

Palliative Care Service Development Guidelines

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PalliativeCare
AUSTRALIA

Acknowledgements

Palliative Care Australia (PCA) would like to acknowledge the people who have contributed to the development of the Palliative Care Service Development Guidelines (2018).

PCA would like to extend a special thank you to the Members of the Service Delivery Review Steering Committee for their contribution and expertise throughout the review process:

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Chair's Foreword

On behalf of the Service Delivery Review Steering Committee, I am pleased to present Palliative Care Australia's Palliative Care Service Development Guidelines. These Guidelines have been developed to articulate PCA's expectations for the palliative care system and service design through a population-based approach.

These Guidelines build on and combine the earlier editions, *A Guide to Palliative Care Service Development: A population based approach (2005)* and *Palliative Care Service Provision in Australia: A Planning Guide (2003)*, by updating information and reflecting contemporary practice, with a continued focus on service characteristics and workforce competencies and capabilities. In conjunction with these updates, the Guidelines outline PCA's expectations for policy and service design and development.

The development of these Guidelines was overseen by the Service Delivery Review Steering Committee, with representatives including Commonwealth and State Governments, Palliative Care Nurses Australia (PCNA), Australia and New Zealand Society of Palliative Medicine (ANZSPM), state palliative care organisations and subject matter experts. The Guidelines were further informed by commissioned research including a literature review and consultation with specialist palliative care stakeholders and representatives from other targeted industries (e.g. primary care, aged care).

These Guidelines are written in conjunction with the revised *Standards for Providing Quality Palliative Care for all Australians* (5th ed.) and together provide an overarching framework for the delivery of needs-based access to high quality specialist palliative care. These documents are also designed to complement the work being undertaken by the Commonwealth to update the *National Palliative Care Strategy* and the Australian Commission on Safety and Quality in Health Care's *National Consensus Statement: Essential elements for safe high quality end of life care*.



Professor Patsy Yates

President's Foreword

On behalf of Palliative Care Australia I would like to thank Professor Patsy Yates and the members of the Service Delivery Review Steering Committee for their expertise in updating this important document.

Palliative Care Australia looks forward to continuing to collaborate with people working towards high quality palliative care for all Australians. On behalf of the Board of Palliative Care Australia, I commend this document to you and hope the information provided informs policy and service design as we work towards achieving our vision of quality palliative care for all.



Dr Jane Fischer

Purpose, definitions and a framework for the palliative care service system



1.1 Purpose

Palliative Care Australia (PCA) has produced these updated Service Development Guidelines which replace two previous guidelines: *Palliative Care Service Provision in Australia: A Planning Guide*; and *A Guide to Palliative Care Service Development: A Population-Based Approach*.

The purpose of these updated Guidelines is to communicate the expectations of PCA for:

- » The range of palliative care services that should be available to people living with a life-limiting illness, their families and carers (outlined in Chapter 2); and
- » The workforce and system capabilities required to deliver an effective network of palliative care services using a population-based and geographic approach to service planning (outlined in Chapter 3).

The primary audience for these updated Service Development Guidelines (Guidelines) is:

- » State and Territory Governments who have responsibility for planning and organising the provision of publicly funded palliative care services;
- » Private health insurers who pay for palliative care services for privately insured patients, with these services being delivered by private or public providers;
- » Directors of specialist palliative care services; and
- » Other health professionals involved in providing palliative care in all service settings.

PCA believes that it is important to be aspirational and set high expectations for the development of palliative care services across Australia. These Guidelines are intended to influence how governments make decisions on the development of these services, how private health insurers make decisions about which services to fund, and how public and private sector providers of palliative care organise and deliver services.

In addition, PCA notes that these Service Development Guidelines are intended to complement, but not duplicate, other key resource documents for the palliative care sector including:

- » The Standards for Providing Quality Palliative Care for all Australians by PCA;
- » The National Palliative Care Strategy by the Australian Government Department of Health; and
- » The National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care produced by the Australian Commission on Safety and Quality in Health Care.

These Guidelines have been developed through a process that has included:

- » A literature review, together with analysis of data on the demand for, and supply of, palliative care services;
- » Consultation with the palliative care sector and other stakeholders with an interest in palliative care; and
- » Review and consensus decision-making through a committee including PCA Board members, jurisdictional representatives and other experts.

These Guidelines are underpinned by a comprehensive Background Report that provides the policy context, detailed evidence and analysis. The Guidelines and the Background Report are complementary:

- » The Guidelines are the 'action guide', setting out the expectations that PCA has developed for the palliative care service system; and
- » The Background Report is the 'evidence guide', comprising analysis of data on the supply and utilisation of palliative care services, together with evidence from the literature and all supporting references.

The Guidelines include short break-out boxes (titled: Background evidence and analysis) that summarise the most relevant evidence and analysis. All the source material for these boxes is included in the Background Report.

1.2 Definitions

This section defines the key terms that are used throughout these Guidelines.

Palliative Care

The World Health Organization (WHO) defines palliative care as follows:

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

Palliative care:

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

PCA acknowledges the historical importance of the WHO definition in creating greater understanding of the concept and value of palliative care.

In alignment with the WHO definition, PCA defines palliative care in the contemporary Australian context as:

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life.

PCA considers that the following elements are integral to understanding this definition of palliative care:

- » Palliative care should be strongly responsive to the needs, preferences and values of people, their families and carers. A person and family-centred approach to palliative care is based on effective communication, shared decision-making and personal autonomy.
- » Palliative care should be available to all people living with an active, progressive, advanced disease, regardless of the diagnosis.
- » Palliative care affirms life while recognising that dying is an inevitable part of life. This means that palliative care is provided during the time that the person is living with a life-limiting illness, but it is not directed at either bringing forward or delaying death.

Person living with a life-limiting illness

The term life-limiting illness is used to describe illnesses where it is expected that death will be a direct consequence of the specified illness. Such illnesses may include, but are not limited to cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease.

The term person living with a life-limiting illness also incorporates the concept that people are actively living with such illnesses, often for long period of time, not simply dying.

Family and carers

The term family includes people identified by the person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as the family of choice and friends (including pets). Carers may include family members and other members of their community (such as close friends and neighbours) who the person agrees to being involved in their care.

Providers of palliative care

The medical management and coordination of care for people living with a life-limiting illness may be undertaken by a wide range of health professionals including GPs, geriatricians, physicians, oncologists, paediatricians, renal specialists, cardiologists, endocrinologists and other specialists. Other essential team members will include nurses, allied health professionals and pharmacists. These health professionals are 'generalists' with respect to palliative care, notwithstanding that many of them may be specialists in their own discipline.

PCA's position is that palliative care is everyone's business. All health professionals who provide care to people living with a life-limiting illness, their families and carers should have minimum core competencies in the provision of palliative care. PCA refers to this type of care that is provided by other health professionals, including general practitioners, as 'palliative care' (although it is also sometimes known as 'generalist palliative care').

People will have different levels of need for palliative care. People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. PCA refers to this type of care that is provided by specialist palliative care services as 'specialist palliative care'.

1.3 A framework for the palliative care service system

PCA has developed a conceptual framework for the palliative care service system (Figure 1.1), which can be used as a roadmap to understand the structure and content of these Service Development Guidelines.

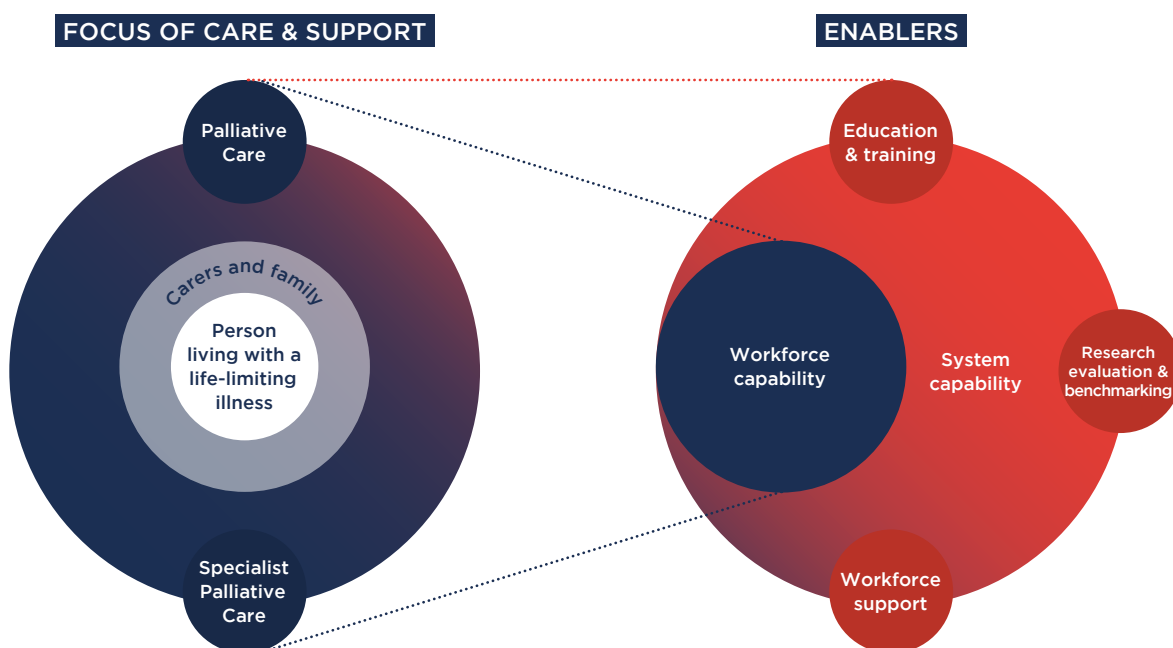
The left-hand side of the framework (detailed in Chapter 2) illustrates the palliative care service system from the perspective of people living with a life-limiting illness, their families and carers. It highlights that:

- » People, their families and carers should be at the centre of the service system.
- » Families and carers often provide significant support for the person living with a life-limiting illness, especially during the time care is provided at home.
- » The palliative care service system should provide care that extends beyond the person living with a life-limiting illness to their families and carers. This differs from many other types of health services where the person with an illness is the only recipient of care.
- » People will have different needs for palliative care. Depending upon the complexity of people's needs, palliative care can be provided by specialist palliative care services and/or by other health professionals with minimum core competencies in palliative care.

The right-hand side of the framework (detailed in Chapter 3) illustrates the system capabilities that need to be planned, resourced and delivered to enable the provision of high-quality palliative care. It highlights that:

- » A robust workforce capability is essential. This must be underpinned by: workforce planning for the specialist palliative care workforce; a capability framework that identifies the continuum of palliative care that can be provided by workforce with different levels of competencies; and an approach to networking and regional planning across the palliative care service system and other health and aged care services.
- » The workforce must be supported through the provision of education and training to support all health professionals involved in providing palliative care, as well as through other workforce support approaches.
- » The systems capability should include a strong research focus, an evaluation capacity and the ongoing development and implementation of benchmarking.

Figure 1.1: A framework for the palliative care service system



Developing the palliative care service system

This chapter outlines the key elements of the palliative care service system from the perspective of people living with a life-limiting illness, their families and carers.

It identifies PCA's expectations in relation to:

- » Who should be able to access palliative care services (Section 2.1);
- » When palliative care services should be provided (Section 2.2);
- » By whom palliative care services should be provided (Section 2.3);
- » Where palliative care services should be available (Section 2.4);
- » How and what palliative care services should be provided to people living with a life-limiting illness (Section 2.5); and
- » What services and support should be accessible to the families and carers of people living with a life-limiting illness (Section 2.6).

2.1 Planning for people who require palliative care services

Palliative care is targeted towards people living with a life-limiting illness; that is, people living with an active, progressive, advanced disease, who have little or no prospect of cure and who are expected to die.

*Background evidence and analysis**

Information is not readily available on the number of people living with a life-limiting illness who might benefit from palliative care.

About half of Australians (11 million people) live with one or more chronic diseases. However, only some of these chronic diseases are life-limiting (such as cancer and chronic obstructive pulmonary disease). Many people live for decades with chronic diseases, so the incidence of chronic diseases is not a good indicator of the real need for palliative care.

More Australians are now living with multiple chronic diseases (known as multimorbidity). Almost one in three people aged 65 years and over lives with three or more chronic diseases. Multimorbidity increases the complexity of patient needs, which has implications for all health professionals – those providing disease-modifying therapies and those providing palliative care.

Almost 160,000 people die each year in Australia. It has been estimated that about 75% of all deaths are expected (such as people living with cancer or end-stage renal disease) and might benefit from the provision of palliative care. This includes palliative care provided by both specialist palliative care services and other health professionals. This means that, based on the number of expected deaths, at least 120,000 Australians may need access to palliative care annually.

PCA expects that state governments will adopt a population-based approach to the planning of palliative care services.

Planning should take into consideration*:

- » Based on 2016 data, there are about 120,000 expected deaths annually in Australia. This is equivalent to 485 of every 100,000 people needing access to palliative care, including both specialist palliative care and palliative care provided by other health professionals.
- » Some populations have higher premature death rates (such as Aboriginal and Torres Strait Islander people, people living in low socioeconomic areas and people living in rural and remote communities).
- » The need for palliative care services also extends beyond people expected to die in any one year to other people living with a life-limiting illness for many years. As examples, children with congenital conditions, people living with neurodegenerative conditions and people with some cancers may benefit from palliative care, in response to specific needs, in the years prior to their death.

Accordingly, population-based planning should be based on analysis of local patterns of morbidity and death.

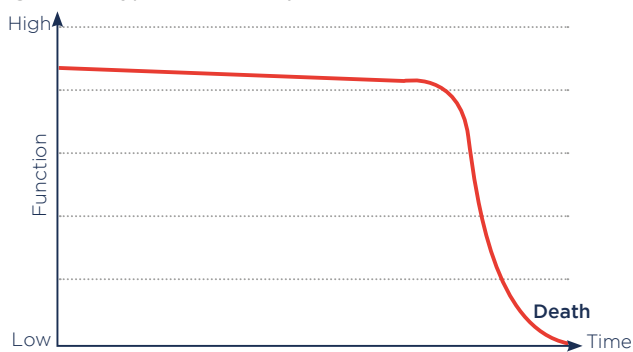
*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

Illness trajectories and need for palliative care

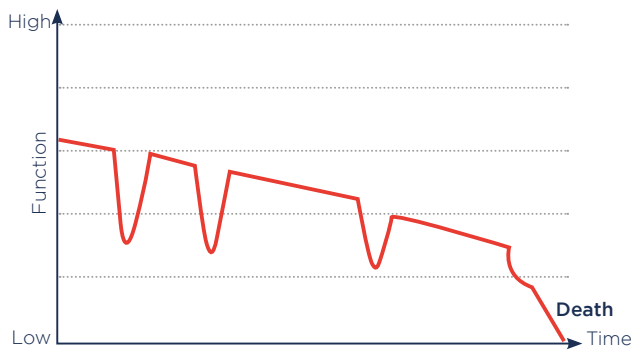
Planning should also be informed by an understanding of typical illness trajectories. Figure 2.1 shows three typical illness trajectories among people dying an expected death comprising:

- » **Short period of evident decline:** there is long maintenance of good function which may be followed by a few weeks or months of rapid decline prior to death. Most reduction in function occurs in the person's last few months of life.

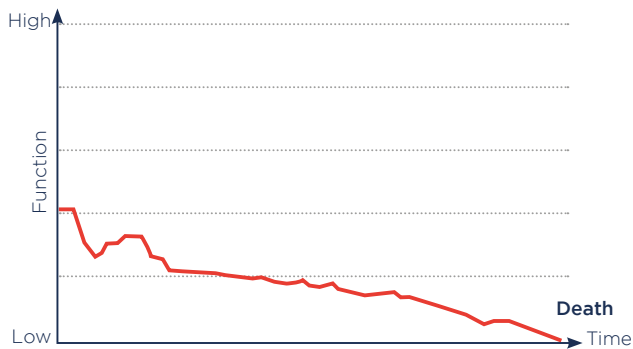
Figure 2.1: Typical illness trajectories



Short period of evident decline



Long-term limitations with intermittent serious episodes



Prolonged dwindling

Reference: Murray SA, Kendall M, Boyd K et al. 2013, 'Illness trajectories and palliative care', *British Medical Journal*, 330 (7498): 1007-11.
Lynn J and Adamson D 2003, *Living well at the end of life: adapting health care to serious chronic illness in old age*, Rand Health: Washington.

- » **Long-term limitations with intermittent serious episodes:** there is a gradual decline in function, interrupted by episodes of acute deterioration. While there is a risk of dying during each of these acute episodes the person may survive but will continue to decline in function. The timing of death usually remains uncertain.
- » **Prolonged dwindling:** there is long-term, progressive disability and reduction in function. Death may follow other events such as infections, falls and fractures.

Based on these illness trajectories PCA has developed a model that conceptualises the population of people living with a life-limiting illness as falling within three broad groups (refer to Figure 2.2), based on the complexity of their needs for palliative care, as follows:

- » People with straightforward and predictable needs: this group comprises people whose needs are generally able to be managed through their own resources (including with the support of family, friends and carers) and/or with the provision of palliative care by their existing health care providers (including GPs, community nurses, geriatricians, oncologists and other health professionals). People in this group do not usually require care delivered by specialist palliative care providers.
- » People with intermediate and fluctuating needs: this group includes people who experience intermittent onset of worsening symptoms (such as unmanaged pain, psychological distress and reduced functional independence) that might result in unplanned and emergency use of hospital and other health services. People in this group may require access to specialist palliative care services for consultation and advice. They will also continue to receive care from their existing health care providers.
- » People with complex and persistent needs: this group comprises people with complex physical, psychological, social and/or spiritual needs that are not able to be effectively managed through established protocols of care. While people in this group will require more ongoing direct care by specialist palliative care providers, this should occur through partnerships and shared care models with existing health care providers.

These three groups are shown in Figure 2.2 which also illustrates that people's needs for palliative care may vary over time, increasing or decreasing in complexity. There is no clear-cut analytical basis for identifying the relative size of the three groups that comprise the population living with a life-limiting illness.

PCA expects that providers of specialist palliative care services will develop suitable models of care to meet the varied needs of people with different illness trajectories and different complexities of need for palliative care.

Disparities in access to palliative care services

Background evidence and analysis*

Specialist palliative care services are still predominantly provided to people with cancer, although the share of services provided to people with non-cancer diagnoses is increasing. In 2016, about three in four people (75.7%) using a specialist palliative care service had a primary diagnosis of cancer.

People living with Alzheimer's disease and other forms of dementia account for 2.4% of all people accessing specialist palliative care services, yet account for 7.8% of all deaths in Australia. People with other chronic life-limiting illnesses also have rates of use of specialist palliative care services that are lower than expected, based on their share of deaths.

Evidence indicates that most health professionals are not aware that specialist palliative care is available to all people with a life-limiting condition, regardless

of diagnosis. Studies also show that there is a lack of recognition that many non-malignant diseases share symptoms in common with cancer (such as pain, breathlessness and fatigue) that would benefit from specialist palliative care interventions.

Aboriginal and Torres Strait Islander people have low rates of use of specialist palliative care services, relative to their high rates of premature mortality. Barriers to use include communication and cultural issues about the approach to dying, lack of knowledge and understanding about palliative care and the costs of transport and accommodation to access palliative care services for people living in remote communities.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

PCA expects that planning of palliative care services by state governments and local hospital networks seek to improve access for populations that currently have inadequate access to these services.

Multi-faceted strategies are likely to be required to tackle barriers including education, communication and funding arrangements, as well as addressing social and cultural issues. Strategies should be guided by the following principles:

- » The provision of palliative care should be based on needs assessment, irrespective of the person's diagnosis, age, gender, Indigenous status, ethnicity, sexual orientation, location or any other factors that are not related to the assessment.
- » Palliative care services should be provided in a way that respects people's individual and cultural differences. Culturally safe health service delivery recognises the cultural and spiritual significance of dying on country for Aboriginal and Torres Strait Islander people.

Figure 2.2: Conceptual model of level of need for palliative care among people living with a life-limiting illness

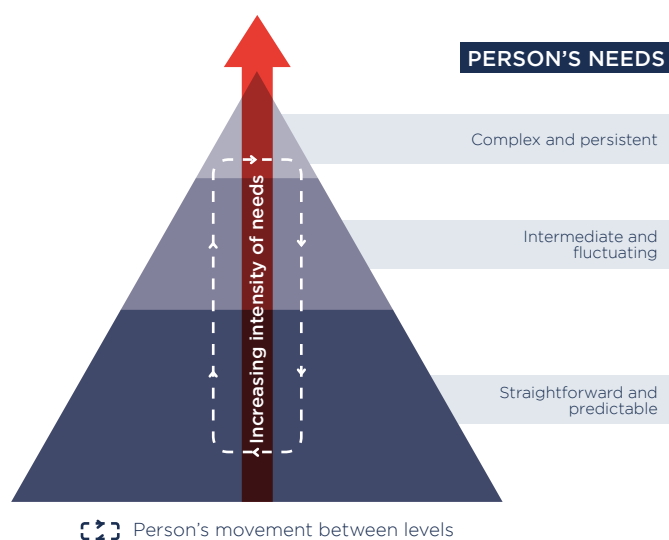
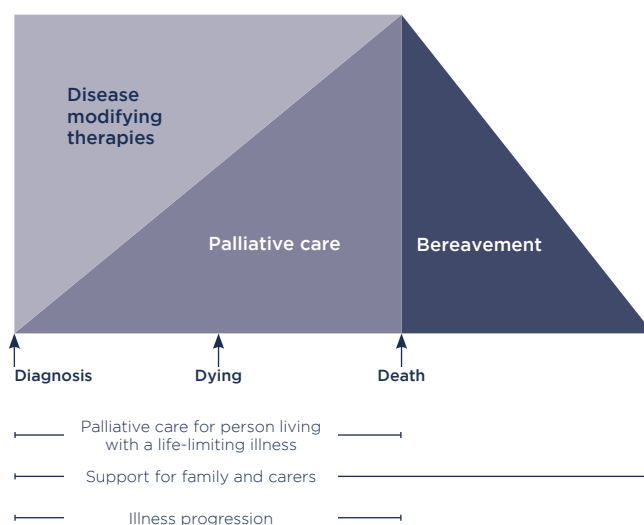


Figure 2.3: Proposed approach to integrating palliative care and disease-modifying therapies



Reference: Australian and New Zealand Society of Palliative Medicine 2008, Submission to the National Health and Hospitals Reform Commission, ANZSPM: Canberra.

2.2 Early introduction of palliative care

Historically, it was assumed that palliative care would commence only once all treatment aimed at ‘curing’ people had finished. Now, it is well-accepted that there is benefit in providing palliative care in association with disease-modifying therapies that aim to prolong life. It is also recognised that many people with life-limiting illnesses are not ‘cured’, but continue to live with these illnesses for many years.

Background evidence and analysis*

There is good evidence that integrating palliative care with disease-modifying therapies improves symptom control, quality of life, and family satisfaction. Moreover, early access to palliative care can reduce the provision of clinically non-beneficial therapies, prolong life in some populations, improve the quality of life of people with a life-limiting illness, and significantly reduce hospital costs.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

PCA expects that palliative care will be provided concurrently with disease-modifying therapies, as required in response to changing needs of people living with a life-limiting illness. This concept is shown in Figure 2.3

2.3 Providers of palliative care

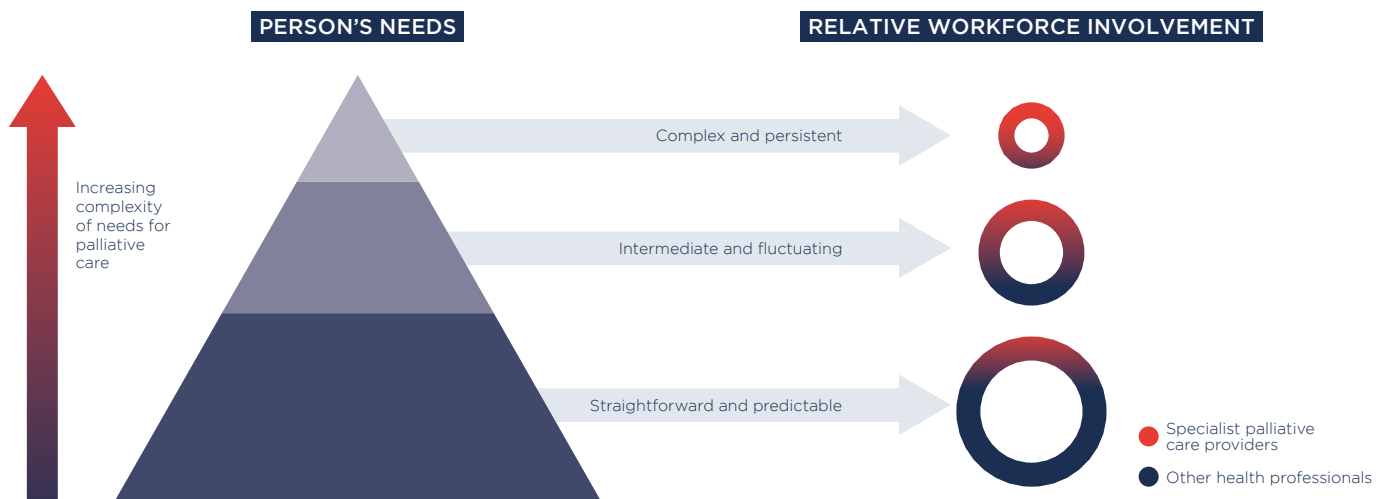
In order to treat people living with a life-limiting illness, health professionals (who are not specialist palliative care providers) should have minimum core competencies to manage physical symptoms, to provide or refer to psychosocial support services, and to discuss the goals of treatment and a person’s prognosis.

People with similar palliative care needs may require care by specialist palliative care providers or they may have their needs well managed by other health professionals with experience and skills in providing care to people living with a life-limiting illness. The capability of the palliative care health workforce to manage the needs of such people is a key factor influencing demand for specialist palliative care services.

Figure 2.4 builds upon the conceptual model of level of need for palliative care (Figure 2.2) to illustrate that as people’s needs become more complex, there should be increased involvement of specialist palliative care services in providing care.

The roles of different types of providers involved in providing palliative care and optimal arrangements for referral and networking of care are further discussed in Chapter 3.

Figure 2.4: Alignment of need for palliative care against workforce capability



2.4 Settings for providing palliative care

People living with a life-limiting illness will need to have palliative care provided in many different settings – in their homes, acute hospitals, hospices which may be community-based or led by tertiary facilities, general practices, specialist clinics, aged care facilities, and other organisations in which people may be living (such as correctional facilities and locations caring for people living with severe mental illness or severe disabilities).

Background evidence and analysis*

Many Australian and international studies have found that most people express a preference to die at home. Some people's preferences change after they are diagnosed with a life-limiting illness, or as their illness progresses, or if their personal circumstances change (such as no longer having a family member to provide care at home).

Australian data indicate that 50% of people (about 80,000 people) die in hospital, while the remaining 50% of people die in community (non-hospital) settings. People who die in community settings may die in their homes, in residential aged care or in other facilities where people live (such as accommodation for people living with a disability or severe mental illness).

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

PCA expects that palliative care services will be provided in a wide range of hospital and community-based settings to meet the needs and preferences of people living with a life-limiting illness, their families and carers. This should include a changed focus in the provision of specialist palliative care consultancy services to support people in all settings.

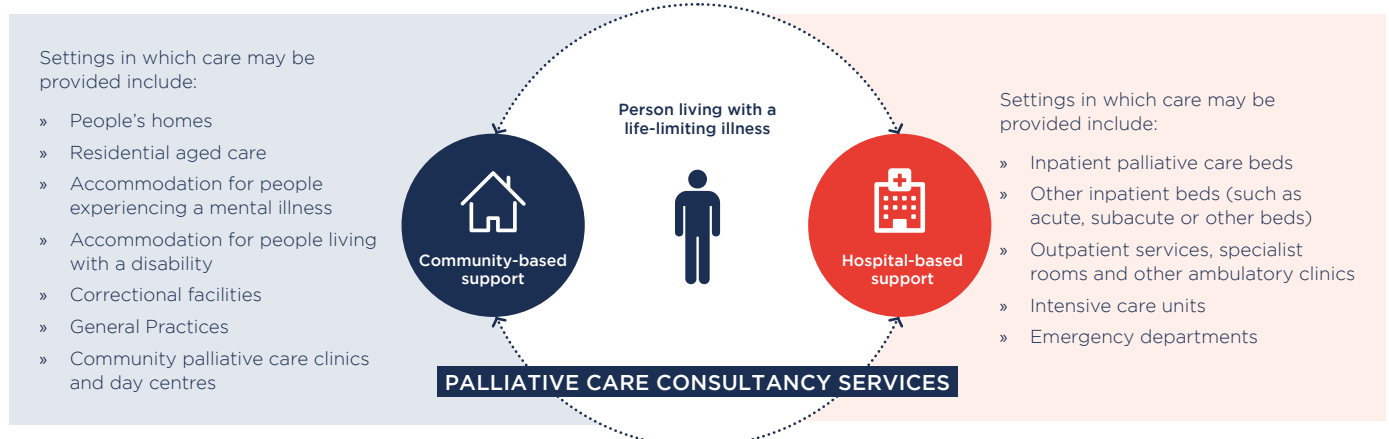
Figure 2.5 is a map of the palliative care service system that illustrates how people need to have palliative care services available in hospitals and in community-based settings. The person living with a life-limiting illness should be at the centre of the service system and be able to access care in different settings, depending on the complexity of their needs. The map relates to both specialist palliative care and palliative care provided by other health professionals.

Figure 2.5 also illustrates another important concept, namely, that specialist palliative care services can provide services directly to people living with a life-limiting illness or provide consultancy services to other health professionals. These specialist palliative care consultancy services, sometimes referred to as consultative support services, allow other health professionals to seek expert advice on the prognosis and management of people who are not under the full-time care of specialist palliative care services.

PCA expects that specialist palliative care consultancy services, where specialist palliative care services provide support to other health professionals involved in caring for people living with a life-limiting illness, will be provided in both hospital and community-based settings.

PCA is using the terms 'hospital-based' and 'community-based' palliative care to describe two broad categories of the settings in which palliative care should be provided. The following are examples of some of the main types of settings that are included in these two categories.

Figure 2.5: Map of palliative care service settings



Hospital-based care

The provision of palliative care services in hospitals may occur via:

- » Inpatient care in 'designated' palliative care beds: in metropolitan areas, hospitals with specialist palliative care services may have dedicated beds (often known as designated beds) that are used to provide palliative care under the clinical supervision of a specialist palliative medicine physician. This may also occur in hospitals in regional centres.
- » Inpatient care in other beds: palliative care may be provided to people receiving disease-modifying or other types of care in acute beds, subacute beds and other types of beds. The provision of palliative care in these settings may involve direct care by specialist or generalist providers of palliative care and/or the involvement of specialist palliative care consultancy services.
- » Outpatient (ambulatory) services: care may be provided on an ambulatory basis in outpatient clinics or specialist rooms. One example of care provided in this setting may be the initial assessment consultation for a person referred to palliative care.
- » Intensive care units and emergency departments: specialist palliative care service team members may be called upon to consult on critically ill patients who are being cared for in intensive care units and emergency departments. While these are not usually considered as routine settings for the delivery of palliative care, there is growing recognition that providing specialist palliative care consultancy services in these settings may improve patient outcomes and reduce the incidence of clinically non-beneficial care.

Community-based care

The provision of palliative care services in the community has to recognise that people live in various types of 'homes' including:

- » Personal residences, whether owned or rented;
- » Residential aged care facilities, retirement villages and other communal living arrangements;
- » Mobile homes, caravans, cars and other locations as appropriate for people who are experiencing homelessness;
- » Correctional facilities, remand centres and detention centres;
- » Group homes and other specialist housing for people with a disability; and
- » Specialist accommodation for people experiencing severe mental illness.

*Background evidence and analysis**

There are significant gaps in access to community-based palliative care services including both specialist palliative care and palliative care provided by other health professionals.

The provision of community-based specialist palliative care is highly variable, both across Australia and within states and between metropolitan and rural areas. Some community-based specialist palliative care services only operate on weekdays, with no care available on weekends. Some community-based specialist palliative care services provide limited or highly targeted packages of care, specifying the number of hours or days of care that are available and the eligibility of patients by diagnosis or expected duration of life.

Among people who are able to gain access to specialist palliative care services, people spend more time waiting to access community-based palliative care than hospital-based palliative care. In 2016 about 12% of people accessing community-based palliative care waited two or more days from when they were ready to receive this care.

In relation to palliative care provided by other health professionals in the community, there is considerable evidence documenting gaps in provision by GPs and for people living in residential aged care. One Australian study found that about one in four GPs did not provide palliative care to their patients living with a life-limiting illness. Factors contributing to lower provision of palliative care in residential aged care include: lack of knowledge about palliative care among some nurses and other staff, limited implementation of effective advance care planning practices, and gaps in the availability of suitably trained and experienced staff.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

PCA notes that there are structural, funding and attitudinal barriers to the provision of palliative care for people living in 'homes' that are not personal residences. This may include: age discrimination; under-provision of health services due to cross-sector issues such as disability care or aged care, Medicare funding requirements, the lack of a regular GP and lack of access to culturally appropriate services.

PCA expects that governments (as funders and planners) and private health insurers (as funders) will implement strategies to improve access to community-based palliative care services, including both specialist palliative care and palliative care provided by other health professionals.

Multiple strategies may be required to improve access to palliative care in the community including:

- » The development of policies, funding models and other approaches that directly promote increased timely provision of community-based palliative care;
- » Strengthening the out-reach focus of specialist palliative care consultancy support services that have traditionally been based in hospitals, to provide more support to health professionals delivering palliative care in the community; and
- » Educational and other strategies that identify the importance for GPs, community nursing services and providers of specialist health services to expand their remit to provide palliative care on an in-reach basis to people living in different types of communal settings.

2.5. Providing a person-centred and effective continuum of palliative care services

PCA expects that people living with a life-limiting illness will have access to an effective continuum of palliative care services.

This is based on key elements including:

- » Timely assessment and referral to the services that best meet the needs of people living with a life-limiting illness;
- » Informed communication on values and priorities for care through mechanisms such as advance care plans;
- » Effective provision of care by multidisciplinary teams with the required workforce competencies; and
- » Continuity and coordination of care as people's needs change and they transition between different types of care.

Each of these elements is discussed below.

Referral and assessment services

*Background evidence and analysis**

Some of the literature on screening and assessment for palliative care identifies the potential value of the 'surprise question' – "*Would you be surprised if the person died in the next 12 months?*" In managing people with advanced disease that is potentially life-limiting, health professionals can use the surprise question as a basis for considering whether the person might benefit from a referral for a palliative care consultation.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

Factors that may prompt referral to palliative care for people living with life-limiting illness include:

- » Increasing (including unplanned) use of hospital and other health services;
- » Concerns expressed by the person, family or carers about their prognosis;
- » Increase in physical or psychological symptoms that are not being effectively managed; or
- » Changes in functional independence that significantly limit the person's activities.

PCA expects that people with life-limiting illnesses will receive timely referral to palliative care and comprehensive assessments of their care needs.

Differences in illness trajectories mean that it is not always straightforward to determine when people should be referred to palliative care services. Decisions about referral must consider not only the person's physical symptoms, but their psychological and emotional readiness to receive palliative care.

A comprehensive palliative care assessment should include:

- » A medical evaluation (medical and psychosocial history, physical examination);
- » Management of physical symptoms;
- » Assessment of psychological, psychiatric, and cognitive symptoms;
- » Illness understanding and care preferences (i.e. personal goals, expectations, understanding of illness trajectory and risks versus benefits of therapies);
- » Existential and spiritual concerns;
- » Social and economic resources and needs of people living with a life-limiting illness, their families and carers, including for care in the home; and
- » Continuity of and coordination of care across settings.

Palliative care assessments are essential in ensuring that the care preferences of the person living with a life-limiting illness, their family and carers are given effect through providing the suite of services required to meet these needs holistically. This should include checking whether there is an existing advance care plan and whether it still reflects the person's wishes.

The role of advance care planning

Advance care planning is one important mechanism that allows people to reflect on their values and priorities for care. It seeks to create a record of a person's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs, and involves and meets the needs of those closest to them. Advance care planning is an ongoing process, with plans needing to be updated as people's preferences evolve in response to changing health status, social circumstances (including access to carers) and other factors.

Background evidence and analysis*

Advance care planning has been found to increase the agreement between a person's wishes for care as they approach death and the care they ultimately receive. Studies report reduced unwanted interventions, increased use of palliative care and prevention of hospitalisation. Advanced care planning is considered to improve quality of life and other outcomes for people living with a life-limiting illness and their family members.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

Advance Care Planning Australia has produced information for individuals, families and carers, as well as educational and training material for health professionals to increase uptake and implementation of advance care planning.

PCA expects that all health professionals will provide information to, and initiate discussions with, people living with a life-limiting illness, family members and carers on the value of advance care planning.

A team-based approach to service provision

Teamwork has long been an integral part of the philosophy and practice of palliative care in Australia. Palliative care lends itself particularly well to this approach because of the multiple dimensions involved in caring for people living with a life-limiting illness: physical, social psychological, and spiritual, as well as meeting the needs of family and carers.

PCA expects that specialist palliative care services will be provided through multidisciplinary teams.

A team approach to the provision of specialist palliative care services requires a broad mix of health professionals including specialist palliative medicine physicians, nurses, pharmacists and allied health professionals with qualifications, experience or skills in palliative care. Meeting palliative needs requires a diverse range of allied health and associated disciplines including occupational therapy, physiotherapy, speech therapy, social work, psychology, art and musical therapy, grief and bereavement counselling and pastoral care. The workforce profiles required to deliver team-based specialist palliative care are specified in more detail in the workforce Capability framework in Chapter 3.

Continuity and coordination of care

Ensuring continuity and coordination of care for people using palliative care services is essential.

*Background evidence and analysis**

People requiring access to palliative care often transition between receiving care in hospital and care in the community. In 2016 about two in five people (38%) starting an episode of community-based specialist palliative care were 'admitted' from inpatient specialist palliative care. About one-third (31%) of people completing an episode of community-based specialist palliative care were, in turn, admitted to inpatient specialist palliative care, while just under one-third (29%) were admitted to inpatient acute care.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

PCA expects that hospitals, health services and all health professionals should implement systems to ensure continuity and coordination of care including:

- » Timely referral to a palliative care service (preferably early in the illness trajectory, rather than on a crisis basis);
- » Speedy and straightforward admission to suitable inpatient care, when this is needed;
- » Speedy and straightforward transfer from hospital-based palliative care to community-based palliative care, and vice versa as required;
- » Continuity of clinical and allied health professionals across various settings and/or continuity of records to ensure the effective transfer of care between different teams of health professionals;
- » Coordination of care with other health professionals (medical, nursing, pharmacy and community health services) that may be involved in providing other health care or social support requirements, that are separate to the services provided by the palliative care workforce; and
- » Discharge planning that ensures relevant information and advice is provided to the person living with a life-limiting illness, their family and carers, as well as the health professionals with ongoing responsibility for their care.

2.6 Recognising and supporting the contribution of families and carers to the palliative care service system

Families and carers often play a major role in caring for people living with a life-limiting illness. The provision of informal or unpaid care by family members and carers may include personal care (e.g. showering), nursing care (e.g. symptom management which may involve medicines), domestic care (e.g. preparing meals), financial support (e.g. in response to changes in income), practical support (e.g. transportation), social care (e.g. emotional support) and planning care (e.g. coordinating care and support services).

*Background evidence and analysis**

In 2015 almost 2.7 million Australians were carers. About 850,000 of these people were primary carers, undertaking the main support role for a person with limitations related to self-care, communication or mobility. Almost all primary carers (96%) provided care to a family member, with more than half (55%) providing care for at least 20 hours per week. About two-thirds of primary carers provide assistance with health care.

Multiple studies have demonstrated that people with a life-limiting illness, who live alone without a carer, have more hospital admissions and are less likely to die at home than people who have a carer.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

In response to the evidence about their significant contribution, it is vital to provide services that actively support the role of families and carers.

The following sections outline PCA's expectations about the type and range of services required to support family members and carers of people living with a life-limiting illness. Some of these services are targeted directly to families and carers (such as bereavement); while other services will benefit both the person living with a life-limiting illness and their family and carers (such as after-hours access).

Information, education and support for families and carers

PCA expects that an essential component of high-quality palliative care is effective communication between people living with a life-limiting illness, family members, carers and health professionals, underpinned by access to educational and informational resources.

Families and carers have a wide spectrum of information and support needs. This includes information and training on practical aspects of home-based care including pain and symptom management, medication administration and nursing care. Also critical are discussions about the clinical condition of the person living with a life-limiting illness, their prognosis and the goals of care. Family meetings are an essential tool in palliative care to inform, deliberate, clarify, make decisions and set goals for future care. Counselling and psychological support may be required to help family members and carers cope with anticipatory grief, loss of hope, unresolved relationship issues and other concerns that arise.

Families and carers may access information and support from a variety of sources including specialist palliative care services, GPs, nurses, pharmacists, allied health professionals and other health professionals. Support groups may also assist families and carers of people living with certain conditions such as cancer, dementia and Motor Neurone Disease.

After-hours¹ access

After-hours access to support is essential for families and carers.

Within this context of proactive care planning, PCA expects that palliative care services should organise after-hours access to provide advice and/or direct clinical support including responding to crisis situations such as unmanaged pain.

After-hours access arrangements need to support continuity of care and should avoid the situation where families and carers seek emergency assistance in the palliative care context from ambulances, hospital emergency departments or telephone support services (such as HealthDirect) that are not involved in the provision of ongoing care for the person living with a life-limiting illness. Specialist palliative care services should ensure that there are protocols in place with GPs, emergency health and other relevant services, to assist in providing after-hours services that are responsive to the needs of people living with a life-limiting illness, their families and carers.

Background evidence and analysis*

Common medical reasons for seeking access to after-hours services include pain, nausea, vomiting, agitation, breathlessness and fatigue. Pain has been reported as a particularly common cause for people seeking after-hours help. One study found that over 30% of people seeking help did so because of pain, and that over half of this subgroup were already prescribed strong opioid medication. After-hours access may also be required to provide respite for carers and to provide support to families and carers when death is imminent.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

There is a concern among some in the palliative care sector that a focus upon after-hours or 24-hour access may mask a lack of organised, pro-active care planning. That is, referral and anticipatory care planning may preempt after-hours needs for many people, leaving only a small number of people with unanticipated after-hours palliative care needs. For example, effective daytime and anticipatory pain management, including education regarding use of analgesics, and seeking timely help, can positively influence the need for after-hours care.

It is recognised that arrangements for the provision of after-hours access will vary according to:

- » Whether the person living with a life-limiting illness is under the care of specialist palliative care services or other health professionals (such as GPs) that are providing generalist palliative care; and/or
- » Whether the person is living in a metropolitan area, major regional centre or rural and remote locations;
- » Whether there are formalised after-hours services available.

PCA expects that after-hours access should be available as follows at a minimum:

- » For all people in metropolitan areas and major regional centres, who are under the care of specialist palliative care services, there should be tiered systems of access including telephone support and home visits by nurses and/or medical practitioners, as required; and
- » For people living in rural and remote locations, or receiving palliative care from other health professionals, the minimum requirement is to have after-hours access to telephone support organised through their treatment team.

1. After-hours care is considered accessible and effective care for people whose health condition cannot wait for treatment until regular care services are next available. In Australia the after-hours period for health service provision is generally taken to mean outside 8 am to 6 pm weekdays, outside 8 am to 12 noon on Saturdays, and all day on Sundays and public holidays (Australian Department of Human Services)

The provision of after-hours access should be built into the resourcing of specialist palliative care services, in recognition that it is an essential element of service delivery. After-hours access through specialist palliative care services can be organised through a tiered or stepped access framework to increasingly higher levels of support and direct care, beginning with telephone advice and progressing to nursing and/or medical support based on needs assessment. Telehealth services are one approach to providing after-hours access, in both metropolitan and rural locations. However, telehealth services must be supported by systems that ensure direct access to medical and/or nursing support, when required.

Equipment and medical supplies for home-based care

PCA expects that funders and providers will work to improve equity of access to equipment (and home modification services), on both a geographic and cost basis, to support families providing care at home for a person with a life-limiting illness.

All providers of palliative care services have a responsibility to advise families and carers about mechanisms to access necessary equipment. Specialist palliative care services that are involved in delivering community-based palliative care should organise the supply of necessary equipment, as well as providing information and training to family members and carers on the use and maintenance of this equipment.

Background evidence and analysis*

The ability to access suitable equipment and medical supplies can influence whether people can remain at home or need to be cared for elsewhere. The lack of access to equipment, often because of cost, has been identified as one of the barriers to dying at home.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

The list of equipment that may be required in home-based palliative care is extensive. In addition to medical equipment such as syringe drivers, oxygen and intravenous fluids, equipment needs can include commodes, continence aids and equipment, hospital beds, over-toilet seats, patient lifting hoists and slings, pressure relieving mattresses, sheepskins and cushions, shower chairs, walking frames and sticks, wheelchairs and wheelie walkers.

Families and carers may access equipment through a range of different programs that are funded in each of the health, aged care and disability sectors, with some equipment also funded by private health insurers and non-government organisations. In most states and

territories, public hospitals also provide equipment and home modification services for at least some people after a hospital admission to support their return home and rehabilitation.

Respite care

In the context of palliative care, respite care is occasional or intermittent temporary relief from the perceived responsibilities for the care, wellbeing and safety of a person living with a life-limiting illness. Respite care may be provided on an inpatient basis, on a day basis or through home-based provision.

Background evidence and analysis*

Respite care is not uniformly available across Australia, nor is it always accessible on a timely basis. The lack of access to local respite care in some rural and remote areas results in some people moving to major cities, where they may be unsupported by family, friends and their community.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

Reasons for using respite vary and may include:

- » To allow carers to attend their own appointments;
- » To allow carers to spend quality time with other family and friends;
- » To allow carers to rest and reduce the stress and fatigue that comes with the continuous provision of care for a family member or friend with a chronic health problem or life-limiting illness; and
- » To provide an opportunity for the person living with a life-limiting illness to increase their own social interactions and vary their activity.

There is no routine information on the provision of respite for family members and carers of people living with a life-limiting illness. In part, this reflects the fact that respite care is provided and funded through multiple programs including:

- » Australian Government's Commonwealth Home Support Program (CHSP). The CHSP consolidates services providing entry-level home support for older people who need assistance to keep living independently.
- » State and territory governments also offer respite care through a range of programs.

PCA expects that palliative care providers should, at a minimum, provide information to families and carers about options to access respite care.

Specialist palliative care services in metropolitan and major regional centres should also organise or facilitate access to respite care, as required by families and carers. This may include home-based respite, day respite, or inpatient respite (in a hospital, residential aged care or an other service).

Grief and bereavement support

Grief is a normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. Personal and social circumstances may place some family members and/or carers at increased risk of experiencing problems in the lead up to and aftermath of a person's death.

*Background evidence and analysis**

Grief can be experienced across many domains including emotional, cognitive, behavioural, physical and spiritual. The experience of grief can vary widely, with some people experiencing complicated grief or grief that lasts for a prolonged period.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

In response to different levels of need, bereavement services should be organised along a continuum comprising:

- » Universal services – these services should be available to support all bereaved people; and
- » Targeted services – these specialist services should be available to support people at risk of, or experiencing, complicated grief.

Support for those experiencing grief can be obtained from many professional and informal sources. Specialist palliative care services are one of many resources that may be involved in providing bereavement support.

PCA expects that specialist palliative care services should operate as part of a continuum of services to provide bereavement support services that are aligned with people's needs.

All providers of palliative care services (whether generalist or specialist) need to have the capacity to assess where family members and carers sit along a continuum of need for bereavement support services and refer accordingly.

Planning the workforce and system capabilities to deliver palliative care services

This chapter identifies PCA's expectations with regard to the workforce and system capabilities that are required to deliver high-quality palliative care services.

It covers:

- » Planning of the specialist palliative care workforce (Section 3.1);
- » Specifying the workforce capabilities required to provide a continuum of palliative care services across both specialist palliative care services and palliative care provided by other health professionals (Section 3.2);
- » Identifying an approach to regional planning of palliative care services and networking arrangements to support effective referral and consultative support services (Section 3.3);
- » Promoting the acquisition of palliative care skills through professional education and training (Section 3.4);
- » Identifying the requirements to support the palliative care workforce (Section 3.5); and
- » Promoting continuous learning and quality improvement through research, evaluation and benchmarking in palliative care (Section 3.6).

3

3.1 Planning the specialist palliative care workforce

Access to specialist palliative care is dependent on a robust approach to the planning of the specialist palliative care workforce. The three components – medical practitioners, nurses, and allied health professionals – are each examined below.

Workforce modelling and planning for specialist palliative care services is significantly constrained due to data gaps about the specialist palliative care workforce.

PCA expects that governments and specialist palliative care services will collaborate to improve workforce data to support enhanced workforce modelling and the development of planning benchmarks. In addition to tackling data gaps, the development of workforce planning benchmarks particularly in relation to nurses and allied health professionals working in specialist palliative care services should be an important research priority.

Specialist palliative medicine physicians

*Background evidence and analysis**

In 2015 there were 213 specialist palliative medicine physicians across Australia, equivalent to a ratio of 0.9 full-time equivalent per 100,000 population.

There are disparities in access to specialist palliative medicine physicians across states and territories. Victoria had the lowest population ratio of specialist palliative medicine physicians (0.7), followed by Western Australia (0.8), Queensland (0.9), New South Wales (1.0), South Australia (1.1) and Tasmania (1.8). In addition, most specialist palliative medicine physicians worked in major cities (84.0%) or inner regional areas (9.6%), where population ratios were lower in rural and remote areas.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

In 2003 PCA set a benchmark for providing access to specialist palliative medicine physicians at 1.5 full-time equivalent specialist palliative medicine physicians per 100,000 population. This was defined as the specialist palliative medicine workforce required to provide inpatient, community-based care and an acute hospital consultative service.

The application of this previous benchmark means that the estimated requirement for specialist palliative medicine physicians in 2017 is 370 full-time equivalent specialists. While there may have been some growth in the supply of specialist palliative medicine physicians since 2015 (latest available workforce data), this benchmark equates to a national shortfall of about 150 specialist palliative medicine physicians in 2017.

PCA is setting a new benchmark of 2.0 full-time equivalent specialist palliative medicine physicians per 100,000 population.

While the 2018 and 2003 benchmarks are not based on workforce modelling, they have been developed through consensus review of evidence relating to the existing supply of, and demand for, palliative care services and changing models of care.

PCA has based the recommended increase in the 2018 benchmark for the supply of palliative medicine physicians on the following factors:

- » There needs to be significantly increased access to specialist palliative care services for people dying from causes other than cancer. Most people living with non-malignant, life-limiting conditions are not currently getting access to specialist palliative care services.
- » There are significant geographic disparities in access to specialist palliative medicine physicians between and within states and territories, and between metropolitan, rural and remote areas.
- » There needs to be expanded access to specialist palliative care for people living in residential aged care and other community-based settings.
 - There are significant gaps in access to community-based specialist palliative care services that limit people’s opportunity to die in their own home or in other community-based settings such as residential aged care.
 - The palliative care needs of the growing number of people living with Alzheimer’s Disease and other forms of dementia should be planned for and met in residential aged care and other community settings, avoiding emergency and unplanned transfers to acute hospitals.
 - The above two issues will require specialist palliative medicine physicians to provide both direct care to people living with a life-limiting illness, as well as strengthening their consultative role in supporting other health professionals who provide palliative care in these settings.
- » A counter-balancing factor is the expansion in nurse-led models of specialist palliative care, often involving nurse practitioners. While this is a welcome development, it does not yet measurably impact on the continued need for expansion of the specialist palliative medicine workforce.

The above population-based planning benchmark of 2.0 full-time equivalent specialist palliative medicine physicians per 100,000 population can be used at a national, state-wide and regional level in workforce planning. Appendix 1 includes medical ratios that can be used at a local level in operational planning of specialist palliative care services.

Palliative care nurses

*Background evidence and analysis**

In 2015 there were 3,321 palliative care nurses in Australia, equivalent to a ratio of 12.0 full-time equivalent per 100,000 population.

There is a more equitable distribution in the supply of palliative care nurses than is the case for specialist palliative medicine physicians.

About one-quarter of palliative care nurses work mainly in community-based settings including with community palliative care services, in residential aged care, in GP offices and Aboriginal Health Services.

There has also been significant growth in the number of nurse practitioners. In 2017 there were almost 1,600 nurse practitioners in Australia, most of whom do not work in palliative care.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

Palliative care nurses provide both direct care and consultative services. Ensuring an adequate supply of palliative care nurses is particularly important in expanding access to community-based palliative care including in people’s homes and in residential aged care.

The value of nurses working in advanced practice roles, including as nurse practitioners, has gained increasing recognition and has allowed the development of more nurse-led models for the provision of specialist palliative care. In addition to providing direct care, nurse practitioners (and other advanced practice nurses) have an important role in providing consultative support to other health professionals (such as GPs) who provide palliative care to people living with a life-limiting illness.

PCA highlights that there are no national benchmarks on a minimum or desirable level of access to palliative care nurses.

In 2003 PCA’s planning guidelines included a set of ratios for palliative care nurses that varied:

- » By type of nurse – clinical nurse consultant, clinical nurse, registered & enrolled nurse;
- » By setting and type of service – community-based service, palliative care designated beds, acute hospital consultative service; and
- » By function – separate ratios were provided for the discharge liaison function.

The 2003 approach to palliative care nurse workforce planning is most suitable for operational planning at the level of individual hospitals and community-based palliative care providers. It is less relevant to national planning of palliative care nurse workforce requirements for several reasons:

- » The 2003 ratios cannot be readily measured at a national level to assess whether there is a shortfall or oversupply of palliative care nurses. This is because they rely on input measures that are not routinely collected at a national level (such as the number of beds or hours of care per patient per day).
- » At a national level, the changing nature of clinical practice (types of patients seen, types of settings in which care is provided) for specialist palliative care services influences the required supply of palliative care nurses.

PCA has determined that there is not a sufficiently robust basis on which to set national workforce ratios for planning the requirements for palliative care nurses that form part of the specialist palliative care workforce.

However, PCA acknowledges that Local Hospital Networks (or equivalent), individual hospitals and specialist palliative care services may find the 2003 nursing ratios useful for operational planning. Accordingly, PCA has included these ratios in Appendix 1, noting their potential value for the purposes of operational planning.

Allied health professionals working in palliative care

*Background evidence and analysis**

In 2015 there were a total of 77,329 full-time equivalent occupational therapists, physiotherapists, psychologists and pharmacists registered and employed in Australia working across all fields. National registration information is not available on other allied health professional disciplines (such as social work and pastoral care) that are routinely involved in providing palliative care.

Within the national registration data, there is also no information available on the types or numbers of allied health professionals that are specifically employed in palliative care services.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

Allied health professionals play an essential role in meeting the palliative care needs of people living with a life-limiting illness, their families and carers. This includes:

- » Providing support to manage physical symptoms including support related to medication, nutrition, communication and mobility;
- » Assisting people with a life-limiting illness to maintain function and independence;
- » Providing a wide range of psychological support, social support, pastoral care and bereavement support;
- » Providing therapies that focus on improving the quality of life that support people, families and carers to achieve their goals; and
- » Sharing information about disease progression and providing education for people living with a life-limiting illness, their families and carers.

PCA expects that specialist palliative care services will have access to a wide range of allied health professionals including: psychologists, social workers, physiotherapists, occupational therapists, speech pathologists, dietitians. In addition, specialist palliative care services should have access to the support of other support workers such as music/art therapists, pastoral care workers and bereavement counsellors.

PCA notes the significant contribution made by volunteers to many specialist palliative care services. Volunteer services complement the role of clinical services and can increase the capacity of specialist palliative care services to meet the needs of people living with a life-limiting illness, their families and carers. Specialist palliative care services will also require access to ancillary services including accredited interpreters.

PCA has determined that there are no national benchmarks, nor a sufficiently robust basis on which to set national workforce ratios for planning the requirements for allied health professionals and other support workers that form part of the specialist palliative care workforce.

Appendix 1 includes PCA's previous allied health professional ratios that can be used for the purposes of operational planning by Local Hospital Networks (or equivalent), hospitals and specialist palliative care services.

3.2 A capability framework for the palliative care workforce

*Background evidence and analysis**

All six Australian states have capability frameworks (sometimes called role delineation frameworks or clinical services frameworks) that use a tiered or stepped approach to identify the different levels of workforce capability required to meet specific service needs of different populations.

Currently, the number of palliative care levels specified by states in these frameworks varies from three to six. Most states use these frameworks to describe a continuum of palliative care including both palliative care (provided by other health professionals) and specialist palliative care services.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

PCA's previous (2005) capability framework comprised one primary care level and three specialist palliative care levels. In updating this framework, PCA has taken into consideration factors including:

- » The desirability of providing a more robust specification of the minimum level of palliative care that should be available to all people living with a life-limiting illness. This recognises that:
 - There are limited numbers of specialist palliative medicine physicians and there are existing disparities in access to their services;
 - Even if the specialist palliative medicine workforce expands, not all people living with a life-limiting illness need to be referred to specialist palliative care services; and
 - The capability of other health professionals (who are not specialist palliative care providers) to provide palliative care for people with straightforward needs should be recognised, supported and strengthened.

- » Feedback received on the number of levels in PCA's previous framework: there were insufficient criteria to delineate three levels of specialist palliative care services. In particular, there was considerable overlap and blurring between what was previously described as specialist palliative care levels 1 and 2. Accordingly, PCA has updated this capability framework to portray two levels of specialist palliative care services, equivalent to the previous specialist palliative care levels 2 and 3.
- » The inclusion of more specific service requirements and competencies for each level of workforce capability: this update includes much greater specificity about PCA's expectations in relation to the scope of services (such as after-hours access), service modalities and workforce profile than were included in the 2005 framework.

The updated national palliative care workforce capability framework is specified below in Table 3.1.

PCA expects that state and territory governments will use the national palliative care workforce capability framework as a broad template for updating their role delineation and clinical services capability frameworks.

Following this table, Section 3.3 provides further information on how states and territories can use the capability framework in state-wide and regional planning of palliative care services, together with information on networking arrangements across and between the three levels of palliative care services, and between palliative care and disease-modifying care.

Table 3.1: National palliative care workforce capability framework

LEVEL 1: PALLIATIVE CARE	
Population needs	People living with a life-limiting illness whose needs are straightforward and predictable; families and carers of these people
Catchment population and service role	Services should be available in metropolitan and rural areas at a local level, in the communities where people live, with no requirement to travel to regional centres to access minimum services Level 1: Palliative Care will usually have a service role as the primary and ongoing provider of health care services for the person living with a life-limiting illness, with established relationships with the person, their family and carers
Scope of services and roles	Management of symptoms including prescription of relevant medications and after-hours access to telephone support Advice about prognosis, treatment options and disease progression Provision of, and/or referral to, counselling and psychological support services for the person living with a life-limiting illness, their family and carers Discussions about advance care planning
Service modalities	Community-based palliative care: organisation of, and/or referral to, community nursing and other home care support services related to managing health care and functional needs Hospital-based palliative care: referral to hospital inpatient services and/or ambulatory (outpatient) services for the management of acute episodes and/or for people who are living with a life-limiting illness and whose care needs cannot be fully supported at home. Services will be provided by the nearest available hospital and care may be provided in acute or other beds (rather than in designated palliative care beds that are managed by specialist palliative care health professionals)
Workforce profile	Medical practitioners with knowledge and experience in palliative care who provide most medical care to the person living with a life-limiting illness – this may be a GP, physician, geriatrician, paediatrician, renal specialist, oncologist or other medical professional Nurses who may include nurse practitioners, registered nurses, community nurses – may work in community settings including people’s homes and residential aged care Personal care workers who provide support in the person’s home or residential aged care Access to allied health professionals Health professionals involved in providing Level 1: Palliative Care do not work full-time in palliative care but have other responsibilities Although there may not be established multidisciplinary teams, responsibility for care coordination will be undertaken by the treating medical practitioner, or if no medical practitioner is available (such as in remote areas), the nurse practitioner or other senior nurse

LEVEL 2: SPECIALIST PALLIATIVE CARE SERVICES

Population needs	People living with a life-limiting illness whose needs range from straightforward and predictable to intermediate and fluctuating; families and carers of these people
Catchment population and service role	<p>Services should be available in metropolitan and rural areas on a regional basis, which may be equivalent to each Local Hospital Network (dependent upon governance models in each jurisdiction)</p> <p>The service role of Level 2: Specialist Palliative Care Services usually involves shared responsibility for meeting the palliative care needs of their catchment population with Level 1: Palliative Care and other health professionals that may be providing ongoing disease-modifying care</p>
Scope of services and roles	<p>Management of more complex pain and distressing symptoms including swallowing and breathing difficulties</p> <p>Provision of after-hours access including telephone advice, nursing and medical support</p> <p>Education and counselling about disease progression, symptom management and care of people living with a life-limiting illness</p> <p>Assessment and management of psychosocial care needs relating to depression, anxiety, grief and existential distress for the person living with a life-limiting illness, their family and carers</p> <p>Active implementation of advance care planning including being responsive to changing wishes as the person's condition progresses; providing advice on ethical issues and potential conflicts between the person living with a life-limiting illness, their family and carers including in situations where the person has cognitive impairments and/or has limited agency</p> <p>Provision of education, training and consultancy support to Level 1 services</p>
Service modalities	<p>Community-based palliative care: provision of more intensive community nursing and other home care support services related to managing more complex health care and functional needs</p> <p>Hospital-based palliative care: provision of hospital services (inpatient and/or ambulatory) for the management of acute episodes and/or for people who are living with a life-limiting illness and whose care needs cannot be fully supported at home. Inpatient services will usually be provided through a direct care or consultative model by specialist palliative medicine physicians in acute or designated palliative care beds although other medical specialists may also be involved in providing treatment</p> <p>Consultative palliative care: provision of consultative support services (by specialist palliative medicine physicians or nurse-led models) to other health professionals involved in caring for the person living with a life-limiting illness</p>
Workforce profile	<p>Multidisciplinary team including medical practitioners, nurses and allied health professionals with skills and experience in palliative care; some team members will have specialist qualifications related to palliative care</p> <p>Where the team does not include a specialist palliative medical physician, access is provided on a visiting medical officer basis and/or through formally agreed consultative arrangements with another health service, such that there is either direct involvement or close supervision by a specialist palliative medical physician in the care of the person living with a life-limiting illness</p> <p>Nursing complement will include some senior and experienced nurses such as nurse practitioners and clinical nurse consultants, some of whom will have completed specialist qualifications related to palliative care</p> <p>Allied health professionals may include occupational therapy, physiotherapy, social workers and psychologists, many of whom will also be involved in the care of other people</p> <p>Personal care workers who provide support in the person's home or residential aged care, with training to support the needs of people living with a life-limiting illness</p>

LEVEL 3: SPECIALIST PALLIATIVE CARE SERVICES

Population needs	People living with a life-limiting illness whose needs include straightforward and predictable, intermediate and fluctuating, or complex and persistent; families and carers of these people
Catchment population and service role	<p>Services should be available in major metropolitan centres including all capital cities and other major cities</p> <p>The service role of Level 3: Specialist Palliative Care Services may include state-wide responsibility for managing some sub-populations of people living with a life-limiting illness. Level 3 services will typically have significant responsibilities for most palliative care needs of the most complex patients, although care may also be provided by other palliative services and other health professionals. Level 3 services will also have responsibility for their local populations, which will include regional, rural and remote locations</p>
Scope of services and roles	<p>Management of complex and persistent symptoms that are not effectively controlled by standard therapies; this may include the administration of palliative sedation therapy, palliative radiotherapy, percutaneous endoscopic gastrostomy and other nutritional approaches (depending upon the wishes of the dying person)</p> <p>Provision of after-hours access including telephone advice, nursing and medical support</p> <p>Education, counselling and support for resolving complex issues related to the management of complex and persistent symptoms, the benefits and impact on quality of life of different palliative management options, and decision-making relating to non-beneficial treatment</p> <p>Assessment and management of complex psychosocial care needs for the person living with a life-limiting illness, their family and carers</p> <p>Active implementation of advance care planning including effective documentation and communication to all other health care professionals involved in the care of the person living with a life-limiting illness to ensure their wishes are respected; responsiveness to the person's wishes including the withdrawal of life sustaining treatment, if requested; mediation and conflict resolution regarding symptom management and cessation of treatment between the person, their family and carers</p> <p>Provision of education, training and consultancy support to Level 1 & 2 services</p> <p>Leadership role in palliative care research including links with academic centres</p>
Service modalities	<p>Community-based palliative care: provision of intensive community nursing and other home care support services including to support dying at home, where this is in accordance with the wishes of the person living with a life-limiting illness</p> <p>Hospital-based palliative care: provision of dedicated hospital (inpatient and ambulatory) services, managed by specialist palliative medicine physicians, for the management of complex episodes and/or for people who are living with a life-limiting illness and whose care needs cannot be supported at home</p> <p>Consultative palliative care: provision of consultative support services (by specialist palliative medicine physicians or nurse-led models) to other health professionals involved in caring for the person living with a life-limiting illness</p>
Workforce profile	<p>Multidisciplinary team including medical practitioners, nurses and allied health professionals, most of whom will have specialist qualifications, extensive experience and skills in palliative care (and for whom this is their substantive role and area of practice)</p> <p>In addition to direct care, medical practitioners and senior nurses may provide consultative services to other health professionals in the same or other hospitals, community and residential care home settings</p> <p>An extensive range of allied health disciplines will be available including occupational therapy, physiotherapy, speech therapy, social workers, psychologists, pharmacists, grief and bereavement counsellors, art and music therapists, spiritual care and pastoral care workers</p> <p>Personal care workers who provide support in the person's home or residential aged care, with training to support the needs of people living with a life-limiting illness</p>

3.3 Regional planning and networking of palliative care services

The national palliative care workforce capability framework (Table 3.1) outlines the expected scope of services, and workforce profile to deliver those services, at each of the three levels of palliative care.

PCA expects that planning of palliative care services by states and territories will ensure that there is a continuum of palliative care services that aligns people's needs with the required workforce capability.

The workforce capability framework can be used by states and territories in planning the distribution of palliative care services at a regional or Local Hospital Network level. PCA's expectations are that:

- » All major metropolitan centres should have Level 3 specialist palliative care services (as well as Level 2 specialist palliative care services and Level 1 palliative care),
- » All regional centres should have Level 2 specialist palliative services (as well as Level 1 palliative care).
- » All people living with a life-limiting illness should, at a minimum, have access to Level 1 palliative care provided by other health professionals with clear processes for referral to specialist palliative care services.
- » Where any of the above requirements are not able to be met, networking, referral and specialist palliative care consultative support services (discussed further below) need to be in place to ensure that people living in locations that do not have direct access to the full range of Level 2 or 3 specialist palliative care services are able to access necessary care.

A population or area-based approach to planning palliative care services can be applied irrespective of the approach used by jurisdictions to the organisation, service models or governance arrangements for palliative care services. PCA recognises that in some states the management of hospital-based palliative care services may be separate to the provision of community-based palliative care services. In some states, community-based palliative care services may be purchased or commissioned at a state-wide level (separate to hospital-based palliative care) and provided by non-government providers.

Regardless of whether hospital and community-based palliative care services are jointly managed or separately purchased, PCA expects that it is the responsibility of states and territories to ensure that there is access in each geographic area (usually equivalent to a Local Hospital Network) to community-based, hospital-based and consultative palliative care services.

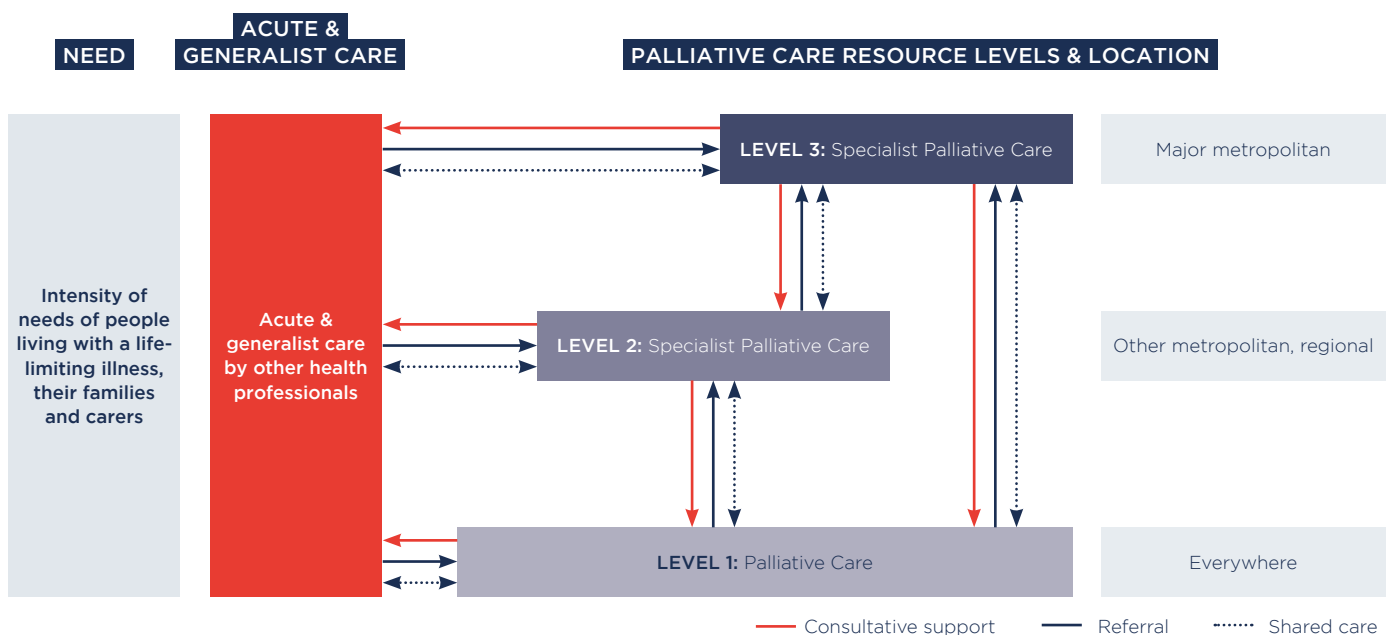
Another critically important feature are the arrangements for networking, referral and palliative care consultative support services that should operate:

1. Between the three levels of palliative care services; and
2. Between palliative care services and health and aged care services provided for people living with a life-limiting illness.

The objective of a networked approach to the provision of palliative care services is to ensure that the right care is provided to the right people in the right setting with the right mix of health professionals.

This is shown diagrammatically in Figure 3.1.

Figure 3.1: Networking framework for palliative care services organisation and delivery



The first type of networking relates to the palliative care needs of the person living with a life-limiting illness. Networking requires that there are effective referral arrangements and consultative support services between generalist providers of palliative care (Level 1) and specialist palliative care services (Levels 2 and 3).

Figure 3.1 indicates that, as required, in accordance with people's needs:

- » Level 1 palliative care providers should be able to refer people directly to either Level 2 or Level 3 specialist palliative care services, depending upon the complexity of the person's palliative care needs.
- » Similarly, Level 2 specialist palliative care services should be able to refer people with more complex needs to Level 3 specialist palliative care services.
- » Level 3 specialist palliative care services should provide consultative support services to Level 2 specialist palliative care services and Level 1 palliative care providers.
- » Similarly, Level 2 specialist palliative care services should provide consultative support services to Level 1 palliative care providers.
- » In most situations where there is referral or consultative support, both levels of palliative care services should continue to share responsibility for the person's care.

Figure 3.1 also illustrates another important element of networking – the effective communication and integration between the providers of disease-modifying care (on the left-hand side of the diagram) and palliative care (on the right-hand side of the diagram). Chapter 2 has previously identified the expectation that palliative care will be provided concurrently with disease-modifying care, where this meets the needs of people living with a life-limiting illness.

3.4 Professional education and training for all palliative care providers

Palliative care requires a specific skills-set to provide effective care to people living with a life-limiting illness, their families and carers. These skills include, but are not limited to:

- » Communication skills, especially when conveying potentially distressing information regarding prognosis and care options for people close to death;
- » Effective management of symptoms including pain;
- » Critical appraisal skills, including the ability to assess a person's palliative care requirements, whether medical, functional, psychological, financial, emotional or spiritual;
- » Skills in providing advice and assisting with advance care planning;
- » Ethical decision making; and
- » Life closure skills related to care provided when people are close to death that aims to preserve the dignity of the person and their family:

Education, training and professional development aim to instil, develop and maintain these skills in the palliative care workforce through undergraduate and post-graduate education, formal courses, workshops and in-services.

PCA expects that governments, the academic sector and professional associations will continue to ensure that suitable courses and programs are available to develop palliative care skills across the disciplines of medicine, nursing, pharmacy and allied health. In particular, ensuring that the workforce can access these educational opportunities must also be factored into planning requirements in resourcing the delivery of specialist palliative care services.

*Background evidence and analysis**

There is considerable evidence indicating a general lack of knowledge and education about palliative care as well as inadequate education on death and dying issues amongst other health professionals (who are not part of specialist palliative care services).

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

There is considerable evidence indicating a general lack of knowledge and education about palliative care as well as inadequate education on death and dying issues amongst other health professionals (who are not part of specialist palliative care services).

The aims of education and training for other health professionals (who are not part of specialist palliative care services) include:

- » To correct misconceptions about palliative care;
- » To assist in the identification of palliative needs in their patients;
- » To upskill providers in the provision of palliative care within their scope of practice and where appropriate
- » Assist in referral to specialist palliative care services or consultation, and when this is required; and
- » To assist providers to work collaboratively with specialist palliative care providers.

Education should also increase the comfort levels of all health professionals with giving information earlier and assisting families in talking with people living with a life-limiting illness about physical, psychological, spiritual, cultural and religious aspects of care.

PCA welcomes the substantial improvements over the past decade in the development of educational resources to support other health professionals who are not specialist palliative care providers. The development of resources has targeted both specific disciplines and specific settings of care, as well as broader approaches to embed learning about palliative care in the undergraduate studies of all health professionals. Some of the resources include:

- » The Palliative Care Curriculum for Undergraduates promotes the inclusion of palliative care education as an integral part of all medical, nursing, and allied health undergraduate and entry to practice training, and ongoing professional development.
- » The palliAGED project is an online evidence base and knowledge resource for aged care workers and GPs. This includes apps for GPs and nurses who are caring for older people living with a life-limiting illness at home or in residential aged care. The Practice Centre provides links to, and information about, evidence based tools and resources.
- » The Program of Experience in the Palliative Approach provides palliative care workplace training opportunities (via clinical placements) and workshops for a range of health care professionals, including nurses, allied health professionals, Aboriginal health workers, general practitioners and other health care workers.

PCA expects that funders and providers will strengthen existing efforts to ensure that an increasing share of the health workforce receives education and training to improve their skills to provide palliative care. This should be measured by increased provision of palliative care services by other health professionals.

3.5 Workforce support in palliative care

Another important system capability is workforce support to assist health professionals in managing the challenges of working in palliative care. Palliative care is a complex and demanding area of work for health professionals. Some of the demands and stressors specific to palliative care can include:

- » Breaking bad news about diagnosis and/or prognosis to a person living with a life-limiting illness and their family;
- » Coping with medicine's inability to offer these people a cure;
- » Repeated exposure to the death of people with whom they may have formed relationships;
- » Involvement in emotional conflicts with people living with a life-limiting illness, their families carers, or with other members of the palliative team;
- » Absorption of the anger, grief, and despair expressed by people living with a life-limiting illness, their families and carers; and
- » Challenges to one's personal belief system about the medical network, teamwork, death, and dying.

There is an urgent need for more rigorous research to identify how best to support all health professionals providing palliative care.

PCA expects that the provision of workforce support should be factored into the capability and resourcing of specialist palliative care services. The lack of workforce support is also a critical issue for other health professionals who may provide palliative care only intermittently and without the benefits of a supportive multidisciplinary team environment. Accordingly, Level 2 and 3 specialist palliative care services should provide advice and support to health professionals involved in the provision of Level 1 palliative care.

3.6 Research, evaluation and benchmarking in palliative care

PCA notes that research, evaluation and benchmarking are essential to drive continuous learning and quality improvement in the organisation and delivery of palliative care services.

Australia is relatively well-served in relation to palliative care research, evaluation and benchmarking capabilities. The Australian Government has funded infrastructure through a mix of projects and ongoing initiatives that contribute to strengthening research, evaluation and benchmarking capabilities in palliative care. The following sections describe some of these initiatives.

National Palliative Care Standards

The National Palliative Care Standards (5th Edition, 2018), clearly articulate and promote a vision for compassionate and appropriate specialist palliative care through 6 Standards focused on care and 3 Standards focused on governance.

The Core Values of the Standards is that quality palliative care is provided by health care workers who:

- » Endeavour to maintain the dignity of the care recipient, their caregiver/s and family;
- » Work with the strengths and limitations of the care recipient and their caregiver/s and family to empower them in managing their own situation;
- » Act with compassion towards the care recipient and their caregiver/s and family;
- » Consider equity in the accessibility of services and in the allocation of resources;
- » Demonstrate respect for the care recipient, their caregiver/s and family;
- » Advocate on behalf of the expressed wishes of care recipients, caregiver/s, families, and communities;
- » Are committed to the pursuit of excellence in the provision of care and support;
- » Are accountable to care recipients, caregiver/s, families and the community.

The Standards have been developed to be utilised by specialist palliative care services to support the delivery of high quality palliative care for the person receiving care, their family and carers.

PCA expects that specialist palliative care services will consider these Standards in the delivery of high quality palliative care.

The National Palliative Care Research Program

This ten-year research program from 2000 to 2010 comprised three rounds of funding to support research and activities aimed at developing capacity within the palliative care research community. Priority research areas included:

- » Palliative care service delivery in rural areas;
- » Assessment of the effectiveness of existing models of palliative care services delivery;
- » The trajectory of the course of illness for advanced disease, other than cancer, addressing biological and social/environmental factors;
- » Symptom assessment and management in palliative care;
- » Support for families and carers;
- » Psychosocial support, which may include bereavement and/or spiritual aspects; and
- » Models of care in palliation.

Subsequently, Australian specialist research groups have emerged in most states, usually as collaborations between academic institutions and clinicians. These include groups either focussing specifically on palliative care or cross-discipline groups that include collaborations with palliative care researchers.

In addition to these academic centres, PCA expects that specialist palliative care services should contribute to palliative care research, with participation in research being a key requirement for Level 3 specialist palliative care services.

CareSearch

CareSearch (the Australian palliative care knowledge network) is a resource providing evidence-based information on palliative care that is targeted to a diverse range of stakeholders. This includes an updated collection of systematic reviews on evidence related to palliative care.

CareSearch maintains a register of Australian research projects and studies in palliative care to increase awareness of current research activities. It also provides access to a research data management system tool that supports data collection and reporting.

Palliative Care Outcomes Collaboration

The Palliative Care Outcomes Collaboration is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. It supports specialist palliative care services to consistently compare and measure the quality of their services to facilitate continuous quality improvement.

Although participation is voluntary, the Palliative Care Outcomes Collaboration had achieved 100% coverage of private and 97% coverage of public specialist palliative care services by 2017. National benchmarks were first adopted in December 2009 and continue to be refined and expanded. In 2016 the Palliative Care Outcomes Collaboration generated national benchmarks on patient outcomes, based on information submitted by 113 specialist palliative care services comprising:

- » 82 inpatient services – this includes patients seen in designated palliative care beds as well as patients receiving consultative services in non-designated beds; and
- » 31 community services – these services mainly include patients seen in the community, although there are some data on patients with ambulatory (outpatient) clinic episodes.

PCA expects that specialist palliative care services will continue to participate in the Palliative Care Outcomes Collaboration.

Palliative care data

While the Palliative Care Outcomes Collaboration collects and reports on outcome data for specialist palliative care services, there are many other data gaps.

*Background evidence and analysis**

There are many data gaps with respect to the provision of palliative care services.

In the health sector, existing data collections are well-established and reasonably comprehensive for hospital-based inpatient palliative care services. However, there is limited information available on non-admitted (outpatient) services provided through hospitals. There is even less information available on community-based palliative care services provided outside hospitals.

The provision of community nursing may be funded under many different programs and provided by a diverse range of government and private sector providers. There is no national collection that captures information on service provision by community nurses, some of which will be related to providing care for people living with life-limiting illnesses.

There is also an information gap with regard to the location of death, especially in relation to people who may be moving between residential aged care and hospitals.

*For additional information and referencing, please refer to the companion document *Background Report to the Services Development Guidelines*

PCA expects that governments, national data agencies and health providers will continue to work towards improvements in palliative care data collections. In 2017 the Australian Institute of Health and Welfare commenced working with stakeholders to develop a framework to improve data collection for palliative care. PCA welcomes this development and looks forward to ongoing improvements in palliative care data collections.

Appendix 1. Medical, nursing and allied health workforce guidelines for operational planning for specialist palliative care services

Appendix 1 includes Palliative Care Australia's revised planning benchmark of 2.0 full-time equivalent specialist palliative medicine physicians and the previous nursing and allied health professional ratios that can be used for the purposes of operational planning by Local Hospital Networks, hospitals and specialist palliative care services. For more information please refer to Chapter 3 of the Palliative Care Service Development Guidelines.

This appendix includes suggested workforce levels for medical practitioners, nurses and allied health professionals that are part of specialist palliative care services. These guidelines are provided for the purposes of operational planning to be used by hospital and community-based specialist palliative care providers.

Table A1: Medical staffing levels for specialist palliative care services per 100,000 population

POSITIONS	COMMUNITY-BASED SERVICE*	CONSULTATIVE SERVICE**	PALLIATIVE CARE DESIGNATED BEDS***	COMMENTS
MEDICAL				
Palliative care consultant	2.0	1.5		Specialist and registrar positions have both community and hospital responsibilities
Registrar	← 1.0 →			
Resident medical officer	-	-	0.25	Resident positions attached to designated palliative care beds only
Liaison psychiatry	← 0.25 →			It is expected that between 30-50% of referrals will have a diagnosable mental illness

Notes

* Full-time equivalent per 100,000 population

** Full-time equivalent per 125 beds

*** Full-time equivalent per 6.7 beds (within acute hospital)

Table A2: Nursing workforce levels for specialist palliative care services per 100,000 population

POSITIONS	COMMUNITY-BASED SERVICE*	CONSULTATIVE SERVICE**	PALLIATIVE CARE DESIGNATED BEDS***	COMMENTS
NURSING				
Clinical Nurse Consultants (CNC)	1.0 plus 2 Clinical Nurses	0.75		Community and acute care consultation teams require CNC level nurses to act independently, provide consultation to primary carers (nursing and medical), and to coordinate, monitor and review patient care. Clinical Nurses are senior palliative care nurses who work under the direction of the CNC.
Registered and enrolled nurses			6.5 hours per patient per day	Designated palliative care beds require a mix of direct care. This care will include CNC, Clinical Nurses, RN and EN level nurses, with a predominance of RNs over ENs. Patient carers may also be part of the workforce mix.
Discharge Liaison	← 0.25 →			This role could be included in a nursing or social work position.

Notes

* Full-time equivalent per 100,000 population

** Full-time equivalent per 125 beds

*** Full-time equivalent per 6.7 beds (within acute hospital)

Table A3: Allied health workforce levels for specialist palliative care services per 100,000 population

POSITIONS	COMMUNITY-BASED SERVICE*	CONSULTATIVE SERVICE**	PALLIATIVE CARE DESIGNATED BEDS***	COMMENTS
ALLIED HEALTH				
Psychology	0.25	0.1	0.1	
Social work	0.5	0.25	0.25	
Bereavement support	0.25	0.1	0.1	
Pastoral care	0.25	0.25	0.25	Pastoral carers offer spiritual support that is quite distinct from the psychological and social support offered by other professionals.
Speech pathology	0.2	0.2	0.2	Speech pathologists assess and treat swallowing dysfunction, and support communication skills, particularly for people with worsening physical disability.
Dietician	← 0.2 →			Dieticians with a particular skill and interest in palliative care can enhance quality of life by planning enjoyable and attractive food within the constraints imposed by the patient's condition.
Physiotherapy (PT)	0.4	0.2	0.2	PT and OT are valued by patients for providing practical help and positive intervention. Ideally the two will work closely together.
Occupational Therapy (OT)	0.4	0.2	0.2	<p>PTs help to keep patients mobile and safe, as well as providing short-term symptom relief for people with lung congestion, etc</p> <ul style="list-style-type: none"> • OTs work with both patients and carers to promote the patient's function, safety and independence in the home and hospital environment • Lymphoedema symptom relief is shared between PT and OT.
Pharmacist	-	0.25	0.1	Both of these positions would have a role in supporting the community-based team. An extensive network of community pharmacists provides valuable primary healthcare for palliative patients in the community by assisting with advice, documentation of medication histories, dosage compliance, and the disposal of medications not required.
Music therapy, art therapy, and/or massage, narrative, diversional, complementary therapies etc.	0.5	-	0.25	<p>These therapies can significantly increase quality of life and provide positive, normalising activities. The appropriate mix will depend on locally available skills and needs.</p> <ul style="list-style-type: none"> • Music and art therapy are professional degree courses, and include a high level of training in psychological and communication skills. • Complementary and other therapists have widely varying levels and types of training, and practitioners' skills will vary. <p>Much can be done in these areas at a group level, rather than one-to-one contact.</p>

Notes

* Full-time equivalent per 100,000 population

** Full-time equivalent per 125 beds

*** Full-time equivalent per 6.7 beds (within acute hospital)

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