

# Background Report to the Palliative Care Service Development Guidelines

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**PalliativeCare**  
AUSTRALIA

# Acknowledgements

This Background Report (Report) has been produced independently by Aspex Consulting on the request of Palliative Care Australia. The information, statements, statistics and commentary (together the 'Information') contained in this Report have been prepared by Aspex Consulting from available material and from discussions held with stakeholders. The Report is attached to the Palliative Care Australia Palliative Care Service Development Guidelines (2018) to provide background information. This Report has been developed based on Information received or obtained, on the basis that such Information is accurate and complete. The views expressed in this Report are not necessarily the views of Palliative Care Australia.

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# Introduction

This Background Report is a supporting companion report to Palliative Care Australia's *Palliative Care Service Development Guidelines* (January 2018). It provides the policy context, detailed evidence and analysis to underpin the expectations developed by Palliative Care Australia for the palliative care service system.

This Background Report is organised as follows:

- » Chapter 1 begins with a person-centred approach to palliative care through examining the needs of people living with a life-limiting illness. Current patterns of death in Australia are presented, as well as information on typical illness trajectories. It also examines the need for a public health approach to palliative care to support broader public debate about dying, death, loss and grief, including policies to encourage uptake of advance care planning.
- » Chapter 2 introduces and defines the concept of palliative care including identifying the difference between specialist palliative care and palliative care provided by other health professionals. It outlines the value of the early introduction of palliative care for people living with a life-limiting illness.
- » Chapter 3 provides the evidence basis and analysis on the demand for, and utilisation of, palliative care services. This includes examination of Australian and international studies that have been used to estimate population-based need for palliative care. A conceptual model of level of need for palliative care is presented, recognising the value in aligning workforce capability with people's diverse levels of need for palliative care. Data is presented on the use of specialist palliative care services, palliative care provided by other health professionals and disparities in access to these services by different population groups.
- » Chapter 4 presents a systems framework for the palliative care service system. It then identifies the key elements of a person-centred and effective continuum of palliative care services for people living with a life-limiting illness, their families and carers. For people living with a life-limiting illness, the key elements considered are: referral and assessment services; settings for the provision of palliative care; a team-based approach to service provision; and continuity and coordination of care. For families and carers, the key elements considered are: information, education and support; after-hours access; equipment and medical supplies; respite; and bereavement support.
- » Chapter 5 examines the workforce and system capabilities required to deliver high-quality palliative care services. Data is presented on the palliative care workforce. An updated workforce capability framework has been developed that includes greater specification of the scope of services that should be provided for each level of palliative care service. A regional approach to planning of palliative care services is outlined, together with a framework to ensure effective networking between and across palliative care services and other health services. The value and current status of other systems capabilities are examined including professional education and training; workforce support; and research, evaluation and benchmarking.

# Caring for people who are living with a life-limiting illness



Historically, health service planning has been based on models of service delivery that have been organised around the needs of hospitals and clinicians. Since 2005, Palliative Care Australia has supported a population-based approach to the planning of palliative care services that, instead, seeks to understand and plan for the health and social needs of the target population.<sup>1</sup>

A population-based approach includes recognising, and responding to, the growth of consumer-focussed models of care that put people, their families and carers at the centre of planning, design and delivery of health and aged care services in Australia. Some recent developments include:

- » In 2013 trials of the National Disability Insurance Scheme commenced, with funding budgets provided to individuals to make decisions about the services and supports that best meet their needs.<sup>2</sup>
- » In 2015, the aged care Home Care Packages Program changed so all packages are delivered under a consumer directed care model to provide clients with greater choice and control.<sup>3</sup>
- » Commencing in 2017, health care homes are being established for enrolled patients with chronic and complex health conditions, to give patients and their carers the knowledge, skills and supports they need to be active partners in their care.<sup>4</sup>

Accordingly, this Background Report begins by outlining the needs of the target population for palliative care services. It refers to this population as people who are living with a life-limiting illness. This acknowledges that people are actively living with, not simply dying from, such illnesses. While people can also be described as 'consumers', this term is less relevant in discussing people who may need palliative care services.

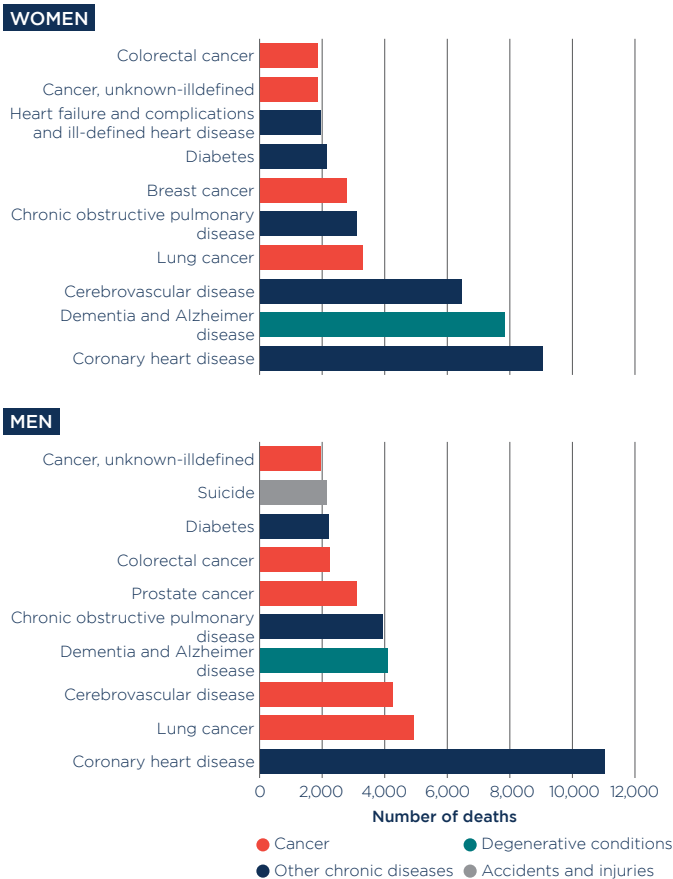
## 1.1 Dying an 'expected' death

In 2016 about 158,500 people died in Australia.<sup>5</sup> An understanding of patterns of death, including age, causes of death and differences across population sub-groups, is relevant to planning palliative care services. Some of the key patterns include:

- » Most deaths occur among older people. About two-thirds (66%) of deaths were among people aged 75 or over. The median age of death was 78.5 for men and 84.8 for women. Less than 1% of deaths are in the 0-4 year age group.<sup>6</sup>
- » Some population groups are more likely to die at younger ages than the general population. The Australian Institute of Health and Welfare reports on premature mortality, defined as deaths among people aged under 75 years. About four in every five deaths among Indigenous people occurred before the age of 75, compared with about one in three deaths for non-Indigenous people. People living in the lowest socioeconomic areas had a premature mortality rate that was twice as high as the rate among people living in the highest socioeconomic areas. People living in remote areas of Australia had a premature mortality rate that was 1.6 times as high as the rate among people living in major cities, while in very remote areas it was 2.2 times as high.<sup>7</sup>
- » Patterns in the cause of death are relevant to understanding the extent to which deaths might be expected (such as people with end-stage renal disease) or unexpected (such as people dying as a result of traffic accidents). Where dying is expected (or does not come as a surprise to the health professionals providing care), some people will require palliative care services.
- » Figure 1.1 shows the top ten leading causes of death for Australian women and men. These have been grouped into: cancers, other chronic diseases (such as coronary heart disease and chronic obstructive pulmonary disease), degenerative conditions (such as dementia) and accidents and injuries.

- » Coronary heart disease accounts for 13.1% of deaths, followed by dementia and Alzheimer’s disease with 7.8% of deaths. With the exception of suicide deaths among men, all the top ten leading causes of death are for causes that result in what might be considered as expected deaths.

Figure 1.1: Leading causes of death, Australia<sup>8</sup>



## 1.2 Illness trajectories and dying

People will experience different illness trajectories, depending upon their health conditions and diagnoses. Among people dying an expected death, three trajectories of illness (shown in Figure 1.2) are commonly described comprising:

- » **Short period of evident decline:** long maintenance of good function 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.
- » **Long-term limitations with intermittent serious episodes:** there is a gradual decline in function, interrupted by episodes of acute deterioration. There is a risk of dying during each of these acute episodes, but the person may survive many such acute episodes. 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.<sup>9,10,11</sup>

These illness trajectories have historically distinguished between cancer and other chronic diseases. However, treatment gains for certain types of cancer have changed the ‘typical’ illness trajectory - some people live with cancer as a chronic disease, rather than experience a rapid decline.

In addition, the illness trajectories shown in Figure 1.2 are complicated by the fact that more people are increasingly living with one or more chronic diseases. In 2014-15 there were more than 11 million Australians (50%) living with at least one of eight selected chronic diseases. Almost one in three people (29%) aged 65 years and over lives with three or more chronic diseases.<sup>12</sup> These patterns of multimorbidity increase the complexity of patient needs and blur the simple distinction that is implied in Figure 1.2.

An understanding of different illness trajectories is relevant to planning services for both individuals and at a whole-of-population level.<sup>13</sup> It can assist in:

- » Identifying people who are nearing the end-of-life and influence the timing and focus of advance care planning discussions;
- » Reducing non-beneficial or futile care through gaining an appreciation that ‘doing everything possible’ may be misdirected, depending on the individual’s position on the illness trajectory;
- » Recognising that ‘one size does not fit all’ and that different models of care are likely to be required for different individuals depending upon their illness trajectory;

- » Reducing the occurrence of unplanned and emergency use of hospital and other health services through encouraging uptake of care pathways that reflect the individual's condition, needs and social circumstances; and
- » Planning care that integrates curative and palliative care while promoting early engagement by palliative care.

Figure 1.2: Typical illness trajectories<sup>13,14</sup>



### 1.3 Eliciting community values and priorities

A person and family-centred approach to planning palliative care services involves understanding that people's priorities and needs are likely to change over the course of an illness and in response to increasing proximity to death.

While dying is intensely personal, it also sits within a societal context. This means that palliative care services also need to be shaped by, and respond to, community values and priorities.

In most western societies, including Australia, dying has become less visible and more medicalised.<sup>15</sup> The experience of earlier generations – in having one or more children die at an early age, as well as other family members die at home – is now uncommon. In 1907 children under the age of five accounted for one quarter of all deaths.<sup>16</sup> Now, dying happens at a much older age, hidden away from the public gaze, frequently in hospitals, aged care homes and other institutions.

As a society, we struggle to talk about death or even accept its inevitability. Euphemisms abound.<sup>17</sup> We talk about people 'passing on' or 'being laid to rest', rather than using the more direct language of death and dying. For many people, death is a taboo subject that is not a topic for polite conversation. The taboo nature of death may reflect many factors such as fear of acknowledging our own mortality; unwillingness to recognise the choices that we may need to make while dying; a desire to protect and shield others from the experience of dying; and concerns that people we love might face a 'bad death'.

Studies estimate that anywhere from one-third to one-half of Australians either do not have a will or do not have a valid will, another indicator of our reluctance to face the inevitability of death.<sup>18,19</sup> Delaying discussion about death and dying can result in difficult choices being made 'in the pressure cooker environment of a hospital', without sufficient time for reflection and discussion with family and friends.<sup>20</sup>

The Western Australian Department of Health has proposed that:

*'A cultural change is required in order to encourage clinicians, patients and families to engage in honest conversations and to assist patients to make decisions about how they want to live until they die. Broader strategies are required to raise awareness and enhance community understanding of issues relating to death and dying, in particular, the limits of medical interventions, the benefits of palliative care and the importance of advance care planning and advanced health directives.'*<sup>21</sup>

A welcome development is the increasing implementation of initiatives that promote public conversations about the limits of medical intervention, the role of palliative care and the choices that people need to make as they approach an expected death.

Many studies have identified widespread use of non-beneficial treatments (sometimes referred to as futile or inappropriate treatment) provided to people at the end-of-life. A recent systematic review of 38 studies across ten developed countries and 1.2 million patients identified that, on average, about one-third (33-38%) of people near the end-of-life received non-beneficial treatments.<sup>22</sup> This included: the provision of active measures such as dialysis and radiotherapy to terminal patients; admission to, and treatment in, intensive care units; the performance of non-beneficial treatments on patients with do-not-resuscitate orders; and the non-beneficial administration of antibiotics, cardiovascular, gastroenterology and endocrine treatments to dying patients.

In Australia the NSW Agency for Clinical Innovation has undertaken pioneering work through its 'Fact of Death Analysis' to examine use of hospital services in the last year of life.<sup>23</sup> This analysis identified that 60% of patients who might benefit from palliative and end-of-life care had emergency (unplanned) admissions. However, only 7% of all hospital admissions in the last year of life were coded as palliative care admissions. As the Agency for Clinical Innovation has noted, unrealistic expectations of modern medicine can result in delayed referrals to palliative care services and militate against a healthy approach to death and dying.

Reducing the provision of non-beneficial treatment as people approach the end-of-life requires action that extends beyond the responsibility of palliative care services. Choosing Wisely Australia is one approach to helping both health professionals and people who use health services have conversations about eliminating unnecessary and sometimes harmful tests, treatments and procedures for different health conditions across the life course. This becomes even more critical as people approach the end-of-life, when there is a need to shift from a paradigm that sees death as treatment failure to recognising its inevitability and focussing, instead, on the quality of the remaining lifespan.

The concept of 'public health palliative care' is an important context and backdrop against which palliative care services are delivered. The goals of public health palliative care are to:

- » Build public policies that support dying, death, loss and grief;
- » Create supportive environments;
- » Strengthen community action;
- » Develop personal skills; and
- » Re-orient the health system.<sup>24</sup>

There are many emerging developments and initiatives, both internationally and in Australia, that are based on the concept of public health palliative care. The Australian Government, with the support of Palliative Care Australia, has been involved in implementing two such initiatives, namely:

- » **Dying to Talk:** The Dying to Talk campaign is helping to build community awareness and engagement in discussions about care at the end-of-life.<sup>25</sup> Through conversation starter cards targeted at both Indigenous and non-Indigenous Australians, Dying to Talk is intended to normalise discussions about death and dying, so that family members and carers are better informed about the wishes of their family members. Dying to Talk encourages people of all ages and all levels of health to talk about dying and to work out what is right for them at the end of their lives.
- » **Compassionate Communities:** Compassionate Communities is an international movement that aims to support communities to recognise the needs of people who are approaching the end of their lives, and develop initiatives to support them. The focus is on integrating more holistic, social approaches to dying, rather than relying only on medical models. In Australia the Compassionate Communities Network encourages support for community capacity building and resilience on issues related to dying, death and bereavement.<sup>26</sup> The Tasmanian Government is implementing the Compassionate Communities concept as part of its state-wide framework for palliative care.<sup>27</sup>

Both these developments recognise that the palliative care service delivery system (targeted at dying people, their families and carers) must be complemented by public health approaches to death and dying (targeted at the whole community) that promote early discussion before palliative care services are needed.



## 1.4 Identifying needs of people living with a life-limiting illness

The concept of 'a good death' is commonly espoused, although there may be different interpretations of what this involves. One widely cited set of principles of a good death was identified in a 1999 British report on the care of older people (Table 1.1).

**Table 1.1: Principles of a good death<sup>28</sup>**

PRINCIPLES OF A GOOD DEATH
<ul style="list-style-type: none"><li>• To know when death is coming and to understand what can be expected</li><li>• To be able to retain control of what happens</li><li>• To be afforded dignity and privacy</li><li>• To have control over pain relief and other symptom control</li><li>• To have choice and control over where death occurs (at home or elsewhere)</li><li>• To have access to information and expertise of whatever kind is necessary</li><li>• To have access to any spiritual or emotional support required</li><li>• To have access to hospice care in any location, not only in hospital</li><li>• To have control over who is present and who shares the end</li><li>• To be able to issue advance directives which ensure wishes are respected</li><li>• To have time to say goodbye and control over other aspects of timing</li><li>• To be able to leave when it is time to go and not to have life prolonged pointlessly</li></ul>

One noteworthy aspect of these principles is that there is a relatively strong emphasis on psychological, emotional and spiritual issues, compared to physical health issues. Subsequent studies, that have examined the issue of a good death from the perspective of people living with a life-limiting illness, their families and carers, have reinforced the importance of psychosocial and spiritual issues.<sup>29,30</sup>

A person and family-centred approach to palliative care is grounded in the understanding that while an illness affects an individual, it also has an impact on their family and carers, so that the focus of care should extend beyond the individual to the family unit.<sup>31</sup> Meeting the needs of family members and carers is discussed in more detail in Section 4.3.

### 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 and have these preferences incorporated in clinical care planning as they approach the end-of-life. For example, planning can establish an individual's preferred place of care and who they would want to be involved in making decisions on their behalf. 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 close to the person.<sup>32,33,34</sup>

Advance care planning has been found to increase the concordance between a person's end-of-life wishes and the care they ultimately receive. Studies report reduced unwanted interventions, increased use of palliative care and prevention of hospitalisation.<sup>35</sup> Accordingly, advanced care planning is considered to improve quality of life and other outcomes for people living with a life-limiting illness and family members,<sup>36,37,38</sup> including those in the aged care population.<sup>39,40</sup>

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.<sup>41,42</sup>

Activities to encourage greater discussion about the value of advance care planning should be supported. 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.<sup>43</sup> Another important development was the agreement on a national framework for advance care directives that provides policy guidance and directions in response to the legislative variation across states.<sup>44</sup>

### Where people die

One element that is usually covered in advance care planning is about how and where death might occur. Having choice and control over where death occurs is often viewed as important, with many people expressing a preference to die at home.<sup>45</sup> A systematic review of over 200 studies from 33 countries on preferences for place of care or place of death found that most people preferred to die at home.<sup>46</sup>

However, many factors may shape or change people's preferences about where they wish to die. Preferences expressed while people are healthy may change after the diagnosis of a terminal illness and as the illness progresses.<sup>47</sup> Changes in family circumstances, such as the loss of potential carers, may reduce the perceived ability to manage dying at home.

Existing Australian data does not support robust measurement of the location of death for all people. What is known definitively is that about half of all deaths occur in a hospital. For example, in 2014-15, almost 77,000 people died during a hospital admission,<sup>48</sup> equal to 50% of the approximately 154,000 deaths reported in 2014.<sup>49</sup>

The other 50% of deaths occur outside hospitals in the community, but their specific distribution cannot be accurately determined. Some of these deaths will occur in people's homes; others will occur in residential aged care and other facilities where people live (such as accommodation for people living with a disability or severe mental illness). Existing data for residential aged care facilities suggests that about four in five residents (81%) who 'exit' from an aged care facility do so due to death.<sup>50</sup> However, these data are misleading in terms of the location of death, as some of the deaths may occur in hospital, rather than in the aged care facilities. There is currently no incentive for residential aged care to record transfers of residents to hospitals, meaning that some of the deaths reported in residential aged care actually occur in hospitals. Similarly, the death data reported by the Australian Bureau of Statistics do not routinely capture place of death.

There is a need to improve the quality of reporting in relation to the place of death in several major data collections managed by the Australian Institute of Health and Welfare and the Australian Bureau of Statistics.

Finally, in considering the issue of preferences for where people want to die, it may be helpful to distinguish between the 'dying phase' and 'death'. While 50% of Australians die in a hospital, the reality is that 'much of the dying phase occurs within the home'.<sup>51</sup> People's preferences for care during the dying phase and death have implications for the planning and provision of the mix of hospital and community-based palliative services.

# Understanding and defining the scope of services for people living with a life-limiting illness

This chapter provides an overview of the types of services that might best support people who are living with a life-limiting illness, their families and carers.



## 2.1 What is palliative care?

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.

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.<sup>52</sup>
  - » Palliative care should be available to all people living with an active, progressive, advanced disease, regardless of the diagnosis.
  - » Palliative care involves a holistic approach to improving the quality of life for people living with a life-limiting illness, their families and carers across three equally important domains. First, it includes early intervention to prevent or relieve pain and other distressing physical symptoms (such as breathing difficulties, nausea, vomiting and delirium). Second, it involves the provision of psychological and spiritual support to reduce suffering and distress related to feelings of helplessness, remorse, loss, anxiety and loneliness as people and their families face mortality. Third, it involves social support to address practical and financial problems related to the person's social and living circumstances, access to carers and their functional independence. The needs of people who are living with a life-limiting illness will determine the timing of when care across these domains is provided.
- » 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 dying, but it is not directed at either bringing forward or delaying death.<sup>53</sup>

In the context of ongoing public debate and legislative reforms, it is important to also note Palliative Care Australia's views, in accordance with international guidelines, that palliative care does not include euthanasia or physician assisted dying.<sup>54</sup> It is noted that:

- » Euthanasia and physician assisted dying are not legal in most Australian jurisdictions. In 2017 the Victorian Government passed legislation that provides a strict framework within which voluntary assisted dying can be provided, commencing in 2019.<sup>55</sup>
- » There is a broad spectrum of opinion and a level of support for reform within the Australian community which reflects diverse cultures, belief systems and populations.
- » Compassion, dignity, respect and participation in decision-making are integral to high quality palliative care. A request for euthanasia or for physician assisted dying requires a respectful and compassionate response.
- » When aligned with a person's wishes, withdrawing or refusing life sustaining treatment (including withholding artificial hydration or providing medication to relieve suffering) do not constitute euthanasia or physician assisted dying.<sup>56</sup>

## 2.2 Early introduction and integration of palliative care

Historically, palliative care and curative care were viewed as being at two ends of a continuum, with access to palliative care only seen as valuable once curative treatment had ceased.

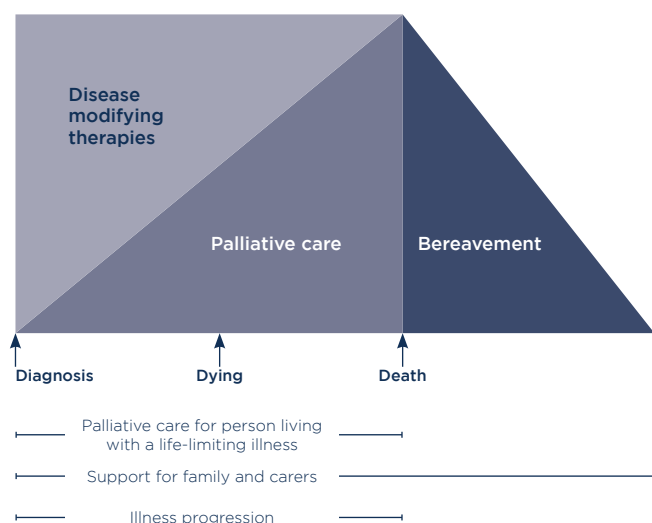
The Australian and New Zealand Society of Palliative Medicine, together with the Australasian Chapter of Palliative Medicine, now recommends that discussions of, and referral to, palliative care for people with serious illnesses should not be delayed simply because of the continuing provision of disease-modifying or curative therapies.<sup>57</sup>

There is good evidence that:

- » Integrating palliative care with disease-modifying therapies improves pain and symptom control, quality of life for the dying person and family satisfaction; and
- » Early access to palliative care can reduce aggressive or futile (non-beneficial) therapies at the end-of-life, prolong life in some patient populations and significantly reduce hospital costs.<sup>58,59,60,61,62</sup>

The evidence supports the concurrent and integrated provision of palliative care with disease-modifying care for people with active, progressive advanced diseases, as shown in Figure 2.1. The approach to integrating palliative care with care provided by other health care professionals is discussed as part of the systems framework for palliative care that is developed in Chapters 4 and 5.

Figure 2.1: Proposed approach to integrating palliative and disease-modifying care<sup>63</sup>



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

## 2.3 Types and providers of palliative care

Many health and aged care professionals are involved in providing care to people who are living with a life-limiting illness, their families and carers. Not all such people need, or indeed want, access to palliative care provided by palliative care specialists.

Some people have needs that can be effectively met through their existing relationship with the health professional or team of health professionals involved in managing and providing their care. The medical management and coordination of care for people who are 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 caring for people with advanced disease. Other essential team members will include nurses and allied health personnel.

One approach to distinguishing the role of these health professionals from the role of palliative care specialists is to consider the different skill sets or competencies that should be expected of the two groups of health care providers. Table 2.1 provides an illustrative listing of competencies that was developed by American palliative medicine specialists.

Table 2.1 identifies that there are some 'core competencies' of palliative care that relate to providing care for people whose needs are relatively simple or uncomplicated. This includes management of physical and other symptoms, provision of, or referral to, suitable psychosocial support services and effective communication about end-of-life issues.

In this Background Report, Palliative Care Australia is using the term 'palliative care' to describe the minimum core competencies that are required of all health professionals involved in providing care to people living with a life-limiting illness, their families and carers.

Table 2.1: Competencies for providers of palliative and specialist palliative care<sup>64</sup>

PROVIDERS OF PALLIATIVE CARE	PROVIDERS OF SPECIALIST PALLIATIVE CARE
<ul style="list-style-type: none"> <li>• Basic management of pain and symptoms</li> <li>• Basic management of depression and anxiety</li> <li>• Basic discussions about prognosis, goals of treatment, suffering, code status</li> </ul>	<ul style="list-style-type: none"> <li>• Management of refractory pain or other symptoms</li> <li>• Management of more complex depression, anxiety, grief and existential distress</li> <li>• Assistance with conflict resolution regarding goals or methods of treatment</li> <li>• Assistance in addressing cases of near futility</li> </ul>

Note: Refractory symptoms are those which cannot be readily controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness.<sup>65</sup>

This basic level of palliative care is sometimes referred to as either 'generalist palliative care' or 'primary palliative care'.<sup>66,67,68</sup> This language reflects several factors which distinguish palliative care from specialist palliative care, namely:

- » Palliative care is usually provided by health care professionals who do not have the same level of specialised skills, competencies, experience or training that characterise specialist palliative care providers. These health professionals are 'generalists' with respect to palliative care, notwithstanding that many of them may be specialists in their own discipline.
- » The initial or primary provision of palliative care is likely to be delivered by the health professional with primary responsibility for the health needs of the person living with a life-limiting illness. However, some dying people will develop more complex and persistent symptoms that will only be able to be successfully managed through the secondary provision of specialist palliative care.

The use of the terms 'palliative care' and 'specialist palliative care' in this Background Report represents an update or evolution of the terminology previously used by Palliative Care Australia in its 2005 Service Development Guidelines.<sup>69</sup>

In particular, Palliative Care Australia is using the term 'palliative care' in preference to its previous language that described a 'palliative approach' being delivered by 'primary care providers'. This use is based on the following factors:

- » The term 'palliative care' conveys enhanced expectations about the core competencies and skills required of all health professionals involved in caring for people living with a life-limiting illness. In contrast, some health professionals perceive that the term 'palliative approach' suggests an under-developed or less professional approach to providing care for most people living with a life-limiting illness.
- » Although the term 'palliative approach' is well recognised in the residential aged care sector, it is generally considered less relevant to care provided in acute settings where the term 'palliative care' is better understood.
- » Finally, the term 'palliative approach' is viewed as less person-centred than the term 'palliative care'. It implies decisions and actions taken by health professionals, rather than a care model that involves shared decision-making between the person living with a life-limiting illness, their family and carers, and health professionals.

Another change that has occurred over the last decade is the increasing uptake in Australia of the term 'end-of-life care'. However, the term end-of-life care is being used and interpreted differently across the country. There are at least three quite distinct uses of the term end-of-life care as follows:

- » In Victoria, the Department of Health and Human Services uses the term end-of-life care to specify the care needed by people who are likely to die in the next 12 months. It separately uses the terms palliative care and specialist palliative care to describe the two distinct groups of providers – palliative care can be delivered by a range of health and community providers while specialist palliative care refers to care delivered by clinicians with specialist qualifications in palliative care and the designated specialist palliative care sector.<sup>70</sup>
- » In NSW, the Agency for Clinical Innovation uses the term end-of-life care to describe 'care provided to people approaching the end-of-life by all health professionals, regardless of where they work in the health and aged care system'. End-of-life is defined as the period when a person is living with an advanced, progressive life-limiting illness. The Agency for Clinical Innovation distinguishes end-of-life care (that is provided by all health professionals) from palliative care (that is provided by specialist services).<sup>71</sup>
- » In Queensland, the Department of Health uses the term end-of-life care as the generic term to include all types of care that may be provided including a palliative approach, palliative care and complementary care (including self-help, support and non-clinical therapies). It further describes that end-of-life care is delivered through a collaboration of three types of providers – specialist palliative care providers, non-specialist palliative care providers and support care providers (including assistants in nursing, healthcare workers, volunteers, non-clinical therapists and family members).<sup>72</sup>

It can be seen that the term end-of-life care is sometimes being used narrowly to describe care provided in a particular period of time (Victoria); sometimes being used to describe the non-specialist providers of care (New South Wales); and sometimes being used broadly to describe all the types of care and all the types of providers (Queensland).

For the purposes of simplicity and to avoid further linguistic misunderstanding, this Background Report does not use the term 'end-of-life care'. Instead, it uses the terms 'palliative care' and 'specialist palliative care' as outlined above to describe the types of health professionals involved in providing care to people who are living with a life-limiting illness.

The Background Report does use the term 'end-of-life' to describe the period of time during which people are living with an active, progressive advanced disease and are expected to die. As it is difficult to estimate when someone will die, a specific time period (such as 12 months or the last month) is not designated as the end-of-life period. Instead, the term 'end-of-life' will be used to refer to the whole time during which people who are dying might benefit from the provision of palliative care.

# Assessing the need for, and use of, palliative care services

# 3

This chapter examines population-based approaches to estimating need for palliative care and the extent to which there are disparities in access to palliative care services in Australia.

## 3.1 Estimating total population need for palliative care

In most countries, palliative care services have predominantly been provided to people with cancer. However, the increasing prevalence of other chronic diseases, together with population ageing, has led to widespread recognition that other populations with different illness trajectories (as illustrated in Figure 1.2) may benefit from receiving palliative care services. This context has driven research to identify and compare different methods to estimate population-based need for palliative care. Table 3.1 identifies the key characteristics and findings of major Australian and European studies published from 2000 onwards.

The consensus view that has emerged from these analytical studies is that about 75% of all deaths may benefit from the provision of palliative care. This estimate relates to all providers of palliative care comprising both specialist palliative care providers and other health professionals who provide care to people who are living with a life-limiting illness.

As there are currently approximately 160,000 deaths annually in Australia (Section 1.1), this suggests that about 120,000 Australians may need access to palliative care in any one year. In the context of an Australian population of about 24.7 million people,<sup>73</sup> this is equivalent to a rate of 485 people with a potential need for palliative care per 100,000 population.

## 3.2 Variation in need for palliative care across different populations

The estimate that about 75% of all deaths in Australia will require access to palliative care assumes that all people dying an expected death from advanced, progressive diseases will benefit from some access to palliative care, whether it is provided by specialist or generalist providers of palliative care.

However, many factors will influence the degree of expressed need for palliative care including:

- » Some illness trajectories will result in need for palliative care that may extend over several years. Children and adolescents comprise a relatively small share of deaths. In 2014 about 1,450 children and adolescents died in Australia before the age of 14 years.<sup>74</sup> However, children and adolescents are likely to have longer and more variable illness trajectories than those of adults, generating particular needs for palliative care.<sup>75</sup>
- » The extent of need for palliative care can vary by diagnosis. For example, the Worldwide Palliative Care Alliance and the World Health Organization use estimates for the prevalence of symptoms including physical pain as an indicator of need for palliative care, citing high rates of pain prevalence for people dying with cancer, HIV/AIDs and Parkinson's disease, but lower pain rates for people dying with renal failure, multiple sclerosis and Alzheimer's disease.<sup>76</sup> However, these indicators do not capture the need for palliative care arising from other symptoms including psychological distress.
- » The complexity of needs (including physical symptoms, psychological distress, family and social support, information and practical needs) may also vary for people with the same diagnosis, so that diagnosis alone is not necessarily a good predictor of palliative care needs.<sup>77</sup>

Accordingly, Figure 3.1 conceptualises the population of people who are dying expected deaths as falling within three broad groups based on the complexity of their needs for palliative care comprising:

- » **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.

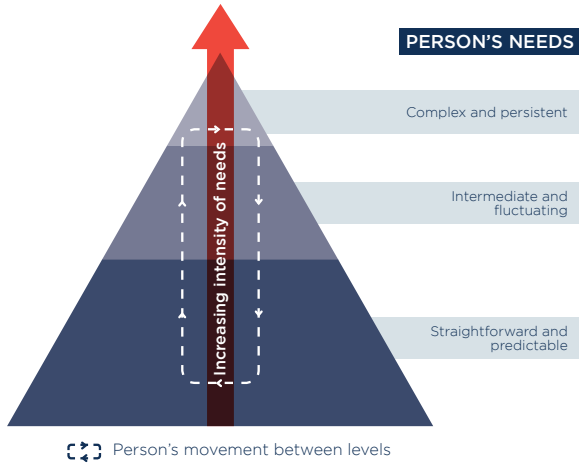
- » **People with complex and persistent needs:** this group comprises people with complex physical, psychological, social and/or spiritual needs that are not able to be effectively managed through established protocols of care. While people in this group will require more ongoing direct care by specialist palliative care providers, this should occur through partnerships and shared care models with existing health care providers.

**Table 3.1: Estimates of need for palliative care services**

STUDY, YEAR & COUNTRY	POPULATIONS INCLUDED & METHOD	ESTIMATES OF NEED
Rosenwax et al. 2005, Australia (Western Australia) <sup>78</sup>	Analysis of disease-specific mortality (for all cancers and other specified conditions), also incorporating use of linked hospitals admission data Ten conditions examined comprised cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, neurodegenerative disease, Huntington's disease, motor neurone disease, Parkinson's disease, Alzheimer's disease and HIV/AIDS	Produced 3 estimates: <ul style="list-style-type: none"> <li>• <i>Minimal</i>: deaths due to any of 10 specific conditions (50.0% of all deaths)</li> <li>• <i>Mid-range</i>: all deaths hospitalised with same condition as certified on the death certificate sometime in the year before death (55.5% of all deaths)</li> <li>• <i>Maximal</i>: all deaths excluding those from poisoning, injury, maternal neonatal or perinatal deaths (89.4% of all deaths)</li> </ul>
Gomez-Batiste et al. 2012, Spain <sup>79</sup>	Examines all causes of death, also considers prevalence of people living with chronic diseases and dementia, people living in residential aged care and prevalence of symptoms in older people	<ul style="list-style-type: none"> <li>• States that 75% of all deaths will be from chronic progressive diseases (25% cancer, 50% from other chronic diseases)</li> <li>• Estimates that at any time, 1.2-1.4% of people of such populations will suffer from advanced chronic conditions and have limited life expectancy</li> </ul>
Murtagh et al. 2014, England <sup>80</sup>	People dying from malignant or non-malignant conditions between 2007-2011 in England Compared previous methods and refined the Rosenwax method to update underlying cause of death to current practice, as well as including information on contributing cause of death for selected conditions	<ul style="list-style-type: none"> <li>• Estimated need for palliative care services ranging from a minimum of 63% of all deaths; but in high-income countries, the lower and upper mid-range estimates were that 69-82% of dying people would benefit from palliative care</li> <li>• Estimate relates to all palliative care, including care provided by generalist and specialist palliative care providers</li> </ul>
Kane et al. 2014, Ireland <sup>81</sup>	Applied the Murtagh et al. approach to Irish national mortality data for both malignant and non-malignant conditions	<ul style="list-style-type: none"> <li>• Estimated that 80% of all deaths were from conditions with palliative care needs (30% cancer deaths, 50% non-cancer deaths)</li> <li>• This estimate is for need for either generalist and/or specialist palliative services</li> </ul>
Scholten et al. 2016, Germany <sup>82</sup>	Applied the Rosenwax et al. (minimal, maximal estimates) and the Murtagh et al. approach to German national mortality data	Produced 2 estimates: <ul style="list-style-type: none"> <li>• Using Rosenwax, 40.7% of all deaths were potentially in need of palliative care</li> <li>• Using Murtagh, 78.0% of all deaths were potentially in need of palliative care</li> </ul>
Etkind et al. 2017 England <sup>83</sup>	Used English mortality data including prevalence of deaths from specified chronic diseases (based on the Murtagh et al. approach)	Produced 2 estimates: <ul style="list-style-type: none"> <li>• Assumes 75% of people die from chronic progressive diseases and that these people may benefit from specialist or non-specialist palliative care</li> <li>• Prevalence based on specified chronic diseases resulted in estimate of 74.9% of all deaths in need of either specialist or non-specialist palliative care</li> </ul>

Figure 3.1 also illustrates that people's needs for palliative care may vary over time, increasing or decreasing in complexity.

Figure 3.1: Conceptual model of level of need for palliative care among people living with a life-limiting illness

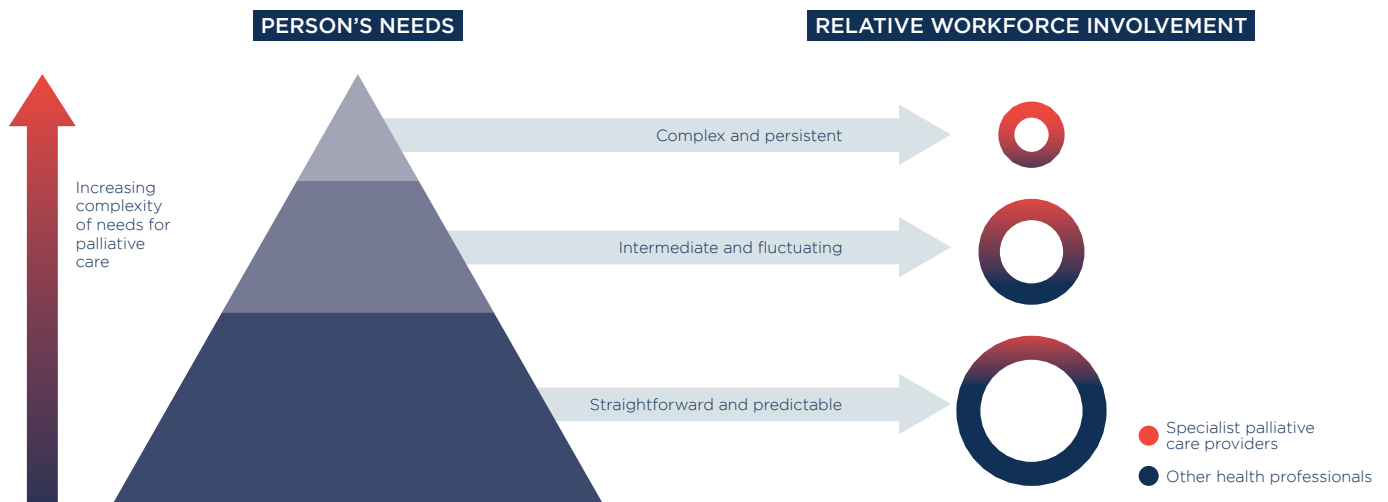


There is no clear-cut analytical basis for identifying the relative size of the three groups (complex and persistent needs, intermediate and fluctuating needs, and straightforward and predictable needs) that comprise the population facing an expected death. Needs are not absolute, but reflect the perceptions and subjective experience of individuals. The same symptoms may be less well tolerated by some individuals than others, prompting an escalation of their needs.

In addition, there is a complex interplay between the needs of people living with a life-limiting illness and the skill level and capability of the health professionals providing care. People with similar levels of 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 dying people. The capability of the non-specialist (palliative care) health workforce to manage the needs of people living with a life-limiting illness is a key factor influencing demand for specialist palliative care services.

This concept is illustrated in Figure 3.2 which shows the required alignment between people's needs and the relative workforce involvement between specialist palliative care providers and other health professionals. This shows that at each level of need, similar people might have their palliative care needs managed mainly by specialist palliative care providers or by their existing health professionals. In fact, as noted earlier, partnerships and shared care models are preferable for many people living with a life-limiting illness, rather than exclusive care by either specialist palliative care providers or by other health professionals.

Figure 3.2: Alignment of need for palliative care against workforce capability





### 3.3 Utilisation of palliative care services by people who are living with a life-limiting illness

Planning palliative care services involves understanding the size of any gap between the demand (or need) for these services and the supply and/or utilisation of these services.

This is challenging for several reasons. First, there is considerable blurring in reporting of specialist palliative care and palliative care services. Most reporting on use of hospital inpatient services is based on the care type of the patient (that is, whether they are classified as palliative). It does not specifically relate to the supply or use of designated palliative care services. Second, there is limited information on the provision of palliative care by other health professionals (who are not specialist palliative care providers). This is particularly true for services provided outside hospitals such as GPs, community nursing and allied health services, whether provided to people who are dying at home or people living in other settings such as residential aged care.

The next sections examine use of, and disparities in access to, specialist palliative care services and palliative care services provided by other health professionals.

#### Utilisation of specialist palliative care services

The most comprehensive information on specialist palliative care services is reported through the Palliative Care Outcomes Collaboration. It reports exclusively on services provided to patients for whom a dedicated palliative care service (that is, a specialist palliative care service) accepts responsibility for assessment and/or treatment.

In calendar year 2016, the 113 specialist palliative care services contributing data reported providing care for 39,206 patients.<sup>84</sup> This is equivalent to about one in three of the 120,000 Australians, who are expected to die annually, accessing specialist palliative care services.

However, this overstates access as not all the treated patients will die in that year. For example, of the 39,206 patients treated by specialist palliative care services in 2016, about one-half (19,711) died in 2016. Some patients may receive care from specialist palliative care services over many years. Hence, the population requiring access to specialist palliative care services is broader than the population expected to die in any one year. However, we do not have good information on the denominator of the actual population needing access to palliative care services; the only published information is on the annual number of deaths.

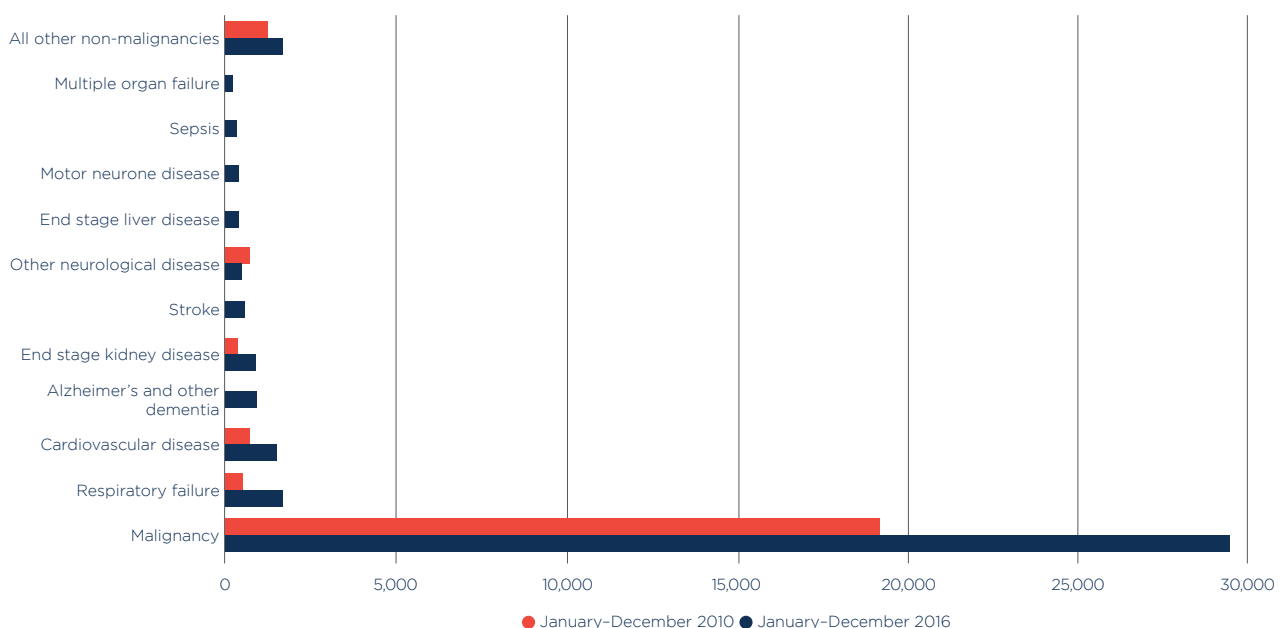
#### Disparities in access to specialist palliative care services

The Palliative Care Outcomes Collaboration data also profile the characteristics of people using specialist palliative care services. This allows measurement of the relative use of these services by diagnosis, by age and by Aboriginal and Torres Strait Islander status.

#### People with cancer or non-cancer diagnoses

Beginning with diagnosis, specialist palliative care services are still predominantly provided to people who are dying of cancer, although the share of services provided to people with non-cancer diagnoses is increasing. In 2016 about three in four patients (75.7%) accessing a specialist palliative care service had a primary diagnosis of cancer. This represents a reduction in the share of cancer patients from over four in five (83.7%) in 2010 (see Figure 3.3).

Figure 3.3: Primary diagnosis of patients accessing specialist palliative care services, 2010 & 2016<sup>85,86</sup>



Other key changes or notable findings include:

- » In 2016 the data indicate that 941 people with Alzheimer's and other dementias were provided with specialist palliative care services. This represents a significant shift relative to earlier years where there was no discrete reporting on service provision for this population. However, people with Alzheimer's and other dementias are still under-represented, accounting for 2.4% of all patients accessing palliative care services but 7.8% of all deaths in Australia.<sup>87</sup>
- » Between 2010 and 2016 there was significant growth in the number of people accessing specialist palliative care services with a primary diagnosis of respiratory failure (203%), end stage kidney disease (118%) and cardiovascular disease (103%).
- » This growth in the provision of specialist palliative care services for people with diagnoses other than cancer has occurred through providing additional services, rather than reducing services to people with a cancer diagnosis. The growth between 2010 and 2016 in the number of people with cancer accessing specialist palliative care services (about an extra 10,300 patients) is still greater than the total number of people with non-cancer diagnoses accessing these services in 2016 (about 9,500 patients).

The lower levels of access to specialist palliative care for people dying from causes other than cancer is common across most countries and has been well studied internationally. It has been suggested that limited access to specialist palliative care services for non-cancer patients is due, at least in part, to:

- » Lack of understanding of specialist palliative care

(e.g. one study found that nearly all primary care and cardiology providers interviewed were unaware that specialist palliative care is not prognosis dependent and may be administered concurrently with life-prolonging therapy);<sup>88</sup>

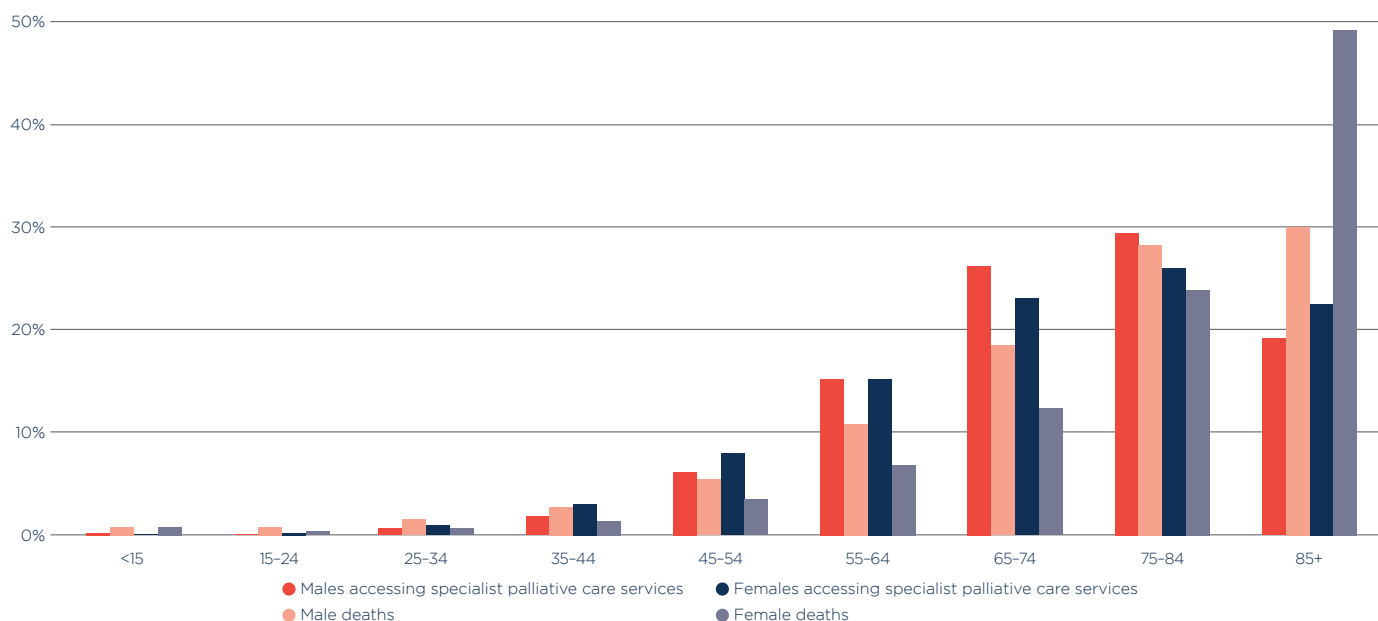
- » The treating (non-palliative care) doctors feel able to manage their own dying patients and that palliative care specialists are seen to be inaccessible;<sup>89</sup>
- » Difficulty in identifying the appropriate time to refer to specialist palliative care or the belief that such care only offers end-of-life care;<sup>90,91</sup>
- » Concern expressed by certain specialist groups (e.g. cardiologists) regarding a perceived lack of expertise within the specialist palliative care team;<sup>92</sup> and
- » The lack of recognition that many non-malignant diseases share symptoms in common with cancer (e.g. pain, breathlessness and fatigue) that would benefit from specialist palliative care interventions.<sup>93</sup>

The underuse of specialist palliative care for non-cancer diseases has been observed even in very recent studies,<sup>94,95,96</sup> and this underuse is also associated with higher reported unmet needs for the carers of this group.<sup>97</sup> It has further been suggested that, in the absence of clear guidelines for referring people with non-malignant conditions to specialist palliative care, only those people who are very close to death will tend to be referred.<sup>98</sup>

### Age

Figure 3.4 compares the age distribution of people accessing specialist palliative care services against the age distribution of deaths in the Australian population.

Figure 3.4: Age distribution of patients accessing specialist palliative care services and of deaths in the Australian population<sup>99,100</sup>



For each gender and each age group, the difference between the light and dark-shaded bars shows the use of specialist palliative care services relative to the share of deaths expected for that gender and age group. For example:

- » Men aged 55-64 account for 10.9% of all male deaths, but they represent 15.2% of men accessing specialist palliative care services; and
- » Similarly, women aged 55-64 account for 7.0% of all female deaths, but they represent 15.3% of women accessing specialist palliative care services.
- » In contrast, men aged 85+ account for 30.2% of all male deaths, but they represent only 19.3% of men accessing specialist palliative care services; and
- » Similarly, women aged 85+ account for 49.2% of all female deaths, but they represent only 22.6% of women accessing specialist palliative care services.

As with diagnosis, the phenomenon of age-based inequalities in access to specialist palliative care services has been well-documented internationally.<sup>101,102</sup> Some of the factors that may contribute to the disparities shown in Figure 3.4 include:

- » The diagnosis of a life-limiting illness in young to middle-aged people may generate more complex palliative care needs, including psychological support and counselling for children, other family members and carers.
- » Carer age has been found to be at least as important as patient age in predicting access to home-based specialist palliative care services. It has been suggested that younger family members and carers may be more proactive and effective in accessing palliative care services than carers of older people who are living with a life-limiting illness.<sup>103</sup>
- » Among very old populations, the presence of multiple chronic and debilitating diseases may make it challenging to determine the point at which 'really sick becomes dying'. This is particularly the case for people diagnosed with non-malignant conditions.<sup>104</sup>
- » There may also be attitudinal and professional barriers to providing care to older people. For example, older people dying in hospitals may have their care needs met by geriatricians and other 'generalist' providers who provide palliative care as a routine part of their usual care, rather than referring these people to specialist palliative care teams.<sup>105</sup>

### Aboriginal and Torres Strait Islander people

The Palliative Care Outcomes Collaboration data indicate that, in 2016, only 1.4% of people accessing specialist palliative care services were of Aboriginal and/or Torres Strait Islander origin.<sup>106</sup> This compares with 2.8% of the Australian population that identified as Aboriginal and Torres Strait Islander in the 2016 Census,<sup>107</sup> indicating comparatively low utilisation of specialist palliative care services by this population. This underuse is even more significant in the context of higher rates of premature mortality among the Aboriginal and Torres Strait Islander population. For the Aboriginal and Torres Strait Islander population born in 2010-2012, life expectancy has been estimated to be 10.6 years lower than that of the non-Indigenous population for males (69.1 years compared with 79.7) and 9.5 years for females (73.7 compared with 83.1).<sup>108</sup>

Barriers to use of specialist palliative care services by Aboriginal and Torres Strait Islander people include lack of knowledge and understanding of palliative care, as well as significant communication and cultural issues about the approach to dying.<sup>109</sup> The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives has highlighted the importance of culturally safe health service delivery as a key strategy in addressing inequities in access to specialist palliative care services. This includes recognising the cultural and spiritual significance of 'dying on country' for many Aboriginal and Torres Strait Islander people at the end of their lives.<sup>110</sup> For Aboriginal and Torres Strait Islander people living in remote communities, the costs of transport and finding accommodation for family members are other barriers. Poor care 'in community' may be viewed as preferable to accessing specialist palliative care services in a hospital or facility which is not on country and does not allow access to family and community support.

## Utilisation of, and barriers to, palliative care services provided by other health professionals

Moving on from specialist palliative care services, there is very little routine national data in Australia on the provision of palliative care by 'generalist' providers of palliative care. Instead, some surveys and observational studies measure the provision of palliative care in different settings including for people seen in general practice and people living in residential aged care.

Key findings of studies into the involvement of Australian GPs in palliative care include:

- » A 2007 survey of Sydney GPs indicated that one in four GPs did not provide palliative care to their patients. Barriers to GP involvement in palliative care included lack of interest and knowledge, concerns about remuneration levels for home visits, the challenge of providing after-hours care due to family and personal commitments, and lack of confidence about the management of psychosocial problems and technical aspects of palliative medicine.<sup>111</sup>
- » Another Australian survey of GP management of people diagnosed with cancer found that more GPs were willing to be involved in cancer diagnosis (85%) than to provide subsequent palliative care (68%), coordinate psychological support (70%) or provide supportive care to manage the symptoms of cancer treatment (52%).<sup>112</sup>
- » There are systematic barriers to case finding (that is, identifying people who may benefit from palliative care) and case planning in Australian general practice. In contrast, the United Kingdom has introduced the Gold Standards Framework that involves a systematic evaluation of palliative care needs in general practice.<sup>113</sup>
- » GPs can play a critical role in supporting people to die at home. This can include providing palliative care directly, in association with community nurses, or being involved as partners in care delivery with community-based palliative care teams.<sup>114</sup>

Turning to people living in residential aged care, there may be issues in accessing both specialist palliative care services and palliative care provided by other health professionals including GPs and nurses.

In 2015-16 there were about 175,000 people living in permanent residential aged care (that is, as non-respite residents). About one-third (56,000) of these permanent residents died in 2015-16, having lived in residential aged care, on average, for just over three years.<sup>115</sup>

Given this significant demand for palliative care for people living in residential aged care, Palliative Care Australia has long advocated that end-of-life care should be recognised as part of the normal scope of practice of residential aged care, and as a core competency for aged care workers.<sup>116</sup> However, studies have demonstrated gaps in access to both generalist and specialist palliative care for people living in Australian residential aged care facilities as follows:

- » A study of nurses and assistants in nursing at high care residential aged care facilities in Sydney identified significant gaps in knowledge of palliative care, highlighting the need for ongoing education in palliative care.<sup>117</sup>
- » In addition to workforce education and training, another factor that might influence transfer rates from residential aged care to acute hospitals is the level of organisational awareness and implementation of advance care planning in residential aged care. Prior to the implementation of a national program on advance care planning, studies in both Victorian and South Australian residential aged care services identified variability and limitations in the approach to advance care planning practices, with the workforce having limited experience in discussing and documenting advance care planning with residents.<sup>118,119</sup>
- » However, more positively, the implementation of end-of-life care pathways championed by Link Nurse leaders in residential aged care has been found to result in fewer inappropriate transfers of residents to hospitals and improved outcomes for dying residents.<sup>120</sup>
- » A Western Australian analysis found that people living in residential aged care were much less likely to have accessed specialist palliative care in the last year of life (only 14.9% of this cohort) than people living in a private residence (55.9%).<sup>121</sup>

In conclusion, both historical and more recent Australian studies have demonstrated gaps in access to specialist palliative care and palliative care provided by other health professionals based on patient diagnosis, age, Aboriginal and Torres Strait Islander status and the setting in which care is received. These are not the only populations impacted, with other population groups and geographic regions also likely to experience disparities in access to palliative care.

# Developing the palliative care service system

This chapter describes the core elements of the desirable palliative care service system in the future. It provides a framework for how governments can make decisions on the development of these services, as well as how public and private sector providers of palliative care can organise and deliver services.

# 4

## 4.1 A systems framework for palliative care

Figure 4.1 provides an overview diagram of the palliative care service system.

People, their families and carers should be at the centre of this service system. The inner circles depicting the person living with a life-limiting illness surrounded by their family and carers are intended to highlight two critical features of the palliative care service system:

- » First, the palliative care service system needs to provide care not only to the person living with a life-limiting illness, but also to their family and carers. This differs from many other health services where the person with an illness is the only recipient of care; and
- » Second, the family and unpaid carers of the person living with a life-limiting illness often provide most of the support for that person, particularly during the periods when the person is living at home. The contribution of family and carers to providing physical, practical and emotional support should be recognised and supported. Education and other support for family and carers is essential in order to enable this continuing role.

The diagram also shows that palliative care may be provided by specialist palliative care services and/or by the health professionals who have an existing relationship with the person living with a life-limiting illness. There needs to be effective communication and coordination of care across all health professionals involved in providing palliative care. Specialist palliative care services may have a direct role in service delivery and they may also provide consultative services to other health professionals involved in providing care.

Moving outwards from the care and support functions, the palliative care service system requires a systems capability that includes resources and enablers so that it is a continuously learning and self-improving system. At the core of this systems capability is a robust workforce capability. This includes clear delineation of the roles and capabilities of the multidisciplinary teams needed to deliver effective palliative care services. This 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. Finally, the systems capability should include a strong research focus, an evaluation capacity and the ongoing development and implementation of benchmarking.

This chapter discusses the components of the systems framework on the left-hand side of Figure 4.1, namely, the care and support that is provided to individuals, their families and carers. The enabling components of the systems framework – workforce and other system capabilities – are discussed in Chapter 5.

## 4.2 Providing a person-centred and effective continuum of palliative care services

From the perspective of people needing palliative care, the health system needs to be organised to refer people to the services that best match their needs; to provide services in all relevant settings; to ensure that care is provided effectively through teams with the right skills; and to promote continuity and coordination of care as people's needs change and they transition between different types of care. Each of these four elements is discussed below. The elements of care needed for families and carers, which often overlap with their dying family members, are considered later in Section 4.3.

### Referral and assessment services

The different illness trajectories shown in Figure 1.2 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. This is often occurring in the context of ongoing provision of disease-modifying care by other health professionals.

The sources of referrals to palliative care are also likely to vary according to the person's illness trajectory. People dying with cancer are likely to be referred by their oncologist, while people with advanced chronic diseases and degenerative conditions may be referred by GPs and other health professionals (such as geriatricians and renal specialists).

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 trigger for considering referral for a palliative care consultation.<sup>122</sup> Other factors that may prompt referral to palliative care for people with advanced disease include:

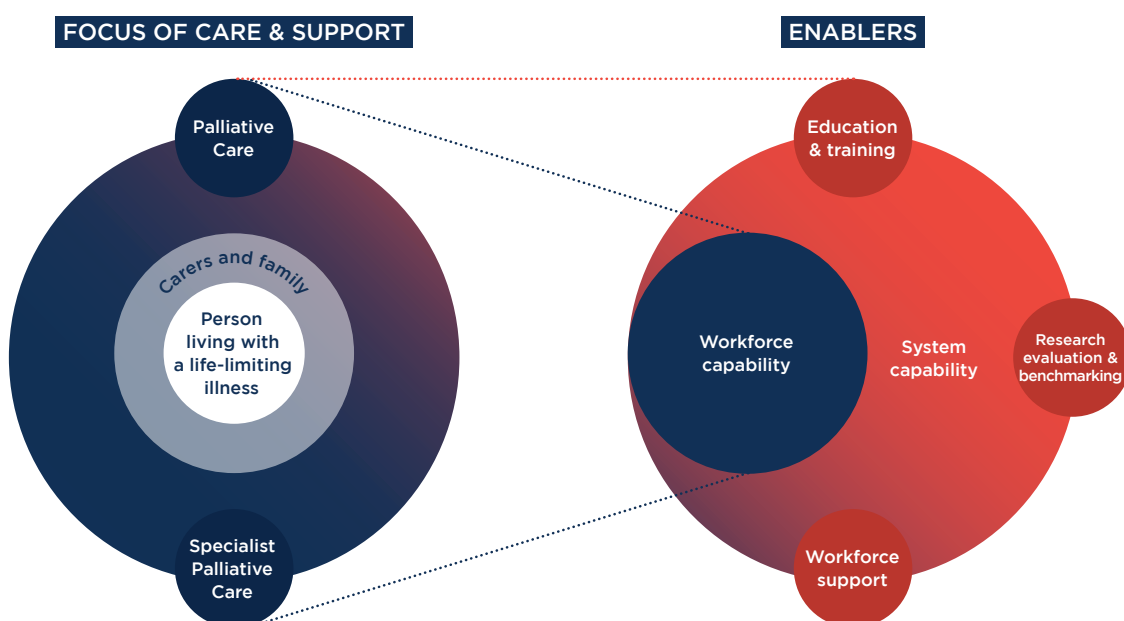
- » Increasing (including unplanned) use of hospital and other health services;
- » Concerns expressed by the person, family or carers about their future prognosis;
- » Increase in physical or psychological symptoms that are not being effectively managed; or
- » Changes in functional independence that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

Figure 3.2 identified that palliative care needs may be met by a mix of specialist palliative care providers and other health professionals, depending on the complexity of needs among people living with a life-limiting illness. This means that the referring health professional may refer some people to specialist palliative medicine physicians for assessment, while for other people the 'referring' health professional may undertake the assessment directly as a prelude to the delivery of generalist palliative care services.

In general, while including the traditional components of medical evaluation (medical and psychosocial history, physical examination), a palliative care assessment also includes assessment of domains including:

- » Management of physical symptoms;
- » Assessment of psychological, psychiatric, and cognitive symptoms;
- » Illness understanding and care preferences (i.e.

Figure 4.1: A systems framework for the palliative care service system



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.<sup>123</sup>

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 translated into 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.

Advance care directives (which go under different names in different states) are legally binding documents which allow people to consent to, or refuse, particular types of medical treatment or care if they become unable to make or communicate their wishes in the future. Figure 4.2 shows the relationship between advance care plans and advance care directives and how these can be translated into clinical care planning to ensure that palliative care services are provided in accordance with the person's wishes.

Figure 4.2: Conceptual map of advance care planning<sup>124</sup>

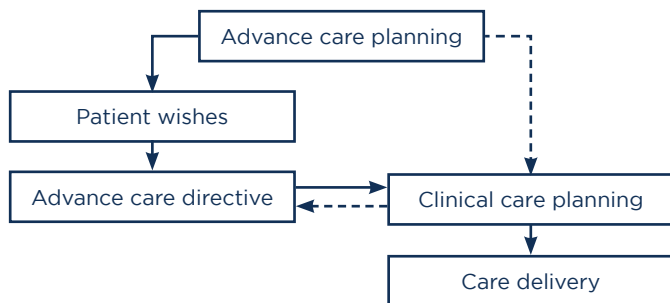
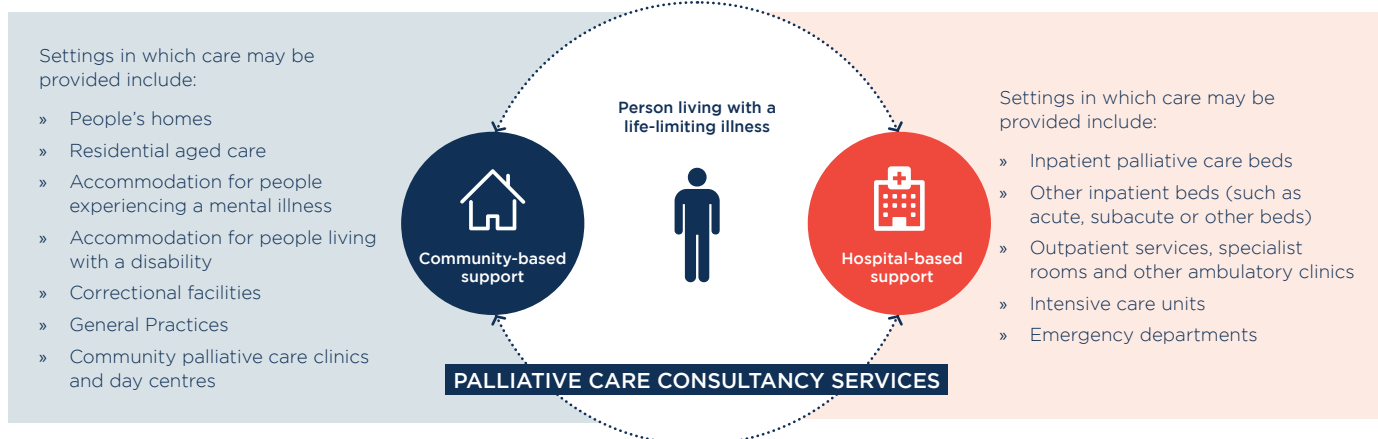


Figure 4.3: Map of palliative care service settings



### Settings for the provision of palliative care

Palliative care services should be able to be delivered in a wide range of settings, in accordance with the wishes of the person living with a life-limiting illness.

Typically, most Australian states and territories (as well as providers of private palliative care services) organise their specialist palliative care services into the two major streams of community-based and hospital-based services. Similarly, palliative services provided by other health professionals may be provided in hospitals or in the community.

Figure 4.3 is a map of the palliative care service system that shows the relationship between these two main settings of care (community and hospitals). It covers both specialist palliative care services and palliative services provided by other health professionals. The person diagnosed with a life-limiting illness is at the centre of the service system and has care provided in different settings according to the complexity and intensity of their needs.

Figure 4.3 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 palliative care consultancy services to other health professionals. These 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 medicine physicians. As shown in Figure 4.3, specialist palliative care consultancy services should be provided in both hospital and community settings.

It is valuable to drill down below the high-level split of hospital and community-based services to outline the real-world settings and types of palliative care services that are provided in these 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 also 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 also 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 palliative care consultancy services in these settings may improve patient outcomes and reduce the incidence of non-beneficial care.<sup>125,126,127</sup>

## Community-based care

Community-based care is sometimes simply equated with providing care in people’s homes. This does not take into account 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.

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. Chapter 3 also identified the gaps in access to both generalist and specialist palliative care for some people living in residential aged care homes.

It is necessary to tackle such barriers to ensure that people living with a life-limiting illness, irrespective of where they live, are better able to access palliative care services in the community. This requires that specialist palliative care services (which have traditionally been based in hospitals) have a strengthened out-reach focus. It also requires that other health professionals (such as GPs, community nursing services and providers of specialist health services) expand their remit to provide palliative care on an in-reach basis to people living in different types of communal settings.

## A team-based approach to service provision

Teamwork has long been an integral part of the philosophy and practice of palliative care in Australia.<sup>128</sup> 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.<sup>129</sup>

A team approach to the provision of specialist palliative care services requires a broad mix of health professionals including specialist palliative medicine physicians, nurses and allied health professionals with qualifications, experience or skills in palliative care. Meeting palliative needs will require a diverse range of allied health and associated disciplines including occupational therapy, physiotherapy, speech therapy, social work, psychology, pharmacy, art and musical therapy, grief and bereavement counselling and pastoral care.

The workforce profiles required to deliver team-based palliative care are specified in more detail in the updated Capability Framework in Section 5.2.



## Continuity and coordination of care

Ensuring continuity and coordination of care for people using palliative care services is essential. Team-based care is one valuable approach that can be used to promote continuity and coordination of care.

Data on the use of specialist palliative care services demonstrate that there is considerable movement of patients between hospital and community-based palliative care services. For example, the data indicate that in 2016:

- » Of patients starting an episode of community-based palliative care, about two in five (38%) were 'admitted' from inpatient palliative care; and
- » Of patients completing an episode of community-based palliative care, about one-third (31%) were admitted to inpatient palliative care, slightly less than one-third (29%) were admitted to inpatient acute care and one quarter (25%) died.<sup>130</sup>

Continuity and coordination of care should include:

- » 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 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.

An important mechanism for promoting continuity and coordination of care is the effective networking of palliative care services and health services provided by other health professionals. A networking framework to achieve this objective is developed in Section 5.3.

## 4.3 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. While families come in all shapes and sizes, an important aspect is that 'family' comprises people identified by the person living with a life-limiting illness to be family members. This can 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).<sup>131</sup> Family members, such as a spouse or partner, child, parent or other relative, may take on a role as a primary carer in providing support to a person living with a life-limiting illness. However, carers may also include close friends, neighbours and other people who the person living with a life-limiting illness agrees should be involved in their care.

The provision of informal or unpaid care by family members and carers may include:

- » Personal care (e.g. showering);
- » Domestic care (e.g. cleaning, meal preparation);
- » Auxiliary care (e.g. shopping, transportation);
- » Social care (e.g. informal counselling, emotional support, conversing);
- » Nursing care (e.g. symptom management which may involve medicines); and
- » Planning care (e.g. coordinating care and support services).<sup>132</sup>

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. While the number of carers who specifically provide support to dying family members is not recorded in national surveys, about two-thirds of primary carers provide assistance with health care.<sup>133</sup>

Population ageing, employment patterns and changes to family structures (such as smaller families, divorce and geographic mobility) impact on the number of people able to take on a caring role. In 2016 almost one in four Australians (24%) lived in single-person households.<sup>134</sup>

Multiple studies, including those conducted in Australia, have provided evidence that people living with a life-limiting illness who live alone without a carer have more hospital admissions and are less likely to die at home than those who have a carer.<sup>135,136,137,138</sup> However, enabling people to be cared for and to die at home can be very challenging for family and carers. The burden on family

members can be immense, and supports and services must be in place to relieve this burden.<sup>139</sup>

Another factor underpinning the importance of providing effective support for family members and carers is the downstream impact on reducing stress and anxiety for the dying family member. Self-perceived burden, where care recipients believe they are creating a burden on carers, is reported as a significant problem by many people living with a life-limiting illness and is correlated with loss of dignity, suffering and a 'bad death'.<sup>140</sup>

The following sections outline the evidence about the type and nature 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**

Effective communication between people living with a life-limiting illness, family members, carers and health professionals is an essential component of high-quality palliative care.<sup>141,142</sup> However, families and carers of people receiving palliative care consistently report that they have unmet information needs.<sup>143,144</sup>

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 management, medication administration and nursing care. Also critical are discussions about the clinical condition of the person living with a life-limiting illness. 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, GPs, nurses, pharmacists, allied health professionals and other health professionals. Support groups may also assist families and carers of people living with long-term degenerative conditions such as dementia and motor neurone disease.<sup>145,146</sup>

### **After-hours access**

After-hours access to support is essential for families and carers, particularly during the time that the person with a life-limiting illness is being cared for at home. Common medical reasons for seeking access to after-hours services include pain, nausea, vomiting, agitation, breathlessness and fatigue.<sup>147</sup> Pain has been reported as a particularly common cause for people to seek after-hours help,<sup>148</sup> with one retrospective review in the United Kingdom reporting that over 30% of those seeking help did so because of pain, and that over half of this subgroup were already prescribed strong opioid medication.<sup>149</sup>

There is a concern among some in the palliative care sector that 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 pre-empt after-hours needs for many people, leaving only a small proportion of people with unanticipated after-hours palliative care needs. For example, effective daytime and anticipatory pain management, including patient education regarding effective use of analgesics, and seeking timely help, can positively influence the need for after-hours care.<sup>150</sup>

Within this context of proactive care planning, 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 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.

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;
- » Whether the person is living in a metropolitan area, major regional centre or rural and remote locations; and
- » Whether there are formalised after-hours services available.

In terms of specialist palliative care services, after-hours access should be a core component of service delivery that is built into resourcing. Some jurisdictions have specified the infrastructure requirements that are needed to support an after-hours community-based palliative care service. One example is the Victorian After-hours Palliative Care Framework which has identified six key elements of a model of after-hours palliative care comprising:

- » Client care planning;
- » Electronic and paper-based client information systems;
- » After-hours telephone triage (workforce, processes and tools);
- » After-hours nursing;
- » After-hours medical support; and
- » Activities following an after-hours contact including quality assurance activities.<sup>151</sup>

The Victorian Framework envisages 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 assessment of needs.

After-hours access, involving a combination of telephone advice and home visits by nurses and/or medical practitioners, should be available to all people under the care of specialist palliative care services in metropolitan areas and major regional centres. 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. 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**

The ability to access suitable equipment and medical supplies can influence whether people living with a life-limiting illness 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.<sup>152</sup>

The list of equipment that may be used 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.<sup>153</sup>

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.

It is important to ensure equity of access to equipment (and home modification services), on both a geographic and cost basis, to support families to provide care for family members dying at home. All providers of palliative care services have a responsibility to advise families and carers about mechanisms to access necessary equipment. Specialist palliative care providers 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.

### **Respite care**

In the context of palliative care, respite (or respite care) can be defined as occasional or intermittent temporary relief from the perceived responsibilities for the wellbeing and safety of a person living with a life-limiting illness, where the primary beneficiary is a carer and/or the dying person.<sup>154,155,156</sup>

The term respite care can refer to inpatient, day or home-based provision. In Australia inpatient respite care may be provided on an inpatient basis, on a day basis or through home-based provision.

Historically there has been no consensus definition of respite nor explicit criteria agreed for the purpose of respite services in palliative care.<sup>157</sup> 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.<sup>158,159</sup>

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:

- » The 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.

Respite care is not uniformly available across the country, with limited access in rural and remote areas. The lack of access to local respite care in more remote

areas results in some people relocating at the end of their life to metropolitan areas, where they may be unsupported by family, friends and their community.<sup>160</sup>

At a minimum, providers of palliative care services should provide information to families and carers about options to access respite care. Ideally, 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.

### 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. Grief can be experienced across many domains including emotional, cognitive, behavioural, physical and spiritual.

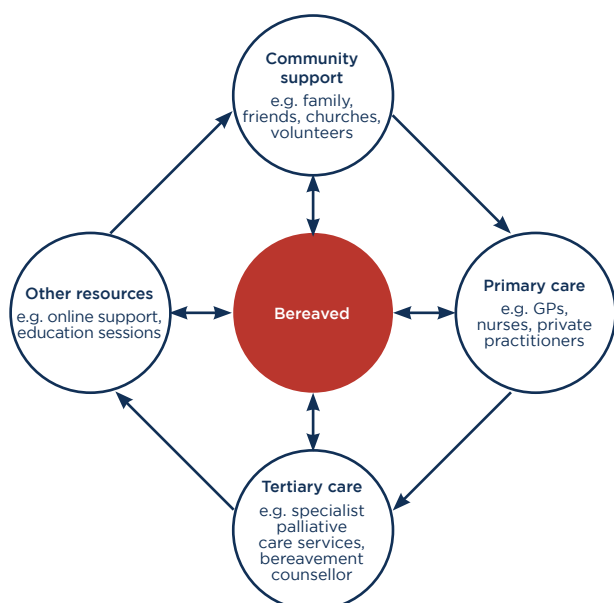
The experience of grief can vary widely, with some people experiencing complicated grief or grief that lasts for a prolonged period. Support for those experiencing grief can be obtained from many professional and informal sources, as shown in Figure 4.4. Specialist palliative care services are one of many resources that may be involved in providing bereavement support.

Several Australian states (including Tasmania and Victoria) distinguish between 'universal' strategies (that should be available to support all bereaved people) and 'targeted' (or specialist) strategies (that should be available to support people at risk of, or experiencing, complicated grief).<sup>161,162</sup>

Underpinning this approach is the concept that bereavement support must align with people's needs and risk factors. Primary and specialist bereavement care providers should operate as part of a continuum. This means that in relation to Figure 4.4, referral to suitable services and support needs to occur at all points of the continuum based on the person's relative needs.<sup>163</sup>

It is vital to align bereavement support services 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.

Figure 4.4: Continuum of bereavement care<sup>189</sup>



# Planning the workforce and system capabilities to deliver palliative care services

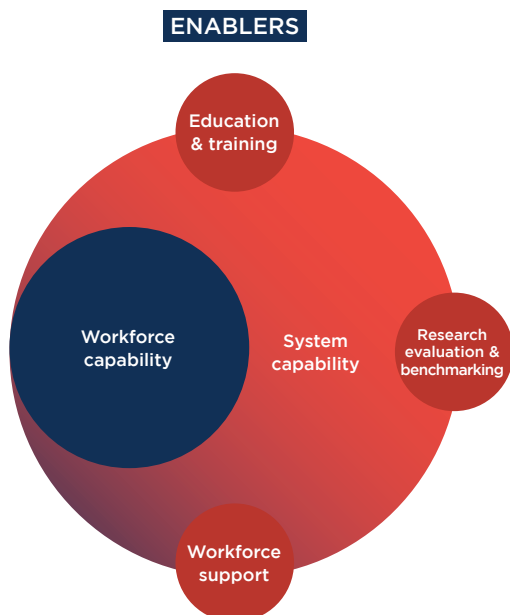
This chapter outlines an approach to identifying and planning the workforce and system capabilities required to deliver high quality palliative care services. The focus is on the key enablers as outlined schematically in Figure 5.1.

## 5.1 The existing palliative care workforce

In 2013 Palliative Care Australia's advocacy was focussed around the theme that 'palliative care is everyone's business'. This recognised that all health professionals have a vital role to play in palliative care. Providers across all health disciplines will be required to meet the needs of people who are dying across many settings – acute hospitals, aged care facilities, general practice, specialist clinics, community health services, allied health services, community aged care services, other settings in which people may be living (such as correctional facilities and specialist accommodation for people experiencing severe mental illness) and people's homes.

Table 2.2 has previously identified the importance of ensuring that all health professionals have minimum levels of core competencies to provide care for people with a life-limiting illness whose needs are relatively straightforward. This includes management of physical

Figure 5.1: Key enablers of palliative care services



symptoms, management of depression and anxiety and effective communication with people living with a life-limiting illness. However, the conceptual model of need triangle for palliative care (Figure 3.1) makes it clear that some people dying an expected death will have needs that can only be met by specialist palliative care providers.

Accordingly, planning palliative care capability must start with a robust profile of the specialist palliative care workforce.

### Specialist palliative medicine physicians

Between 2012 and 2015, there was a substantial growth (43.9%) in the number of employed specialist palliative medicine physicians. However, in 2015 (latest available workforce data) there were still only 213 specialist palliative medicine physicians across Australia, equivalent to a ratio of 0.9 full-time equivalent per 100,000 population.<sup>164</sup>

The workforce profile also indicates that there are disparities in access to specialist palliative medicine physicians including:

- » **Between states:** 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).
- » **Between metropolitan and rural areas:** Most specialist palliative medicine physicians worked in major cities (84.0%) or inner regional areas (9.6%), so that population ratios were lower in rural and remote areas.
- » **By setting of employment:** Most specialist palliative medicine physicians were employed in a hospital (77.9%), although a sizeable number were employed in a community-based setting (10.3%).<sup>165</sup>

Previous Australian benchmarks proposed for providing access to specialist palliative medicine physicians were:

- » In 2003 Palliative Care Australia proposed a benchmark of 1.5 full-time equivalent specialist palliative medicine physicians per 100,000 population to provide inpatient, community-based care and an acute hospital consultative service;<sup>166</sup> while
- » In 2009 the Australian and New Zealand Society of Palliative Medicine proposed a minimum of 1.0 full-time equivalent specialist palliative medicine physicians per 100,000 population.<sup>167</sup>

Based on Palliative Care Australia's 2003 benchmark, the estimated requirement for specialist palliative medicine physicians in 2017 would be 370 full-time equivalent specialists.<sup>168</sup> While there will have been some growth in the supply of specialist palliative medicine physicians since 2015, this benchmark would equate to a national shortfall of about 150 specialist palliative medicine physicians in 2017.

However, both the 2003 and the 2009 benchmarks are relatively conservative in that they reflect models of care and target populations for specialist palliative care that are now quite dated. In particular, the supply of specialist palliative medicine physicians (as well as palliative care nurses and other members of the specialist palliative care team) will need to increase in response to:

- » **Expanding access to specialist palliative care to people dying from causes other than cancer:** Chapter 3 identified the significant changes since 2010 in the share of people with a non-cancer diagnosis accessing specialist palliative care services (from 16.3% to 24.3% of patients treated). However, these populations are still significantly under-served relative to their share of expected deaths.
- » **Providing more opportunity for people to die at home:** Community-based models of care are relatively resource-intensive compared to hospital bed-based models of care. There are already 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. Any change to support more people dying at home will have significant implications for the specialist palliative workforce.
- » **Expanding access to direct care and consultative services to people dying in residential aged care and other settings:** The 2003 Palliative Care Australia guidelines did not include access to specialist palliative care for people living in residential aged care, nor the provision of specialist palliative consultative services on an in-reach basis to these locations. This is becoming increasingly essential with the growth in the number of residents living

with Alzheimer's disease or other dementias. The preferred model of care should now be to support these residents in their aged care facilities as much as possible and avoid emergency or unplanned transfers to acute hospitals.

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.

In response to changing models and settings of care and a sizeable expansion in the scope of the population who would benefit from access to palliative care services, it is clear that previous Australian benchmarks for the provision of specialist palliative medicine physicians need to be increased. Given these factors, it would be reasonable to increase the benchmark from 1.5 to 2.0 full-time equivalent specialist palliative medicine physicians per 100,000 population.

### Palliative care nurses

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.<sup>169</sup>

In general, there is a more equitable distribution in the supply of palliative care nurses than is the case for specialist palliative medicine physicians. The workforce distribution of palliative care nurses varies:

- » **Between states:** The Northern Territory had the lowest population ratio of palliative care nurses (9.7), followed by New South Wales (10.9), Queensland (11.3) Western Australia (11.7), South Australia (12.5), Victoria (13.6), the ACT (14.2) and Tasmania (17.6).
- » **Between metropolitan and rural areas:** Population ratios varied from 12.7 in major cities, 12.4 in inner regional areas to a low of 2.3 in remote and very remote areas.
- » **By setting of employment:** About two-thirds (67.1%) worked in a hospital or hospice, while a further 22.7% worked in a community-based setting.<sup>169</sup>

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. As at September 2017, there were almost 1,600 nurse practitioners in Australia.<sup>170</sup> However, there are no data specifically on the number of nurse practitioners working in palliative care.

Palliative Care Australia's previous 2003 planning guidelines included a set of ratios 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.

These ratios also had three different denominators: full-time equivalent per 100,00 population, full-time equivalent per 125 beds for acute hospital consultative services; and full-time equivalent per 6.7 beds for palliative care designated beds.

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 'translated' 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 range of clinical practice (types of patients seen, types of settings) for specialist palliative care services described above for specialist palliative medicine physicians also impacts on the required supply of palliative care nurses.

Palliative Care Nurses Australia does not publish ratios on what constitutes a minimum or desirable level of access to palliative care nurses, nor are there commonly accepted international benchmarks. 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.

### **Allied health professionals working in palliative care**

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.

A wide range of allied health professionals are required to provide specialist palliative care services including: psychologists, social workers, physiotherapists, occupational therapists, speech pathologists, dietitians, pharmacists, music/art therapists, pastoral care workers and bereavement counsellors. However, national registration data are available for only some of these types of allied health professionals. 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.<sup>171</sup> 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. As with nurses, the registration data does not provide any information on the number of allied health professionals employed in palliative care services.

Volunteers significantly contribute 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.

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 that form part of the specialist palliative care workforce.

### **Workforce ratios for operational planning**

Palliative Care Australia's 2003 planning guide<sup>172</sup> included a series of proposed staffing levels for medical practitioners, nurses and allied health staff working in specialist palliative care services. These workforce ratios cannot readily be used for national planning of the palliative care workforce. This is because they rely on data (such as the number of palliative care designated beds or the number of nursing hours per day) that are not routinely collected in national information collections.

However, these workforce ratios may be useful at a local level for operational planning. Accordingly, Appendix 1 includes the previous 2003 workforce ratios for medical practitioners, nurses and allied health staffing levels for specialist palliative care services. The population-based ratio for palliative care consultants in community-based services has been increased from 1.5 to 2.0 per 100,000 population to align with the proposed increase in the national benchmark for specialist palliative medicine physicians.

## 5.2 A capability framework for the palliative care workforce

The capability to provide palliative care services is about much more than the numbers of individual specialist palliative medicine physicians, palliative care nurses and allied health professionals.

Improving equity of access to palliative care requires the development and implementation of a palliative care workforce Capability Framework that:

- » Classifies people dying an expected death based on their complexity of need for palliative care;
- » Identifies the catchment population and the role that each service level has as part of a networked system of palliative care services;
- » Identifies the expected capabilities (the scope of services) of each of the various levels of palliative care provided by specialist palliative care providers and other health professionals;
- » Identifies the modalities (or approaches) to the way in which palliative care can be provided (such as direct community-based or hospital-based care and consultative services); and
- » Delineates the workforce requirements for each of the levels of palliative care services.

### **Purpose of national palliative care workforce capability framework and relationship to other frameworks**

Palliative Care Australia's 2005 Capability and Resource Matrix<sup>173</sup> provided a broad template which individual states and territories have used as a basis for further specification of their detailed role delineation and clinical services capability frameworks.

There is legitimate variation across jurisdictions in the approach to, and number of, palliative care levels specified in jurisdictional frameworks. Most state frameworks include primary or generalist palliative care, in addition to specialist palliative care services. Currently, the number of palliative care levels specified by states in their individual frameworks varies from three to six.

In updating the national palliative care workforce Capability Framework, factors taken into consideration have included:

- » **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 strengthened.
- » **Feedback received on the number of levels in Palliative Care Australia's previous 2005 Capability and Resource Matrix.** Stakeholders suggested that there were insufficient criteria to delineate three levels of specialist palliative care services. This relates both to the target population who might access these services and to the workforce capability. In particular, there was considerable overlap and blurring between what was previously described as specialist palliative care services levels 1 and 2. Accordingly, the capability framework has been updated to include only two levels of specialist palliative care services, equivalent to the previous specialist palliative care service levels 2 and 3.
- » **The inclusion of more specific service requirements and competencies for each level of workforce capability:** The update includes much greater specificity 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 existence of the National Palliative Care Standards.** Issues relating to the quality of care and quality improvement are already specified in Palliative Care Australia's 2017 National Palliative Care Standards. These Standards apply to all providers of specialist palliative care services, regardless of their level. Accordingly, the national palliative care workforce Capability Framework does not include any reference to quality improvement programs.

The updated national palliative care workforce Capability Framework is specified in Table 5.1.



**Table 5.1: National Palliative Care Workforce Capability Framework**

<b>LEVEL 1: PALLIATIVE CARE</b>	
<b>Population needs</b>	People living with a life-limiting illness whose needs are straightforward and predictable; families and carers of these people
<b>Catchment population and service role</b>	<p>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</p> <p>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</p>
<b>Scope of services and roles</b>	<p>Management of symptoms including prescription of relevant medications and after-hours access to telephone support</p> <p>Advice about prognosis, treatment options and disease progression</p> <p>Provision of, and/or referral to, counselling and psychological support services for the person living with a life-limiting illness, their family and carers</p> <p>Discussions about advance care planning</p>
<b>Service modalities</b>	<p>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</p> <p>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)</p>
<b>Workforce profile</b>	<p>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</p> <p>Nurses who may include nurse practitioners, registered nurses, community nurses – may work in community settings including people's homes and other residential aged care</p> <p>Personal care workers who provide support in the person's home or other community-based settings such as residential aged care</p> <p>Access to allied health professionals</p> <p>Health professionals involved in providing Level 1: Palliative Care do not work full-time in palliative care but have other responsibilities</p> <p>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</p>

## LEVEL 2: SPECIALIST PALLIATIVE CARE SERVICES

<b>Population needs</b>	People living with a life-limiting illness whose needs range from straightforward and predictable to intermediate and fluctuating; families and carers of these people
<b>Catchment population and service role</b>	<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>
<b>Scope of services and roles</b>	<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>
<b>Service modalities</b>	<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>
<b>Workforce profile</b>	<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 patients</p> <p>Personal care workers who provide support in the person's home or other community-based settings such as residential aged care, with training to support the needs of people living with a life-limiting illness</p>

### LEVEL 3: SPECIALIST PALLIATIVE CARE SERVICES

<b>Population needs</b>	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
<b>Catchment population and service role</b>	<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>
<b>Scope of services and roles</b>	<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 &amp; 2 services</p> <p>Leadership role in palliative care research including links with academic centres</p>
<b>Service modalities</b>	<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>
<b>Workforce profile</b>	<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 other community-based settings such as residential aged care</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 other community-based settings such as residential aged care, with training to support the needs of people living with a life-limiting illness</p>

### 5.3 Regional planning and networking of palliative care services

The workforce capability framework in Table 5.1 outlines the expected scope of services and workforce profile to deliver those services at each of the three defined levels of palliative care services. It indicates that palliative care services should be organised along a continuum that aligns the needs of people living with a life-limiting illness with the required workforce capability.

Table 5.1 can be used by states and territories in planning the distribution of palliative care services at a regional or Local Hospital Network level. The workforce capability framework indicates 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 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.

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. Despite these differences, the above population or area-based approach to planning palliative care services can be applied to ensure that there is equitable access in each geographic area to community-based, hospital-based and consultative palliative care services.

Another critically important feature is the 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 5.2.

The first type of networking relates to the palliative care needs of the person living with a life-limiting condition. 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 5.2: Networking framework for palliative care services organisation and delivery

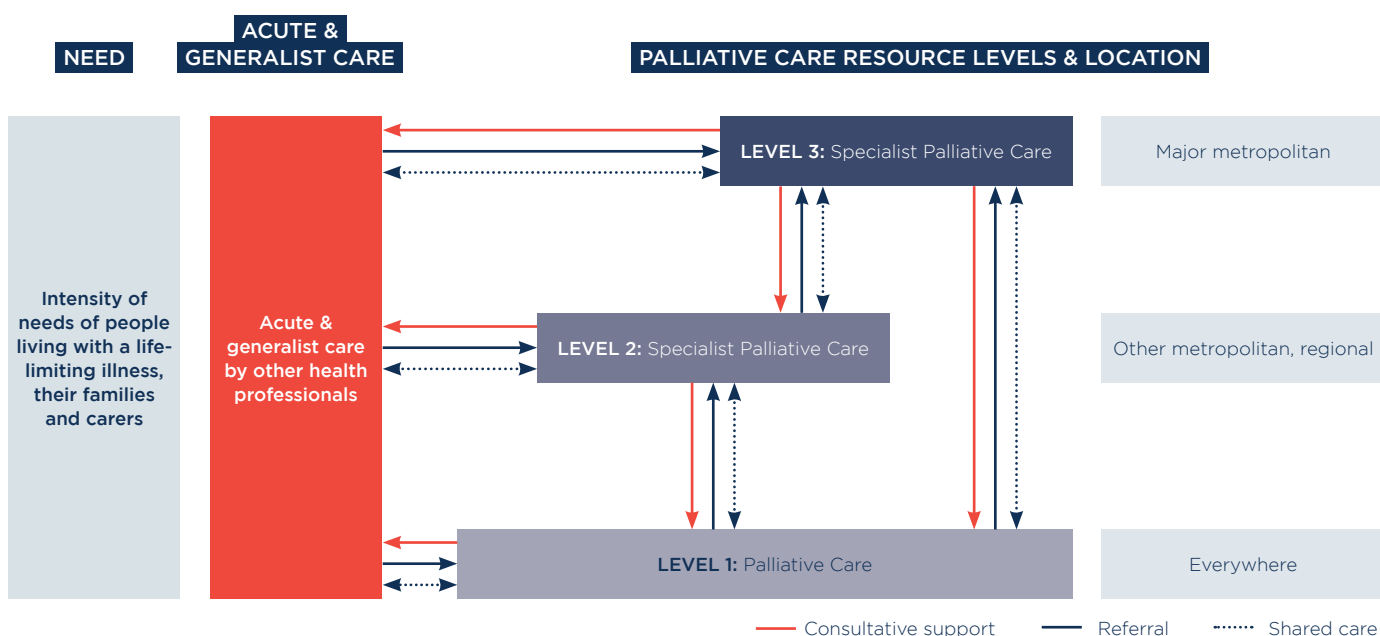


Figure 5.2 indicates that, as required, in accordance with people's needs:

- » 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.

The second type of networking is about ensuring that there is effective communication and integration between the providers of palliative and disease-modifying care. Figure 2.1 previously highlighted the desirability of the early introduction of palliative care, which is often provided concurrently with disease-modifying care. Many people living with a life-limiting illness will continue to receive active treatment (including chemotherapy, surgical interventions and medication) that will be managed by medical practitioners including oncologists, surgeons, physicians, paediatricians, geriatricians, other specialists and GPs. These medical practitioners may be providing care in settings including the community (such as a general practice clinic or specialist rooms), in residential aged care and other institutions where people live (such as prisons, facilities for people with a severe disability, facilities for people with a severe mental illness), and in hospitals (including both inpatient and outpatient services). It is vital that there is effective communication between these health professionals who are providing care in a diverse range of settings and the providers of generalist or specialist palliative care services.

## 5.4 System capabilities required for the development of the palliative care service system

The provision of palliative care services to people living with a life-limiting illness, their family and carers, together with the support of the workforce providing this care, must be underpinned by a set of system capabilities or enablers including:

- » Professional education and training for the specialist palliative care workforce and for other health professionals;
- » Workforce support to assist health professionals in managing the challenges of working in palliative care; and
- » Research, evaluation and benchmarking to drive continuous learning and quality improvement in the organisation and delivery of palliative care services.

### Professional education and training

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;
- » Multi-disciplinary team skills including ability to conduct joint patient assessment sessions, communicating information to team members, conducting team meetings, case conferences and family meetings;
- » Skills in using end-of-life care pathways and end-of-life decision making;
- » Ethical decision making; and
- » Life closure skills (related to care provided when people are close to death, aiming to preserve the dignity of the dying person and their family).<sup>174,175:</sup>

Education, training and professional development aim to instil, develop and maintain these skills in the specialist palliative care workforce through undergraduate and post-graduate education, formal courses, workshops and in-services. Governments, the academic sector and professional associations are responsible for ensuring that suitable courses and programs are available across the disciplines of medicine, nursing, pharmacy and

allied health. Ensuring that the workforce can access these educational opportunities also must be factored into planning requirements in resourcing the delivery of specialist palliative care services.

To the extent that there are gaps in health professionals' knowledge and awareness of palliative care, this can adversely impact on access and referral to palliative care for people living with a life-limiting illness and their families.<sup>176</sup> Indeed, 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 health professionals.

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.<sup>177</sup>

Education should ideally 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.<sup>178</sup>

It is essential to educate other health professionals, who are not part of specialist palliative care teams, on the value of palliative care. Some of these other health professionals may be involved in providing Level 1 palliative care services (as described in Table 5.1), while other health professionals will primarily be practising their own specialty or discipline across community, hospital and other settings of care.

Over the past decade, there have been substantial improvements 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.
- » End-of-life Essentials provides e-learning opportunities and resources for doctors, nurses and allied health professionals to improve the quality and safety of end-of-life care in acute hospitals. This is linked to the Australian Commission on Safety and Quality in Health Care's National Consensus Statement.<sup>179</sup>

### Workforce support

Palliative care is a complex and demanding area of work for health professionals. Some of the demands and stressors specific to palliative care include:

- » Breaking bad news about diagnosis and/or prognosis to a person living with a life-limiting illness, their family and carers;
- » Coping with medicine's inability to offer these people a cure;
- » Repeated exposure to the death of patients 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.<sup>180</sup>

These challenges can eventually contribute to the development of occupational or job stress. In addition to resulting in poor quality patient care, job stress can lead to physical symptoms, psychiatric disorders and burnout among health professionals. The prevalence of burnout in palliative care professionals is estimated at 17%.<sup>181</sup>

Techniques which have been suggested to prevent burnout or job stress in palliative care workers include:

- » Acquisition of effective time management skills;
- » Setting of limits and boundaries;
- » Practicing healthy personal habits such as adhering to healthy nutrition, getting restful sleep, and engaging in physical activity;

- » Engaging in recreational, non-work-related activities;
- » Attending continuing education opportunities such as attending conferences and workshops, reading books and journals;
- » Getting support via networking, supervision, and connecting with colleagues; and
- » Allowing debriefing, which provides the worker with honest, though sensitive, feedback about their caring skills and practices.<sup>182</sup>

However, a systematic review concluded there is limited research in this area, and it is of inadequate quality to establish the effectiveness of psychosocial interventions to improve the psychological wellbeing of the palliative care workforce.<sup>183</sup> There is an urgent need for more rigorous research to identify how best to support all health professionals providing palliative care.

The provision of workforce support is an essential element of the capability of specialist palliative care services that needs to be suitably resourced. The lack of workforce support is a critical issue for other health professionals who may provide palliative care only intermittently and without the benefits of a supportive multidisciplinary team environment. This means that it is incumbent on Level 2 and 3 specialist palliative care services to provide advice and support to these other health professionals, whether through their consultative role or other mechanisms.

### Research, evaluation and benchmarking

Australia is relatively well-served in relation to palliative care research, evaluation and benchmarking capabilities. In The Economist's 2015 Quality of Death Index, Australia was ranked second out of 80 countries. The report cited factors contributing to Australia's strong global performance on the quality of palliative care including several related to systems capabilities:

*Informed policymaking and extensive data gathering are the hallmark of Australia's responsive government approach to palliative care. Publicly funded research centres inform the national debate, while advanced training and continuing education opportunities abound for professionals...A balanced system of self-assessment and ministerial oversight strengthens care delivery. Widespread use of patient satisfaction surveys bolsters overall transparency; feedback is used effectively to improve services. Thanks to efforts by government-backed Palliative Care Australia, awareness is on the rise among the general public along with heightened visibility in mainstream media.*<sup>184</sup>

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.

### 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 to rural areas;
- » Assessment of the effectiveness of existing models of palliative care services delivery;
- » Refining the definitions and management of cachexia and its related symptoms,
- » The trajectory of the course of illness for end-of-life disease, other than cancer, addressing either or both biological and social/environmental factors;
- » Symptom assessment and management in palliative care;
- » Families and caregiver support;
- » Psychosocial support, which may include bereavement and/or spiritual aspects, and
- » Models of care in palliation.<sup>185,186</sup>

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.

### 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 promote 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.<sup>187</sup>

Participation in the Palliative Care Outcomes Collaboration can also provide evidence for organisations and specialist palliative care services to meet core actions in the National Safety and Quality Health Service standards.

### 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.

In 2016 the Productivity Commission observed that:

*There is significant scope to improve the public accountability of end-of-life care. Of particular note is the lack of comprehensive, publicly available national data on even the most basic elements of community based end-of-life care, such as the total number of patients and total government expenditure in each state and territory.<sup>188</sup>*

The lack of robust data on community-based care is not unique to the palliative care sector. Similar issues are faced by other sectors (such as mental health) for which a high proportion of care is provided on an ambulatory basis in the community. In the health sector, existing data collections are well-established and reasonably comprehensive for hospital-based inpatient services. However, there is limited information available on non-admitted (outpatient) services provided through hospitals and even less information available on other ambulatory services provided in a community setting. For example, there is no national collection that captures information on service provision by community nurses.

In 2017 the Australian Institute of Health and Welfare commenced working with stakeholders to develop a framework to improve data collection for palliative care.



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

This appendix is based upon the staff planning guidelines in Palliative Care Australia's 2003 *Palliative Care Service Provision in Australia: A Planning Guide*. These guidelines are provided for the purposes of operational planning 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
<b>MEDICAL</b>				
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
<b>NURSING</b>				
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
<b>ALLIED HEALTH</b>				
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"> <li>OTs work with both patients and carers to promote the patient's function, safety and independence in the home and hospital environment</li> <li>Lymphoedema symptom relief is shared between PT and OT.</li> </ul>
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"> <li>Music and art therapy are professional degree courses, and include a high level of training in psychological and communication skills.</li> <li>Complementary and other therapists have widely varying levels and types of training, and practitioners' skills will vary.</li> </ul> <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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