that is more functionally integrated (Department of Human Services 2004b). The strategy is achieving significant system improvements, including improved coordination of services and better management of waiting lists and the engagement of Divisions of General Practice and general practitioners. Service coordination is delivering a consistent, statewide approach to collecting and sharing consumer information, streamlining referral between agencies and across sectors and leading to successful collaboration between primary care providers (Department of Human Services 2004b). The Department of Human Services has mandated that all service providers use the primary care partnerships service coordination tools from July 2006.

In line with this mandate, specialist palliative care providers need to develop ways in which they can participate in the service coordination activities of their local primary care partnerships to:

- complement common practices, processes, protocols and systems to integrate the way in which consumers come into contact with the service system, how needs are identified and assessed, and the way in which care is planned and managed
- enhance the flow of information between service agencies and between service providers and consumers
- adopt the initial needs identification, referral and client consent tool templates
- contribute to the Statewide Health Services Directory.

More information on the primary care partnerships is available at <http://www.dhs.vic.gov.au/phkb> (Primary Health Knowledge Base).

The Statewide Health Services Directory is Victoria's most extensive health and community support services directory. It provides access to a current, accurate database of health and associated community support services in Victoria and contains information on more than 30,000 health and community services across Victoria. This directory can be used to assist providers to identify a wide range of health and care services available in a particular geographic location. It provides contact details for services and can assist timely access to a service.

Continuity of care is critical to efficient and effective treatment, the prevention of crises, and patients' satisfaction with their experience of care. Many factors can influence continuity of care, including streamlined assessment, links between providers, accessible patient information, good communication and the coordination of care. The following discussion examines ways of facilitating continuity of care.

Assessment

Patients and their carers do not want to be subjected to repeated or inadequate assessments. Service providers using and strengthening common assessment processes and approaches, along with developing specific assessment tools, should streamline assessment and enable care providers to share assessment data at key points so individual care can be planned without assessment by another provider.

The Department of Human Services is exploring functional dependency assessment tools across several programs within the department to identify the potential for common assessment tools and what additional tools might need to be developed to meet the specific assessment requirements of specialist practice areas, such as palliative care.

Care coordination

Complex patients require a care coordinator who the patient, carer or other community care providers can contact for advice, support and planning for service provision. Care coordination enables continuity of care, avoids duplication of services and ensures meeting consumer needs is paramount (over the needs of individual service providers) and not hampered by program boundaries (Department of Human Services 2004c).

The care coordinator might be one of a number of providers over the course of the patient's illness and might depend on the primary need and care provider of the patient at the time. The role as described by the National Institute of Clinical Excellence (2003) involves:

- negotiating with providers, patients and their carers to achieve the most efficient way in which to provide care for the patient
- communicating the agreed care plans in a timely manner to all providers involved in the care
- assisting the transition of care from hospital to community and from community to hospital and being a point of contact for the patient or carer for help or advice.

While there is considerable support for the case coordinator role within palliative care and other complex speciality health areas (for instance, cancer services as demonstrated in the Cancer Services Framework (Barton et al. 2004) and Optimising Cancer Care (Clinical Oncological Society et al. 2003)), its effectiveness might depend on the skills set of the designated coordinator, how the role is enacted within an interdisciplinary team, how





communication is facilitated across the team and the development of contingency plans for the unexpected crisis. Further clarification and evaluation of this role's effect on patient outcomes is required to ensure it facilitates case management and coordination.

A specialist palliative care provider's liaison with hospitals, general practitioners and other community providers can also streamline the transition of care across settings. The specialist palliative care provider can be a contact for general practitioners and patients seeking advice on specialist palliative care, a contact for acute care specialists seeking information on palliative care services, and a palliative care resource for general care providers in the community or hospital.

Patient records

The Department of Human Services recognises access to electronic patient records provides an opportunity to decrease data redundancy, hard copy recording and test duplication, while improving access to patient information across the acute and primary care sectors. This access is a priority of the HealthSmart strategy, which focuses on systems that support the provision of care across the acute and primary care sectors and across any agencies (Department of Human Services 2003f).

Literature has identified handheld health records as having benefits for both consumers and health professionals (Drury et al. 2000). Such records have the potential to give patients more control over their information and also a greater ability to be involved in their treatment and care. They also improve communication about patient care between providers and enable all providers to have the most current information about the patient to ensure timely and accurate provision of care.

Interdisciplinary care

The needs of people with a life-threatening illness and their carers and families might include managing pain and symptom distress, emotional or spiritual concerns, nutritional, speech or swallowing related issues, psychiatric problems, practical difficulties (such as with transport or financial advice), and problems with accessing information (Fitch 2000).

Depending on the type of need, a variety of skill levels might be required: a combination of generalist and specialist providers and volunteers might therefore work together to meet a patient's needs. These needs can be best met by an interdisciplinary team that collaborates to provide the most appropriate care for the person by the most appropriate member of the team. This includes occupational therapy, physiotherapy, dietetics, social work, pastoral care and pharmacy. It is important that specialist palliative care providers access the appropriate members of a team when required.

People with a life-threatening illness and their carers and families might experience significant psychological and emotional distress as a result of their diagnosis or treatment, with the prevalence of long-term psychological distress in patients with cancer ranging from 20 per cent to 60 per cent (Zabora et al. 2001). There is some evidence that psychological needs are more commonly reported to be unmet in cancer patients (Sanson-Fisher et al. 2000). The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (National Breast Cancer Centre and National Cancer Control Initiative 2003) is a valuable resource for clinicians in guiding the psychological care of people with cancer. All health professionals are encouraged to use these guidelines to ensure best practice in managing these patients.

Many of the issues and strategies highlighted in these guidelines are also relevant for all people facing a life-threatening illness.

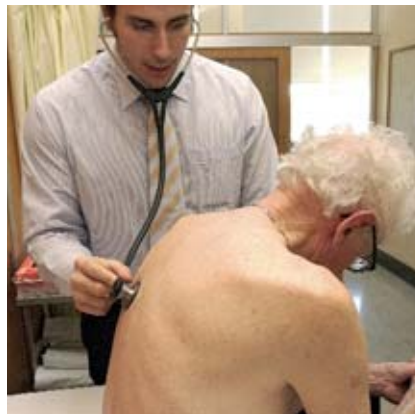
Psychological interventions include (in increasing skill level) self-management, support groups, anxiety management, and psychological therapies, such as cognitive behavioural therapies and specialist psychiatric interventions (National Institute of Clinical Excellence 2003). Access to a range of staff with the appropriate skill level is an important element of psychological care for people with a life-threatening illness.

General practitioners

While the prime responsibility for care varies depending on the setting in which the care is provided, all members of the care team must be informed of decisions about care planning. The hospital–community interface has been identified as an area in which communication frequently breaks down (Street et al. 1999). General practitioners are usually the first point of contact for people seeking primary health care (Street et al. 1999). They have the ability to provide contextual knowledge of the patient and family dynamics, to undertake medical monitoring, to intervene to prevent or control symptoms, and to provide medical care for the carer (Mitchell, Reymond & McGrath 2004). As such, general practitioners are a fundamental part of the care team for people with a life-threatening illness and their carers and families.

The majority of general practitioners might care for only one palliative patient during the year (Street et al. 1999). There is also some evidence that general practitioners are less likely to identify symptoms they find difficult to control (Grande, Barclay & Todd 1997). However, general practitioners still provide much of the medical care required by patients who die in the community (Mitchell 2002). Further, general practitioners consider they should be involved in the care of their terminally ill patients (Street et al. 1999). Appropriate education and support for general practitioners about both the palliative approach and referral to specialist palliative care providers can result in stronger general practitioner engagement with palliative care services, improved care and early specialist referral (Loddon-Mallee Palliative Care Service 2002).

However, for general practitioners to provide advice and support to patients, they need timely information about a patient's diagnosis and drug treatment from specialist teams. In addition, general practitioners need to be informed when a specialist refers a patient to community services (Street et al. 1999).



Good practice example: General practitioner after hours (rural palliative care service)

This innovative project ensures all palliative care patients in the region have after hours access to skilled palliative expertise by rostering the two palliative consultants and a team of local general practitioners with a special interest in palliative care. The project also provides telephone advice to rurally-based general practitioners in the area.

Monthly clinical meetings are held with the palliative consultants and general practitioners for operational and educational updates. Participating general practitioners have clinical appointments with the regional health service and are remunerated when participating on the roster. Visits to the general practices in the community by the two palliative consultants and community palliative care nurse coordinator also occur to promote palliative care excellence.

Strategies general practitioners have suggested as valuable are faxed discharge letters from hospitals, including the general practitioner's name on the bed card, and formal regularised channels of communication with general practitioners or hospitals when patients are readmitted (Street et al. 1999). Standardised referral, discharge and management strategies, as well as a proposed set of communication strategies, would aid communication and improve continuity of care (Street & Blackford 2001). A palliative care physician with a general practitioner background who is attached to a palliative care service is also reported as a valuable resource for general practitioners (Street et al. 1999), and the sessional employment of a palliative care physician by community palliative care services has facilitated successful communication networks (Street & Blackford 2001).

Territorialism has been identified as potentially jeopardising the continuity of care (Street & Blackford 2001), although share care models have been successfully implemented (Mitchell, Reymond & McGrath 2004). Further, general practitioners are more willing to share care with specialist teams if they have experienced shared management (Yuen et al. 2203). This model requires clear identification of and agreement on the roles of the general practitioner and the specialist palliative care team.

As part of the Enhanced Primary Care Package, the Australian Government introduced Medicare Benefits Schedule item numbers which would enable general practitioners to be reimbursed for their time spent coordinating the care of patients with complex multidisciplinary care needs. These items have been used to improve links between hospitals and general practitioners in discharge planning and coordination (Department of Human Services 2004d). Using teleconferencing, attending multidisciplinary team meetings, good discharge planning and involving general practitioners might all assist continuity of care. The current refinement of the Enhanced Primary Care package will also facilitate its further uptake by both health services and general practitioners.

Achieving principle five

Key objectives

- To have specialist palliative care services and health and community care providers using common assessment and referral processes and protocols
- To give people with a life-threatening illness who have complex care needs a single person with appropriate expertise to coordinate their care
- To have specialist palliative care services using the service coordination tools developed by the primary care partnerships
- To have specialist palliative care providers using interdisciplinary teams that include acute care, general practitioners and community care providers

5.1 Action areas for the department

5.1.1 To work with health and community care services to streamline reporting requirements

5.1.2 To assist health and community care services to implement service coordination processes and protocols

5.1.3 To develop a patient-held record for people with a life-threatening illness and their carers and families

5.1.4 To strengthen the role of general practitioners in palliative care by working with the Australian Government and General Practice Divisions of Victoria to:

- encourage the uptake of the Enhanced Primary Care items
- promote training and career advancement opportunities for general practitioners
- develop education packages to support general practitioner training (Links with principle six).

5.2 Action areas for health and community care providers

5.2.1 To work with other service providers and adopt the department's service coordination tools which will facilitate timely and effective communication of patient information across providers, and in particular with general practitioners

5.2.2 To develop common standards and protocols for access and referral to specialist palliative care

5.3 Additional action areas for specialist palliative care providers or consortia

5.3.1 To allocate and review the care coordinator role for people with complex care needs

5.3.2 To work with local Divisions of General Practice and individual general practitioners to assist general practitioners to meet patients' palliative care needs. This might include the uptake of Enhanced Primary Care principles and processes in the health service

5.3.3 To develop specific protocols and mechanisms that will enhance communication within health services and between health and community services

Principle six

People with a life-threatening illness and their carers and families have access to quality services and skilled staff to meet their needs.

Principle six: expected outcomes

- People with life-threatening illness and their carers and families receive care and support from suitably qualified service providers and trained volunteers.
- All staff and volunteers involved in the care of people with life-threatening illness and their carers and families practice the palliative approach.
- People with life-threatening illness and their carers and families receive the best care available based on current research evidence.

Specialist palliative care services are required to demonstrate that their service includes the elements of quality that are critical to the palliative approach. These elements are included in the current Standards for Palliative Care Provision (Palliative Care Australia 1999). The Self Assessment Services Audit (Palliative Care Australia 2001) provides a structured method for assessing the standards of a palliative care service. Palliative Care Australia is revising these standards (and the associated audit tool) so they differentiate between generalist and specialist palliative care services. It is expected the revised standards and audit tool will be published by mid 2005 (Palliative Care Australia personal communication).

The current and future assessment process can be used as evidence of achievement and verification in the accreditation process of the Australian Council on Healthcare Standards. Services are encouraged to undertake this process as part of their quality improvement program.

The limited availability of trained medical and nursing palliative care staff is consistent with the difficulties in recruiting health care staff nationally and internationally. Demand for these staff is expected to rise further with the increasing age of the population and the improvements in lengthening the life of people with a terminal illness. To meet the workforce challenge in a range of health and community care areas, the Department of Human Services has established a project to improve its capacity to undertake workforce planning and to respond to workforce issues. A range of workforce initiatives is in place to influence the number of graduates, their distribution across Victoria, postgraduate vocational training, skills maintenance and career choices.

General practitioners

The majority of care for patients in their last 12 months of life occurs at home with the support of general practitioners and community service providers (Hinton 1994). The involvement in palliative care of general practitioners who can make home visits and provide after-hours care is critical in supporting people with a life-threatening illness to remain at home. There have been several projects to support general practitioners' work. The remuneration provided by the Enhanced Primary Care items, for example, aims to improve interdisciplinary care planning and to facilitate communication between general practitioners and other providers (Yuen et al. 2003).

The Australian Government has also recently undertaken a project researching training and support opportunities for general practitioners in palliative care in three specific areas:

- Indigenous and transcultural populations
- rural and remote communities
- people in home-based and residential aged care facilities.

This project's results will direct future training and experience in palliative care. Further, a project of the Caring Communities Program that the Mornington Peninsula Division of General Practice is undertaking provides experiential training for general practitioners across community and inpatient settings.

Good practice example: Strengthening general practitioners' skills – (Division of General Practice with local palliative care service)

Working with the local palliative care service, the Division of General Practice is implementing a project to strengthen local general practitioners' palliative care skills and referral practices. Over three years, 50 to 60 local general practitioners will spend four half-days with different palliative care services and providers. Early feedback is very positive, with an increase in referral from general practitioners who have already undertaken the program.

'Some GPs will use the experience to develop more awareness and be better practitioners. Others will develop a special interest and become more involved in care. A few may undertake more study and training.'

Service Manager

Education and training programs

The Australian Government has focused on training for nurses and allied health staff to develop skills in the palliative approach. The Program of Experience in the Palliative Approach was established to provide primary health practitioners with professional exposure to and experience in palliative care through a workforce placement with a specialist palliative care service.

The Australian Government is also presently undertaking a project to develop an educational resource that will incorporate palliative care approaches and techniques into the undergraduate curricula of medical practitioners, nurses and allied health professionals.

The Department of Human Services supports a number of training and development positions for medical, nursing and allied health providers within inpatient palliative care services. The department also offers postgraduate scholarships in palliative care nursing to support tertiary study by people who have demonstrated a commitment to the palliative care area.

In addition, services need to address the ongoing professional development and support needs of their staff. This might include access to formal internal and external education and skills development programs. Given the nature of palliative care work and its potential impact on staff, staff debriefing and professional supervision might be considered a critical element of professional development.

Volunteers

Volunteers make a significant contribution to people with a life-threatening illness and their carers and families. It is important that volunteers have appropriate training and ongoing supervision and support. Developing best practice principles in volunteer training and support and consistency of volunteer training across the state would enable the sharing of resources and the opportunity to access training in a different region if necessary. Volunteer coordinators play a vital role in planning and supporting the role of volunteers and are a necessary component of the volunteer program.

Good practice example: Strengthening supports to palliative care volunteers (rural palliative care service)

There was an identified need to strengthen the integration of the palliative care volunteer services across a wide catchment area with 17 different palliative care volunteer services while retaining local service ownership and identity. This had to be achieved with minimal paid support.

The auspicious agencies and volunteer coordinators met collectively and agreed to work on a common memorandum of understanding to improve partnerships with their sub-regional and regional palliative care services. They developed a common vision and mechanisms and structures for support at a local and regional level. Volunteers and their coordinators meet regionally and assist in developing common protocols and shared training.

As a result of this project, strong partnerships have successfully developed between rural palliative care volunteer services and regional palliative care services, other health providers and the local communities.



Academics

The Department of Human Services funds three academic positions: Professor of Palliative Care and Associate Professor of Palliative Care Nursing at the University of Melbourne, and Professor of Palliative Care at Monash University. The chairs were established to meet ensure the education and training of relevant staff (including medical, nursing and allied health staff) and more generally to broaden the community's awareness and understanding of palliative care.

The positions at the University of Melbourne and Monash University have a multidisciplinary training role and provide a consultancy service in their areas of expertise. They contribute to providing general practitioner, nursing and other medical accredited training and have a role in establishing the education curricula for other disciplines. Both universities have established research programs.

In addition to these department-funded academic positions, a number of other universities have academic positions in palliative care, including La Trobe University, Monash University and the Australian Catholic University. This significant academic investment in palliative care research and education in Victoria can underpin and facilitate this document's policy directions.

Achieving principle six

Key objectives

- To make available appropriately skilled specialist palliative care staff to meet the needs of people with a life-threatening illness and their carers and families
- To make available appropriately trained and supported volunteers to support people with a life-threatening illness and their carers and families

6.1 Action areas for the department

6.1.1 To undertake an audit of existing skills, qualifications, experience and professional development activities in the specialist palliative care sector (including acute health services with palliative care beds) and develop a plan to address identified gaps and issues

6.1.2 To work with the department's service and workforce planning units to address the specialist medical and nursing palliative care and allied health workforce supply issues

6.1.3 To work with the Australian Government and all education providers (universities, palliative care academic positions and TAFE organisations) to ensure the palliative approach is included in the undergraduate and postgraduate education of nurses, doctors, allied health professionals, patient care attendants and residential aged carers

6.1.6 To explore with the Australian Government models of remuneration for general practitioners, such as the Commonwealth's Better Outcomes for Mental Health Care Initiative

6.1.3 To work with providers to achieve consistent volunteer training and support across the state

6.2 Action areas for specialist palliative care providers or consortia

6.2.1 To ensure a sufficient capacity of appropriately skilled palliative care medical, nursing, allied health and counselling services to meet the needs of people with a life-threatening illness and their carers and families

6.2.2 To facilitate flexible approaches to staff support and professional development through debriefing and counselling and the development of professional supervision

6.2.3 To have department-funded palliative care academics disseminate information on their research outcomes and identify practice implications

6.2.4 To develop and implement a volunteer strategy that includes:

- employing volunteer coordinators on a regional or sub-regional basis
- providing consistent regional and local training and support.

6.2.5 To comply with current and future Standards for Palliative Care Provision (Palliative Care Australia 1999)

Principle seven

People with a life-threatening illness and their carers and families are supported by their communities.

Principle seven: expected outcomes

- Communities are able to actively support friends, family, neighbours, work and social contacts who have life-threatening illness and their carers and families.
- Community awareness of the needs of and supports for people with life-threatening illness and their carers and families is enhanced through community promotion and education.

Public health initiatives focus on improving the health of whole populations by addressing health inequalities and the underlying determinants of health and by empowering people and communities to achieve a state of wellbeing. Health promotion is the process that 'embraces actions directed at strengthening the skills of individuals, and changing social, environmental and economic conditions so as to influence their impact on public and individual health' (World Health Organization 2004b).

Health promotion initiatives include community development, community education, social policies and practices, and prevention strategies (Palliative Care Australia 2003). As in many other health care areas, health promotion initiatives can contribute to care for people with a life-threatening illness and their carers and families by building communities' capacity to respond to death, dying, loss and care.

Health promotion strategies might include death education, interpersonal skills training and a contribution to policies recognising death and dying as an element of life. A key aspect of health promotion is partnerships with schools, workplaces, community organisations, local councils and residential care facilities. One of the key deliverables of the Primary Care Partnerships Strategy is strengthening the existing service system's capacity to plan, deliver and evaluate effective, integrated health promotion programs (Department of Human Services 2004b). The reform's strength lies in the partnerships that have developed.

Current health-promoting palliative care initiatives are opportunistic with a limited understanding of the contribution they can make to communities. A systematic implementation of health promotion strategies would enable a community to more readily respond to the needs of people with a life-threatening illness and their carers and families. Not strengthening this community support will increase the burden on community, health and residential respite services.



Specialist palliative care providers need to participate in the Primary Care Partnerships Strategy and use the available opportunities to contribute to the integrated health promotion strategy as part of the Primary Care Partnerships community health plan.

The Palliative Care Unit at La Trobe University was established as a demonstration project in 1998 with funding from the Department of Human Services. The unit provides health promotion education and training, community development, direct service and research for clinical palliative care and related service providers throughout Victoria. It offers in-service death education and health-promoting palliative care programs, as well as conventional undergraduate elective subjects.

Good practice example: Exploring health-promoting palliative care in local rural communities (rural palliative care service)

This project arose out of the need to increase the capacity of community groups, organisations and services to use local community social networks to raise awareness that death, dying, loss and care is a shared concern for all communities. Using a health-promoting palliative care approach, a group of trained service providers and volunteers encourages palliative care awareness activities in the local community. A health promotion resource team and a pool of flexible health-promoting funds support these activities. Strategic partnerships are formed within the wider community to provide education, awareness and supportive environments for these activities.



Achieving principle seven

Key objective

- To have specialist palliative care providers' policies and practices reflect health-promoting palliative care

7.1 Action areas for the department

7.1.1 To work with Palliative Care Victoria, Palliative Care Australia, specialist palliative care providers and the Australian Government to raise community awareness of palliative care

7.2 Action areas for health and community care providers

7.2.1 To develop a planned approach to health-promoting palliative care which includes community development initiatives, health and death education, and partnerships with other palliative care services and community organisations

7.2.2 To contribute to the integrated health promotion strategy as part of the Primary Care Partnerships Strategy community health plan

7.3 Additional action areas for specialist palliative care providers or consortia

7.3.1 To strengthen the capacity of palliative care staff in community development/health promotion by actively recruiting staff with these skills and providing in-service training to staff.

Implementation

The Continuing Care Unit of the Department of Human Services' Metropolitan and Aged Care Services Division's Programs Branch will coordinate this policy's implementation.

Palliative care implementation advisory committee

A Palliative Care Implementation Advisory Committee will be convened in 2004. This committee will comprise representatives of relevant peak bodies, inpatient and community palliative care services and other key stakeholders from metropolitan and rural Victoria. Its proposed role and functions will include:

- advising and supporting the implementation of this policy document, *Strengthening palliative care: a policy for health and community care providers*
- advising on the key priorities for implementation
- providing links with expert and professional bodies and consumer groups to guide the strengthening of palliative care across Victoria
- strengthening collaboration and coordination between the department and palliative care services and among palliative care services
- providing advice on monitoring and evaluating the overall implementation of this policy and its initiatives.

The following table summarises the expected achievements in the first two years of the policy implementation.

Timeframe	Expected achievements
By December 2004	<ul style="list-style-type: none"> • Implementation working group/advisory committee established • Local regional consortia formed to develop and implement initiatives to achieve an integrated service system • Memorandum of understanding for consortia signed by agencies
By June 2005	<ul style="list-style-type: none"> • Regional plans with priority actions developed • Initiatives commenced to address service key delivery priorities identified in the regional plan • Work commenced on regional protocols and referral pathways • Links established with integrated cancer services • Population needs-based funding formula developed • Evaluation framework developed to monitor implementation of regional planning and overall policy • Strategy developed to address the needs of Indigenous people with life-threatening illness • Priorities and outcomes for subsequent years agreed
By December 2005	<ul style="list-style-type: none"> • Key service delivery initiatives underway • Health services given access to specialist palliative services through role designation • Agreed priorities for 2005–06 implemented
By June 2006	<ul style="list-style-type: none"> • Progress of regional initiatives reviewed • Service coordination tools adapted and implemented

Appendix 1

World Health Organization definition of palliative care

Palliative care improves the quality of life of patients and their families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor to 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.

Sourced from WHO web site, 16 July 2004

Appendix 2

Palliative care providers funded by the Palliative Care Program

Following is a list of palliative care providers funded by the Department of Human Services' Palliative Care Program.

Designated palliative care units

Metropolitan Melbourne

Austin and Repatriation Medical Centre	Monash Medical Centre (Clayton)
Calvary Health Care Bethlehem	Peninsula Health
Broadmeadows Health Service	St Vincent's Hospital
Caritas Christi Hospice	Sunshine Hospital
Mercy Werribee Hospital	

Rural

Bairnsdale Regional Health Service	Latrobe Regional Hospital
Ballarat Health Services	Mildura Base Hospital
Bass Coast Regional Health	Northeast Wangaratta Hospital
Barwon Health	Portland District Health
Bendigo Health Care Group	Seymour District Memorial Hospital
Central Gippsland Health Service	South West Healthcare
Colac Area Health	Western District Health Service
Djerriwarrh Health Services	West Gippsland Health Care Group
East Grampians Health Service	Wimmera Health Care Group
Gippsland Southern Health Service	Wodonga Regional Health Service
Goulburn Valley Health	

Community palliative care services

Metropolitan Melbourne

Banksia Palliative Care Services	Mercy Western Palliative Care
Calvary Health Care Bethlehem	Peninsula Hospice Service
Eastern Palliative Care	South East Palliative Care Ltd
Melbourne Citymission Palliative Care	

Rural

Barwon South Western Region

Barwon South Western Palliative Care:	
Barwon Health	Portland District Health
Bellarine Community Health	South West Healthcare
Colac Area Health	Western District Health Service

Gippsland Region

Gippsland Palliative Care:

Bairnsdale Regional Health	Gippsland Southern Health
Bass Coast Regional Health	Latrobe Community Health
Bass Coast Community Health	Lakes Entrance Community Health
Central Gippsland Health	West Gippsland Health Care

Grampians Region

Grampians Palliative Care:

Ballarat Hospice Care Incorporated
 Grampians Regional Palliative Care Consultancy Team (Ballarat Health Services)
 Central Grampians Palliative Care (East Grampians Health Service)
 Wimmera Hospice Care (Wimmera Health Care Group)
 Djerriwarrh Health Services, Palliative Care Service

Hume Region

Hume Regional Palliative Care:

Benalla and District Palliative Care Service	North East Health, Wangaratta
Goulburn Valley Hospice Care Service Incorporated	Wangaratta Palliative Care
Lower Hume Palliative Care	Wodonga Palliative Care Service
Moira Palliative Care	

Loddon Mallee Region

Loddon Mallee Regional Palliative Care:

Bendigo Community Palliative Care Service
 Echuca Community Palliative Care Service
 Macedon Ranges Palliative Care Service
 Maryborough Community Palliative Care Service
 Mount Alexander District Nursing and Palliative Care Service
 Sunraysia Community Health Palliative Care Service
 Swan Hill Palliative Care Service

Department-funded consultancy services

Bayside Health
 Eastern Health
 Peninsula Health
 Southern Health

Appendix 3

Public consultation paper May 2004 – stakeholder response

Submissions were received from the following organisations or individuals:

- anonymous (2)
- Austin Health
- Australian Department of Health and Ageing
- Australian Greek Welfare Service
- Australian Nursing Federation, Victorian Branch
- Australian-Polish Community Services Incorporated
- Ballarat Health Services
- Ballarat Hospice
- Bairnsdale Regional Health Service, District Nursing Unit
- Banksia Palliative Care
- Barwon Health
- Bass Coast Community Health Service
- Bayside Health
- Bellarine Community Health Incorporated
- Broadmeadows Health Service
- Cabrini Health
- Central Grampians Palliative Care
- Dr Adrian Dabscheck
- John Dalla
- Department of Human Services Eastern Metropolitan Region
- Department of Human Services Loddon Mallee Region
- Department of Human Services Hume Region
- Department of Human Services Primary and Community Health
- Djerriwarrh Health Services
- Eastern Palliative Care
- Echuca Regional Health Community Palliative Care Service
- General Practice Divisions Victoria
- Gippsland Regional Palliative Care Advisory Committee
- Goulburn Valley Hospice Care Service
- Hume Region Palliative Care
- Graham Inglis
- La Trobe University/Austin Health Clinical School of Nursing
- Latrobe Regional Hospital
- Loddon Mallee Palliative Care Service
- Dr Brian McDonald
- Sharyn McGowan
- Melbourne Citymission
- Mercy Western Palliative Care
- Robyn Mitchell
- Monash University School of Nursing
- Motor Neurone Disease Association of Victoria
- Mt Alexander Hospital
- Dr Lisa Newton
- Claire Nicholson
- North Grampians Shire Council
- Omeo District Hospital
- Palliative Care Victoria
- Peninsula Hospice Service
- Peter MacCallum Cancer Institute
- Dr Maria Pisasale
- Karen Quinn
- Regional Information and Advocacy Council Incorporated
- Royal Children’s Hospital
- Royal District Nursing Service
- South East Palliative Care Ltd
- South West Healthcare
- Southern Health
- St Laurence Community Services
- Stawell Regional Health
- Very Special Kids Incorporated
- Victorian Association of Health and Extend Care Centres
- Victorian Cooperative Oncology Group Palliative Medicine Committee, The Cancer Council Victoria
- Victorian Paediatric Palliative Care Program
- Werribee Mercy Hospital Palliative Care Unit
- Western District Health Service
- Western Health
- Wimmera Hospice Care.

Glossary

care coordination: coordination of the range of services required by the consumer so they are delivered in the most efficient and effective way to meet the consumer's needs. It enables continuity of care, avoids duplication of services and ensures meeting consumer needs is paramount (over the needs of individual service providers) and not hampered by program boundaries (Department of Human Services 2004b)

carer: someone (usually a family member) who provides support to children or adults who have a disability, mental illness or chronic condition or are frail aged. Can be parents, partners, sons, daughters, brothers, sisters or friends of any age

consultancy service: specialist palliative care service based in a hospital which is provided to clinicians for patients in non-designated palliative care beds

in-reach consultancy service: specialist palliative care services based in hospitals or the community and provided to patients in non-designated palliative care beds or in residential care

community palliative care service: specialist palliative care services provided to patients in their home, residential aged care facility or community residential care facility. A community palliative care service must have access to the following team members: a specialist palliative nurse, medical support that has specialist palliative care training, and staff trained in grief and bereavement care.

designated palliative care unit: inpatient care funded by the Palliative Care Program of the Victorian Department of Human Services. The unit can be a standalone facility or located within an acute or sub-acute care facility. It provides symptom control, respite care and end-of-life care. A designated palliative care unit must have onsite access to the following team members: a specialist palliative nurse, medical support that has specialist palliative care training, and staff trained in grief and bereavement care.

end-of-life (terminal) care: care that is appropriate when the person is in the final days or weeks of life

health and community care providers: providers of health services, such as hospitals, general practitioners, health centres, community-based and ambulatory care services, and providers of community care services, such as local government, non-government organisations and not-for-profit organisations

health services: the acute and sub-acute campuses of a hospital as well as the additional programs the health service provides in the community

life-threatening illness: chronic illness that will result in a significant shortening of life and is not amenable to health care treatment. Includes both cancer and non-cancer diagnoses, such as neurodegenerative diseases and advanced organ failure

palliative approach: an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. It does so through the prevention and relief of suffering by identifying early, assessing and treating pain and other problems, including physical, psychological, social and spiritual problems (adapted from World health organization 2004).

Palliative Care Program: a Victorian Department of Human Services program that funds services, including palliative care beds, specialist palliative care providers in the community, hospital consultancy services, and statewide services for specific patient groups

specialist palliative care: care that reflects expertise in complex symptom control, loss, grief and bereavement, along with sufficient time available to spend with patients and their families to address complex issues. ‘These services may accept prime responsibility for care, or work indirectly through advising patients’ professional carers’ (Kristjanson, Toye & Dawson 2003).

supportive care: all generalist and specialist services required to support people with a life-threatening illness and their carers and families. This care reflects the fact people have supportive care needs from initial pre-diagnosis through to death and bereavement (National Institute of Clinical Excellence 2003).

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