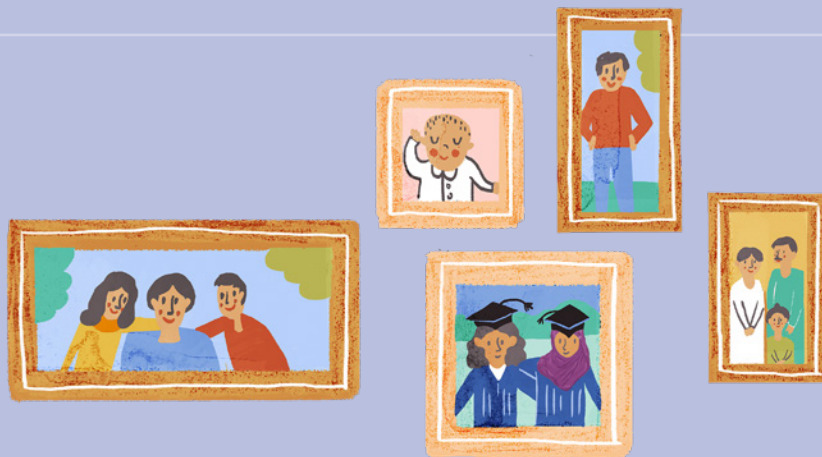


# National Palliative Care Strategy 2018



Australian Government  
Department of Health





## Foreword

Every day across Australia, people will die from life-limiting illness. Palliative care is holistic care that helps people nearing the end of their life to live as well as possible for as long as possible. For many people, accessing effective palliative care will mean the ability to live longer and to experience each moment of their lives more fully as a result of effective pain and symptom management, and holistic assessment of physical, psychological, social, emotional and spiritual needs.

Australia has been identified as a world leader in the provision of palliative care and in the quality of our palliative care research programs. All people require evidence-based and person-centred care at the end of their lives, and it is recognised that appropriate care should be based on appropriate need. At the same time, palliative care is not equally available to all people across Australia, for reasons of geography, awareness, economics, workforce, and accessibility. Aboriginal and Torres Strait Islander people, in particular, are impacted by unique factors such as intergenerational trauma, cultural dislocation, oppression, and systemic racism that influence their decision making around end of life considerations. In addition other groups of people are historically under-served including people from culturally and linguistically diverse backgrounds, people in rural and remote locations, and people with disability. People do not always have a choice in deciding where and how they wish to be supported, including where they wish to spend their last days and where they wish to die.

The National Palliative Care Strategy represents the commitment of the Commonwealth, state and territory governments to ensuring the highest possible level of palliative care is available to all people. It builds on previous strategies and on a legacy of investment into research, education and training, workforce and service development, and community awareness and engagement. This version of the Strategy has been produced following the 2016 evaluation of the National Palliative Care Strategy 2010 and has been developed through extensive consultation with Commonwealth, state and territory health departments, carers, peak bodies for consumers and service providers, clinicians, service managers, and a range of public, private and not-for-profit organisations involved in palliative care. We would like to acknowledge the contribution of all those who took part in the consultation or who provided feedback on earlier drafts of the Strategy, as well as the contribution of state and territory representatives through the former Community Care and Population Health Principal Committee (CCPHPC) of the Australian Health Ministers' Advisory Council and the End of Life Care Working Group under the Council of Australian Governments.

There is more to be done to maintain Australia's high standards of palliative care and to ensure that care is available to those who need it as well as their families and carers, including bereavement support following the death of a loved one. This Strategy is intended to provide direction and accountability so that people affected by life-limiting illnesses are able to receive the care they need and can live their lives as fully as possible.

*Endorsed by Australian Health Ministers*

---

## Table of Contents

Summary	4
Guiding principles	10
Goal 1: Understanding	12
Goal 2: Capability	14
Goal 3: Access and choice	16
Goal 4: Collaboration	18
Goal 5: Investment	20
Goal 6: Data and evidence	22
Goal 7: Accountability	24
Implementation Plan	26
Monitoring and Evaluation Plan	27
Glossary of terms	28
References	32



---

## Summary

Palliative care plays a vital role at the end of life for many Australians, improving quality of life for individuals and the carers<sup>1</sup>, family and friends supporting them as well as reducing the physical and emotional distress of dying. As noted by the World Health Assembly (of which Australia is a Member State),

***“palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”<sup>2</sup>***

It is estimated that 40 million people worldwide would benefit from palliative care but only about 14% receive the care they need.<sup>3</sup> Palliative care is a fundamental component of universal health coverage.<sup>4</sup> While Australia is among a relatively small number of countries currently providing a level of integrated, comprehensive palliative care there is still much work to be done to ensure that people affected by life-limiting illnesses get the care they need to live well.

This National Palliative Care Strategy (National Strategy) is a commitment by all Australian governments to ensure that evidence-based, quality palliative care is available to everyone who requires it.

---

## Purpose

The National Strategy is intended to be used by all Australian governments, as well as organisations and individuals, in guiding the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well.

The National Strategy provides a shared direction and an authorising environment for the continual improvement of palliative care services throughout Australia.

While the key audience for the National Strategy is governments and providers of care, this Strategy also articulates the care that people affected by life-limiting illnesses should expect.

Within each of the goals in the National Strategy there are statements identifying the outcomes of achieving each goal's priorities for people affected by life-limiting illnesses, providers of care, and governments.

The Implementation Plan (refer to page 26) articulates, within a five-year timeframe, the activities critical to realising the priorities identified in the National Strategy. The Monitoring and Evaluation Plan (refer to page 27) provides the mechanism for ongoing assessment of the progress made towards achieving the goals.

<sup>1</sup> For the purposes of this Strategy the term 'carers' refers to unpaid carers such as family members, friends or neighbours who provide personal care, support and assistance to people with life-limiting illness (see Glossary)

<sup>2</sup> Based on World Health Assembly, 2014, Page 1

<sup>3</sup> World Health Organization, 2017a

<sup>4</sup> World Health Organization, 2013

# Overview of the National Palliative Care Strategy

## Vision

This National Palliative Care Strategy provides an overarching vision for palliative care in Australia: that people affected by life-limiting illnesses get the care they need to live well. People who require palliative care may be at different stages of an illness trajectory; they may be young or old, with different cultural, social, emotional, relational and spiritual needs; they may need palliative care for a short period of time, intermittently, or consistently over a period of months or years. Regardless of their circumstances, people affected by a life-limiting illnesses, including carers and families, may benefit from the varied support available through palliative care. Helping people to live as well as possible for as long as possible is ultimately what palliative care is seeking to achieve.

*“People affected by life-limiting illnesses get the care they need to live well”*

## Guiding Principles

Six guiding principles (see pages 10–11) are identified as fundamental to ensure that all people experience the palliative care they need. These are aspirational principles expressed in current and future tenses to emphasise the need for each of these principles to be visible in all palliative care.

*Palliative care is person-centred care.*

*Death is a part of life.*

*Carers are valued and receive the care they need.*

*Care is accessible.*

*Everyone has a role to play in palliative care.*

*Care is high quality and evidence-based.*

## Goals

To make the vision for this Strategy a reality, seven goals are outlined (from page 12 onwards). Priority statements are defined for each goal. These statements are framed as descriptions of the achievement of the goal. For example, if Goal 2: Capability is achieved, then “the needs of people from underserved population groups are identified and respected”. It should be noted that the goals and priorities are numbered to provide ease of reference, and are not attempting to provide a hierarchy of importance.

There are a series of statements, expressed in the first-person, identifying the outcomes of achieving each goal for people affected by life-limiting illnesses, providers of care and governments.

**Understanding**

**Capability**

**Access and choice**

**Collaboration**

**Investment**

**Data and evidence**

**Accountability**

## Implementation Plan and Monitoring and Evaluation Plan

Activities to achieve the priorities are defined within the Implementation Plan.

This includes identified responsibilities and timing for these activities.

Likewise, the statements identifying the outcomes under each goal form the basis of the Monitoring and Evaluation Plan, which sets out indicators for measuring progress towards the goals, data sources and timeframes for monitoring and evaluation.

# A person-centred approach

The availability of palliative care is not limited to one type of illness but can assist all people with life-limiting illness, their families and carers. The World Health Assembly recognised that

*“...palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients’ need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received.”<sup>5</sup>*

The National Strategy affirms that palliative care is a person-centred approach with those affected by life-limiting illnesses at the heart of their care, surrounded by their community and supported by services. The types of palliative care and support that may be needed by an individual, their families and carers will vary and may include one or more of a range of formal and informal supports (see Figure 1 following).

Figure 1—Placing the person at the centre of their care



Palliative care may be required at any age. The needs of children and young people, and their parents and families, are often quite different from those of people facing the end of life at a much older age. Cultural factors, such as kinship and community, and end-of-life practices and rituals of Aboriginal and Torres Strait Islander people need to be considered to enable cultural capability of palliative care services for Aboriginal and Torres Strait Islander people. People with differing illnesses (such as cardiovascular disease, dementia or cancer) will have differing physical, psychosocial and spiritual needs over various timeframes.

Because people's palliative care requirements will differ and will also change over time, it is important that their needs and preferences are assessed regularly and that services are able to adapt accordingly. This includes the needs of families and carers as well as the person with a life-limiting illness.

<sup>5</sup> World Health Assembly, 2014



# Palliative care in Australia

Palliative care, while originally associated primarily with the diagnosis of cancer, is appropriate for anyone with life-limiting illnesses including other chronic conditions, dementia, and non-malignant degenerative diseases.

In the last few decades, palliative care has become available within almost every healthcare setting, including neonatal units, paediatric services, general practices, residential aged care facilities, acute hospitals, and generalist community services. Palliative care is also provided through specialist palliative care services which operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services.<sup>6</sup> Care is also provided in the home, often by carers supported by home-based outreach services from public, private or not-for-profit agencies.

People receiving palliative care have been shown to have fewer hospitalisations, shorter lengths of stay when they are hospitalised, and reduced visits to emergency departments.<sup>7</sup> Those receiving palliative care at home have been shown to have increased quality of life and reduced need for hospital-based care<sup>8</sup>, providing cost-savings for government.<sup>9</sup>

## The need for palliative care

Almost 160,000 people died in Australia in 2015.<sup>10</sup> Many of these deaths were expected, with the leading causes of death being chronic diseases.<sup>11</sup> As the Australian population ages, the number of people dying with chronic diseases, and in many cases complex needs, will increase.<sup>12</sup> Estimates of the proportion of people that may benefit from palliative care vary from 50 to 90 per cent but even conservative estimates identify that around 80,000 people may benefit from palliative care each year.<sup>13</sup>

It is estimated that around 65,000 hospitalisations were palliative care-related in 2014–15.<sup>14</sup> It is more difficult to quantify the palliative care received at home and in community-based settings, given current limited data sources. Data submitted to the Palliative Care Outcomes Collaboration (PCOC)<sup>15</sup> for the second half of 2016 show that almost 44 per cent of reported episodes of care were provided by community-based services.<sup>16</sup> Palliative care received at home and in community-based settings can be provided in different ways including care and support from families and friends, social networks, faith communities, private or not-for-profit nursing and allied health agencies or services, residential aged care facilities, general practitioners, public, private or not-for-profit social services, and specialist outreach services.

## Demand for palliative care is increasing

*It is anticipated that by 2066 around 25% of the population will be over 65.<sup>17</sup>*

*As around 80% of Australians who die in any given year are over 65, the number of people dying each year will increase consistently.<sup>18</sup>*

*The number of people receiving a palliative medicine specialist service through the Medicare Benefits Scheme increased by almost 85% in the five years to 2015–16.<sup>19</sup>*

<sup>6</sup> Australian Institute of Health and Welfare, 2016a

<sup>7</sup> Palliative Care Australia, 2017

<sup>8</sup> McNamara et al, 2016

<sup>9</sup> Palliative Care Australia, 2017

<sup>10</sup> Australian Bureau of Statistics, 2016

<sup>11</sup> Australian Institute of Health and Welfare, 2017b

<sup>12</sup> Australian Institute of Health and Welfare, 2016a

<sup>13</sup> Productivity Commission, 2017

<sup>14</sup> Australian Institute of Health and Welfare, 2017a

<sup>15</sup> Palliative care services are not required to submit data to PCOC so these figures may not be representative of all palliative care.

<sup>16</sup> Connolly et al, 2017

<sup>17</sup> Australian Bureau of Statistics, 2013

<sup>18</sup> Australian Institute of Health and Welfare, 2016a

<sup>19</sup> Australian Institute of Health and Welfare, 2012

## Improving palliative care in Australia

State and territory governments have made significant investments in the development and expansion of palliative care services over the years. More recently there has been a growing focus on improving the ability of specialists to provide outreach services into the community, and assisting people to remain at home for longer through the use of technology and home-based services.

At the national level, the Commonwealth Government has funded the National Palliative Care Projects since the 1990s, as well as Palliative Care Australia, the national peak body for palliative care. The Projects include significant investments in research, clinical education, and ongoing clinical benchmarking. Through the Projects, the Commonwealth has also provided funding for training materials, assessment tools, and other resources to assist health, social service and residential aged care providers, including a focus on the uptake of advance care plans and other mechanisms for increasing awareness and choice about planning at the end of life.

Australia has been rated highly in international assessments of palliative care services, due to the quality of services provided to people at the end of life, affirming the significant progress that has been made in Australia over many years.<sup>20</sup> The evaluation of the National Palliative Care Strategy 2010 found that the National Strategy provided direction to states and territories, and to individual services, in strengthening palliative care service delivery.<sup>21</sup>

While there has been significant growth and improvement in the palliative care Australians receive over the past several decades, there is still much work to be done to ensure that all people affected by life-limiting illnesses get the care they need to live as well as possible for as long as possible.

## History of the National Palliative Care Strategy

The first National Palliative Care Strategy was endorsed in October 2000 by the Australian Health Ministers' Advisory Council. This document was significant because it was the first time that all governments, providers and community-based organisations had come together to agree national priorities for palliative care.

In 2010 the second National Strategy, *Supporting Australians to Live Well at the End of Life*, was launched with the endorsement of health ministers, following significant consultation with the sector. The 2010 National Strategy was broad in scope, with an ambitious set of actions aimed at improving services across all sectors of the health system as well as increasing public and service provider awareness of palliative care.

In 2016, the Commonwealth Government commissioned an evaluation of the 2010 National Strategy. This evaluation included consultation with the public, peak bodies, community and advocacy organisations, clinicians, service providers and managers, policy makers and government representatives as well as a literature review. Overall, the evaluation found "that the Strategy's existence contributes to an authorising environment for the continued expansion and improvement of palliative care service delivery across the health system".<sup>22</sup> One of the actions recommended by the evaluation was to update the 2010 National Strategy to reflect the current service environment and challenges, strengthened by governance and an implementation plan and a monitoring and evaluation framework.

The development of this current Strategy took place in 2017 based on the findings of the evaluation and extensive consultation with over 200 individuals and organisations. This included carers, peak bodies for consumers and service providers, clinicians, public, private and not-for-profit organisations involved in palliative care and Commonwealth, state and territory health departments.

<sup>20</sup> The Economist Intelligence Unit, 2015

<sup>21</sup> Urbis, 2016

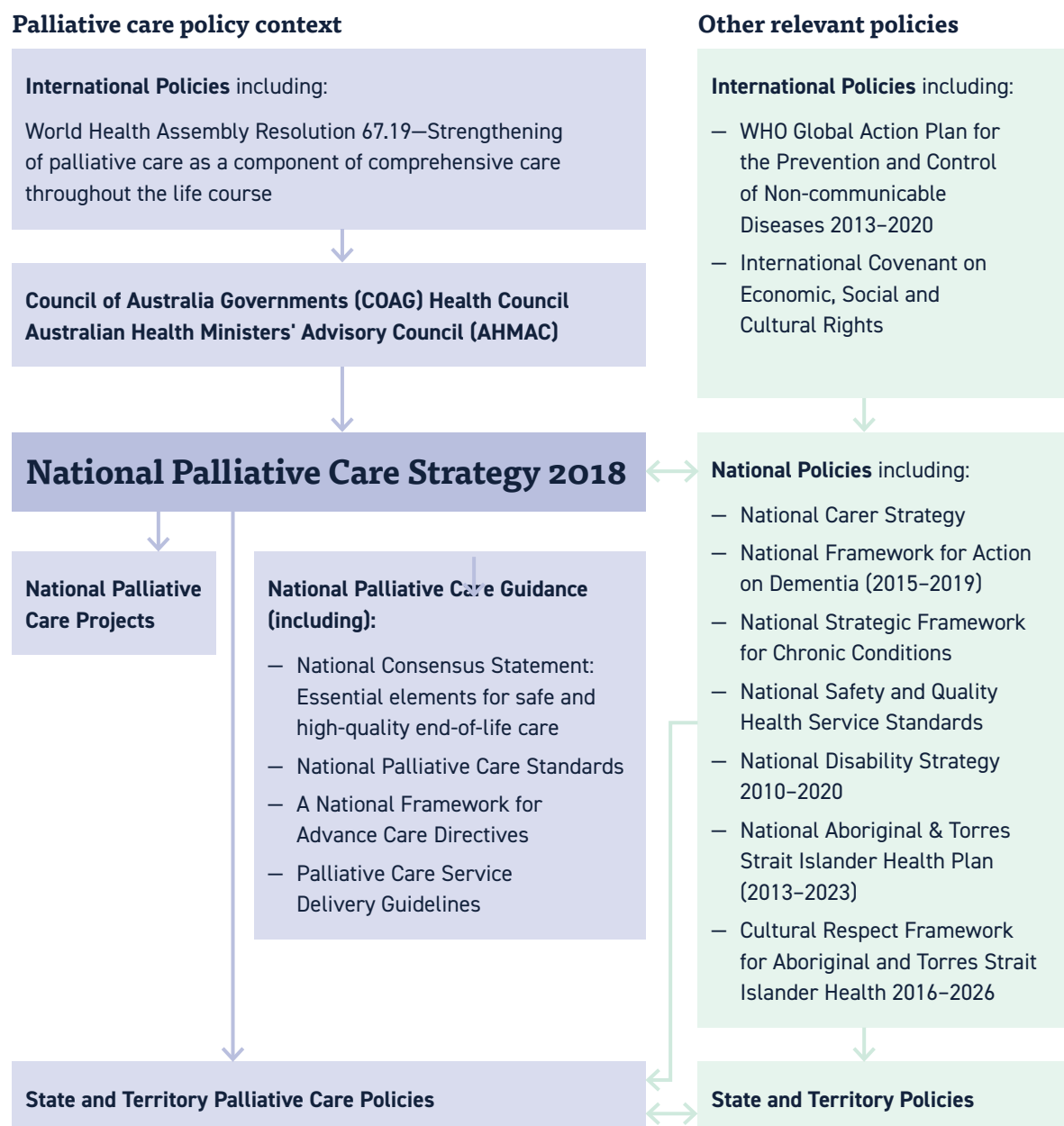
<sup>22</sup> Urbis, 2016, Page i



# Alignment with other national strategic frameworks

Since the 2010 National Strategy, many state and territory governments have either updated or produced new policy frameworks for palliative and end-of-life care. At the international level, the 67th World Health Assembly produced resolution 67.19 in 2014, calling on nations to strengthen palliative care as a component of comprehensive care throughout the life course.<sup>23</sup> Also since 2010, a number of significant national strategic frameworks have been developed which will guide other services that might be required by people who also require palliative care. This update of the National Strategy has sought to align with these strategic frameworks as outlined in Figure 2 below.

Figure 2—Palliative care policy context



<sup>23</sup> World Health Assembly, 2014

---

# Guiding principles

The following six principles are fundamental to good palliative care, and are expected to be demonstrated in all service delivery, quality improvement, policy and research development activities. These principles are aspirational statements that are reflected throughout the goal areas of the National Strategy and are written in the present and future tenses to highlight the expectation that each principle will be evident to those receiving and providing palliative care.

## **Palliative care is person-centred care**

People affected by life-limiting illnesses receive care that is respectful of, and responsive to, their needs, preferences and values. Individuals and their families and carers will be included in decision-making about their care and will be provided with information to make informed choices. People affected by life-limiting illnesses will be represented in the planning and delivery of services at every level.

Palliative care is holistic care and will include attention to physical, emotional, psychological, social, and spiritual needs. It will be provided in a manner that is sensitive and culturally appropriate to the preferences and needs of the person, their family and carers.

## **Death is recognised as a part of life**

Palliative care is an approach that values life and supports people to live as fully as possible for as long as possible, recognising that every life is meaningful. Maintaining quality of life is an important goal of palliative care, however the reality for many people is that impending death can hinder social interaction and leave people feeling isolated and alone. While maintaining social and emotional engagement and talking about the experience of dying can help, Australia has a very diverse society and people living with the expectation of an impending death may have different cultural preferences and varying levels of comfort in discussing, and planning for, the dying process and death itself.

Acknowledging the reality of dying and death can help people to prepare for the end of life in ways that are meaningful to them and their families and carers. This will look different for different people. Early and documented planning with formal care providers and carers can ensure that people facing an expected death are supported physically, emotionally, culturally, and spiritually, including bereavement support for families and carers.

## **Carers are valued and receive the support and information they need**

Carers provide an essential component of palliative care and in many cases provide the majority of care for a person whose life is limited by illness. Uniquely, carers can be both providers and recipients of care and, historically, carers' needs have often not been considered in care planning. Their role will be acknowledged and respected and their health and wellbeing needs considered as a component of holistic palliative care, including bereavement support.<sup>24</sup>

<sup>24</sup> Aoun et al, 2015

## Care is accessible

All Australians will be able to access quality palliative care. There are population groups that are currently under-served, including people who are:

- Aboriginal and Torres Strait Islander
- culturally and linguistically diverse, particularly new migrants
- lesbian, gay, bisexual, transgender and intersex
- living with disability, including cognitive impairment such as dementia
- experiencing homelessness
- in long-term institutional care (including being incarcerated)
- ageing and frail
- living in rural and remote areas.

While many people across society will experience varying levels of access and quality of care, these population groups generally experience additional barriers in accessing services, which will be addressed in initiatives to improve access and equity of care.

Palliative care needs to be flexible and responsive to ensure that care is accessible respectful, culturally safe and appropriate according to need. Specialist palliative care services play an important role in meeting complex needs and supporting others to provide this care.

## Everyone has a role to play in palliative care

Palliative care is provided by an active multi-disciplinary team which includes family and other carers, and considers people's relational, creative, spiritual, cultural and social needs as well as their physical and psychological needs. For that reason, collaboration is essential to ensure that people involved in palliative care are communicating and sharing information, and that those affected by life-limiting illnesses have a seamless experience of palliative care wherever and however they are being supported.

While not everyone will need specialist palliative care, specialist palliative care providers have an important role to play across the health system in building the capacity of those providing palliative care, including people within the community, to ensure that people affected by life-limiting illnesses get the care they need.

## Care is high-quality and evidence-based

Continued investment in research and knowledge sharing will improve the evidence base for the delivery and continuous improvement of quality palliative care. There is also a need for greater focus on the design and collection of meaningful data, including data on outcomes. It is vital that the experiences of people affected by life-limiting illnesses are included in regular monitoring and reporting. This evidence base needs to be accessible and integrated into education and training for care providers to improve the consistency and quality of care.

People affected by life-limiting illnesses will also have access to trustworthy resources to help them make informed decisions about their care.



---

# Goal 1: Understanding

**People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care.**

## Why is this important?

We will all die. Before the advent of our modern hospitals, more people died at home and death was more visible in the daily life of families and neighbourhoods. Today, the experience of dying is largely hidden from view.<sup>25</sup> It is important that the end of life is recognised as an inevitable part of living so we can ensure that our health and social systems provide the support that individuals, carers and families need as life ends, and in bereavement.

The recent rise in public conversations about death and dying is an indication of the importance of end-of-life issues. Many new community-based initiatives have been created in recent years to raise awareness of death and dying. These encourage cultural change and provide opportunities for people to discuss death and its meaning, and to express what is of value to them.<sup>26, 27</sup>

The first goal of the National Strategy is about the public—all of us—because the experience of dying will affect all of us. Research has shown that raising awareness and helping people understand the importance of palliative care is necessary to ensure that they can talk about their wishes for the end of life. In turn, raising awareness of the services available should help individuals, their families and carers to seek and find the support they need to live well till the end of life,<sup>28</sup> and in bereavement.

Evidence also demonstrates the benefits of individuals, their carers and families discussing their care preferences early in their illness<sup>29</sup>. Advance care plans or other similar documents are becoming more widely used and provide an important mechanism to communicate an individual's preferences regarding their care.

The involvement of communities in discussing end-of-life issues and caring for those who are dying has also been shown to increase social capital and build the capacity of a community to care for one another during illness, dying and bereavement.<sup>30</sup>

Families and carers undertake a large share of the responsibility of caring for their loved ones. Improving awareness and understanding of palliative care and its benefits will help communities to care for the carers who often find it difficult to maintain their own health and social well-being, including in bereavement.<sup>31, 32</sup>

<sup>25</sup> Zweig & Oliver, 2009

<sup>26</sup> Noonan et al, 2016

<sup>27</sup> McNamara & Hegney, 2016

<sup>28</sup> McIlfatrick et al, 2013

<sup>29</sup> Senate Community Affairs References Committee, 2012

<sup>30</sup> Horsfall, Noonan & Leonard, 2012

<sup>31</sup> Stajdujar, 2013

<sup>32</sup> Aoun et al, 2015

# Priorities

- 1.1 More people are aware of the benefits and local availability of palliative care
- 1.2 Community-based networks and activities build local capacity to support people who are reaching the end of their life
- 1.3 More people are preparing, using and maintaining advance care plans, including within residential aged care facilities and for people with dementia
- 1.4 Carers have the information, training and support they need to help them undertake caring activities
- 1.5 More people consider and respect cultural beliefs, practices and obligations when discussing palliative care needs

## What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
<p>1a I can access information on palliative care and end-of-life issues and make informed decisions about the care that I want to receive</p> <p>1b I can discuss my end-of-life wishes with my loved ones and develop and maintain an advance care plan</p> <p>1c My community enables me and others to talk about and plan for death</p> <p>1d My carers have the information and support they need</p> <p>1e My cultural health beliefs, health practices and culture are respected</p>	<p>1f We support individuals and the wider community to have informed discussions on palliative care and end-of-life issues</p> <p>1g We build capacity of carers and the wider community to care for people at the end of life</p> <p>1h We provide care that is person-centred and is informed by an individual's choice</p> <p>1i We provide care that is culturally respectful and safe for Aboriginal and Torres Strait Islander people</p> <p>1j We are engaged in partnerships with local Aboriginal and Torres Strait Islander people and acknowledge cultural differences</p>	<p>1k We support the provision of information and education on palliative care and end-of-life care issues</p> <p>1l We facilitate the collection of relevant data and use that data to increase community capacity around end-of-life issues</p>



---

## Goal 2: Capability

**Knowledge and practice of palliative care is embedded in all care settings.**

### Why is this important?

People die in a range of care settings, including in the home, hospitals, residential aged care facilities and hospices. Palliative care may be required at all stages of a person's illness and in all settings to maintain their comfort and quality of life.<sup>33</sup>

Those providing specialist palliative care have an essential role both in providing care to those people with complex needs, and in providing advice and support to other providers who are caring for people with life-limiting illnesses. At the same time, not everyone will have complex needs requiring specialist palliative care and there is significant potential to increase the capacity to deliver palliative care in all care settings, including the home.<sup>34</sup>

There is a great need among care providers for increased knowledge of palliative care<sup>35</sup>, including training in assessment and screening to identify people who would benefit from palliative care. Care providers also need to be able to recognise when an individual is ready to discuss and make choices about palliative care and be able to provide or access services that will meet their needs.<sup>36</sup>

Service providers in all settings need to be able to recognise clinical deterioration and dying.<sup>37</sup> Clinical providers of palliative care also need access to evidenced-based information on the appropriate use of medicine for pain and symptom management. The World Health Assembly recognised that there is an "urgent need to include palliation across the continuum of care, especially at the primary care level, recognising that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care."<sup>38</sup>

The more that service providers can support conversations and planning for the end of life, the more individuals, their families and carers will be able to make the choices that are right for them.<sup>39</sup> A person with a life-limiting illness may be supported by an increasingly complex network of carers.<sup>40</sup> This requires service providers to adapt to each individual's situation to ensure that everyone who should be included in conversations and planning for the end of life can be involved.

The choices that people make may differ due to cultural, religious, or other factors. For example, we know that Aboriginal and Torres Strait Islander people access health services at lower rates than other Australians. It is imperative that policy makers and service providers consider and address barriers to Aboriginal and Torres Strait Islander patients, their families and carers accessing and using palliative care services. Strategies must be implemented to provide culturally safe, responsive and supportive environments for Aboriginal and Torres Strait Islander people at all points along the patient journey including end-of-life care. Meeting the needs of individuals, their families and carers requires, for example, good communication and listening skills to assist people in identifying their needs and preferences. These skills are also necessary to support and provide care for families and carers in bereavement.

<sup>33</sup> Australian Institute of Health and Welfare, 2016a

<sup>34</sup> CareSearch, 2017a

<sup>35</sup> World Health Organization, 2016

<sup>36</sup> McNamara & Hegney, 2016

<sup>37</sup> Mason et al, 2015

<sup>38</sup> World Health Assembly, 2014, Page 2

<sup>39</sup> Kellas et al, 2017

<sup>40</sup> Horsfall et al, 2015



## Priorities

- 2.1 Medical, nursing and allied health graduates can identify and address people's palliative care needs
- 2.2 Clinical and non-clinical service providers can assist individuals, their families and carers to have discussions on palliative care including the development of advance care plans
- 2.3 The needs of people from under-served population groups are identified and respected
- 2.4 Health professionals provide early referrals for palliative care for those affected by life-limiting illnesses based on need with specialist palliative care services playing an important role in meeting complex needs and supporting others to provide this care
- 2.5 There are consistent assessment and screening practices across care settings
- 2.6 People providing palliative care can identify and meet the needs of carers, including during bereavement

## What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
<p>2a The people involved in my care are skilled in talking with me and my loved ones and helping us plan for my care and my end of life</p> <p>2b The people involved in my care respect my needs and preferences</p> <p>2c I am provided with culturally appropriate information on palliative care and supported to access care when I need it</p> <p>2d My family and friends who care for me are supported and able to access the care they need and to advocate for my wishes</p>	<p>2e We are trained and provide high-quality holistic care relevant to our setting</p> <p>2f We facilitate respectful discussions and planning with people about their palliative care</p> <p>2g We identify when someone would benefit from palliative care or specialist palliative care and know how to assist them</p> <p>2h We acknowledge the important role of informal carers and provide the support and care they need</p> <p>2i We promote collaboration and partnerships with Aboriginal and Torres Strait Islander Community Controlled Health Services</p>	<p>2j We work with education providers to make palliative care education and training available for all people who may be required to provide palliative care</p> <p>2k We support initiatives to increase cultural awareness and safety in palliative care</p> <p>2l We support initiatives to increase the number of people in both clinical and non-clinical settings skilled in discussing end-of-life issues and providing the relevant support to all people affected by life-limiting illnesses</p>

---

## Goal 3: Access and choice

**People affected by life-limiting illnesses receive care that matches their needs and preferences.**

### Why is this important?

At the heart of palliative care is the goal of ensuring that people may live as well as possible for as long as possible.<sup>41</sup> Australia is a world leader in the development and delivery of palliative care services, and has been at the forefront of innovative research and development initiatives which seek to improve individuals' experience of the dying process.<sup>42</sup> All states and territories have structures in place to provide palliative care in a range of settings, including the home.<sup>43</sup>

At the same time, not everyone is able to receive the palliative care they need to live well. There are under-served groups (refer to page 11) that experience various barriers in accessing and choosing the care they wish to receive, including geographical, cultural, language, and other barriers. Addressing these barriers and facilitating access can help overcome health disparities, particularly for Aboriginal and Torres Strait Islander people requiring palliative care.

Carers may also experience barriers to accessing the care and support they need. Improving access and choice for people affected by life-limiting illnesses should include frameworks to identify and address the needs of carers while in the caring role and after the death of their loved one.

A person-centred approach means that people affected by life-limiting illnesses are included in all aspects of planning for their care<sup>44</sup>, including identifying and addressing barriers to access and choice. For example, ensuring care environments are welcoming and culturally sensitive, such as displaying signs and symbols to acknowledge local Aboriginal and Torres Strait Islander cultures.

Structural or system barriers to access and choice also exist such as the limited number of specialist palliative care services<sup>45</sup>; concentration of specialist services within metropolitan areas<sup>46,47</sup>; lack of generalist palliative care providers; and siloed funding mechanisms.<sup>48</sup> These critical challenges are also addressed in Goal 2: Capability and Goal 5: Investment.

People's experience of illness will differ widely depending on diagnosis.<sup>49</sup> Children and young people may have a long engagement with palliative care services and need varying levels of assistance during that time. Conversely, people who are frail and aged may not require specialist palliative care until the very end of life, if at all, but may benefit from good symptom management. Improving the use of care pathways<sup>50</sup>, including pathways for transitions between settings and over the course of the dying process, will assist people to receive more coordinated and integrated palliative care tailored to their needs<sup>51</sup>, and reduce unnecessary transfers between care settings.<sup>52</sup> There is also an increasing role for technology in supporting those affected by life-limiting illnesses to access a range of services, including through remote consultations or through the use of tools in the home to support independence.

<sup>41</sup> Palliative Care Australia, n.d.

<sup>42</sup> The Economist Intelligence Unit, 2015

<sup>43</sup> Urbis, 2016

<sup>44</sup> Productivity Commission, 2017

<sup>45</sup> Mitchell, 2011

<sup>46</sup> The Economist Intelligence Unit, 2015

<sup>47</sup> Productivity Commission, 2017

<sup>48</sup> The Economist Intelligence Unit, 2015

<sup>49</sup> Australian Institute of Health and Welfare, 2016a

<sup>50</sup> Hardy et al, 2007

<sup>51</sup> Dy et al. 2013

<sup>52</sup> CareSearch, 2017b

# Priorities

- 3.1 People can receive timely palliative care in the place of their choice
- 3.2 A person-centred approach is embedded in all palliative care planning so that individuals, carers and families are actively engaged in care planning and ongoing needs assessment
- 3.3 More people from under-served population groups access palliative care
- 3.4 The use of technology supports people to access palliative care in all settings
- 3.5 Carers get the support they need, including in-home support, respite care and bereavement support

## What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
<p>3a It doesn't matter who I am, or where I live, I get the care I need when I need it</p> <p>3b I receive care and die in the place that I choose</p> <p>3c I am involved as much as I want to be in planning and decisions about my care</p> <p>3d My loved ones who care for me are cared for as well</p>	<p>3e We provide culturally safe and responsive palliative care where a person wants it and when they need it</p> <p>3f We actively work with the person, their family and carers when planning for and providing care</p> <p>3g We continuously use research to improve our services to meet the palliative care needs of everyone in our community</p>	<p>3h We continue to support and develop community-based palliative care services</p> <p>3i We support ongoing research to identify and address barriers to access and choice</p> <p>3j We work with all providers to improve the access to quality palliative care across care settings</p>





---

## Goal 4: Collaboration

**Everyone works together to create a consistent experience of palliative care across care settings.**

### Why is this important?

Many people with life-limiting illnesses will move between a variety of care settings as they approach the end of life. This is particularly true for children and young people with life-limiting conditions who may have contact with a palliative care service for many years.<sup>53</sup> In many parts of Australia, local collaborative networks have been established to improve consistency of care within as well as between care settings.<sup>54</sup>

Strengthening communication, collaboration and partnerships at local levels will contribute to improving transitions of care, including enhancing care pathways and shared care arrangements. This is evident when Aboriginal and Torres Strait Islander people, communities and organisations are actively engaged and partnered with, will contribute to improve the quality of care.<sup>55</sup>

Primary Health Networks and local hospital or health networks as well as Aboriginal and Torres Strait Islander Community Controlled Health Services, private and non-profit providers all have a contribution to make in working together to reduce duplication and unnecessary transfers to hospital where care could be provided in a more appropriate setting.

The National Palliative Care Projects as well as Palliative Care Australia and its member organisations have an important role to play in sharing innovation and excellence as well as strengthening the evidence base for new treatments and approaches.<sup>56</sup> In addition, greater collaboration between general practice and state/territory health services may reduce duplication of effort<sup>57</sup> and assist in providing greater consistency of service experience. Greater information sharing across jurisdictions should also help to increase the consistency of service for people who may move between states or regions.

Strengthening existing networks for information sharing can help services learn from each other regarding the best ways to improve the quality of palliative care. In addition, there are structural barriers to improve communication and information sharing within and across sectors, including technology systems, such as the My Health Record and funding mechanisms. Addressing these will drive better communication and collaboration.<sup>58</sup>

Involving individuals and their families and carers in the conversation, including in the design and monitoring of services, will improve the ability of services to provide the care that is best for the individual, their carer and family. This should include engagement with representatives from under-served population groups previously identified on page 8 of this National Strategy.

A number of policy frameworks have been developed in Australia in recent years that should align closely with the palliative care needs of particular groups of people (refer to page 6). Improving coordination and information sharing with other sectors will help to improve the consistency of experience of palliative care for people across Australia.

<sup>53</sup> Virdun et al, 2015

<sup>54</sup> Productivity Commission, 2017

<sup>55</sup> Australian Commission on Safety and Quality, 2016

<sup>56</sup> Urbis, 2016

<sup>57</sup> Productivity Commission, 2017

<sup>58</sup> Ibid

## Priorities

- 4.1 Collaboration tools (such as technology and agreed care pathways) are used to monitor and improve the coordination of palliative care and transitions between care settings
- 4.2 Communication between and across national, state/territory, and local palliative care networks improves the consistency of care across jurisdictions
- 4.3 People affected by life-limiting illnesses are included in the development, implementation and evaluation of palliative care services
- 4.4 Funding mechanisms, including existing Medicare Benefit Schedule item numbers, facilitate advance care planning and care coordination across all settings
- 4.5 Collaboration with Aboriginal and Torres Strait Islander people and organisations, guided by the Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander Health<sup>59</sup>

## What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
4a Everyone involved in my care is aware of their role and is accountable for doing their job	4e We work together to ensure that a person receives coordinated palliative care	4j We collect and share data to improve consistency and quality of palliative care
4b I receive high-quality, evidence-based care	4f We continue to strengthen our cultural competence to improve coordination of care for diverse population groups	4k We include people affected by life-limiting illness in the planning, delivery and evaluation of services
4c I am included and can contribute to the planning, delivery and evaluation of palliative care	4g We are actively involved in research and knowledge sharing to continuously improve the palliative care we provide	4l We facilitate the use of tools and mechanisms that enable collaboration at national, state and territory and local levels
4d I receive holistic care that is culturally safe and responsive	4h We include people affected by life-limiting illnesses in the planning, delivery and evaluation of services	
	4i We work together to review the care people receive	

<sup>59</sup> Australian Commission on Safety and Quality, 2016

---

## Goal 5: Investment

**A skilled workforce and systems are in place to deliver palliative care in any setting.**

### Why is this important?

The need for palliative care will continue to increase as the Australian population ages and people live longer with chronic disease and disability.<sup>60</sup> An ageing workforce<sup>61</sup> and shortages of medical and nursing staff trained in palliative care<sup>62</sup> will place increased pressure on services to meet this rising demand. Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed. This will include palliative care specialists who play an important role in not only the delivery of care but building the capacity of other providers of palliative care.

Current models of palliative care rely heavily on a critical number of specialist palliative care providers working within primarily metropolitan-based in-patient environments, while individual preferences and funding constraints point to an increasing need for service delivery in the community, within homes, and in residential aged care facilities.<sup>63</sup> Research and experience have identified the benefits for individuals and families in remaining at home as much as possible.<sup>64</sup> Investment is needed into community-based models that are flexible to accommodate increased demand and public expectations.<sup>65</sup> Resources and infrastructure will be required to provide care in the place a person chooses, including technology and care aids.

Service models must allow providers to respond quickly when an individual's condition changes, to avoid inappropriate or unnecessary emergency department presentations at the end of life and support people to remain in their home, if they choose, for as long as possible.

Strategic workforce planning supports all the other goals in this National Strategy. Workforce planning will need to take into account the current services available, the anticipated increase in demand, how people are likely to want to receive care in the future, and the competencies required to provide high quality palliative care. A national framework for workforce development will assist in strengthening consistency of both availability and quality of services across jurisdictions, and also assist service users and providers who move between states and territories.

In addition to specialist and non-specialist palliative care providers, there are many volunteers and community organisations that support the holistic needs of people affected by life-limiting illnesses. Their contribution needs to be acknowledged and support provided for these essential services. All individuals involved in palliative care need to be supported to maintain their own resilience and well-being while working in this often challenging area.<sup>66</sup>

<sup>60</sup> Productivity Commission, 2017

<sup>61</sup> *ibid*

<sup>62</sup> *ibid*

<sup>63</sup> Senate Community Affairs References Committee, 2012

<sup>64</sup> Gomes et al, 2013

<sup>65</sup> McNamara & Hegney, 2016

<sup>66</sup> Chan et al, 2016



# Priorities

- 5.1 Service models deliver palliative care when and where it is required according to the individual's needs
- 5.2 A national workforce development framework for palliative care provides guidance for future workforce planning, including a competency framework suitable for all care settings
- 5.3 Care providers have the support they need to maintain their health and wellbeing
- 5.4 Technology supports the delivery of palliative care in any setting
- 5.5 Investment in palliative care in all jurisdictions includes expansion of primary, community-based and tertiary services

## What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
<p>5a My care is flexible and able to accommodate my changing needs</p> <p>5b My care is respectful of my cultural beliefs and practices, social and spiritual needs</p>	<p>5c We develop and improve the way we plan and deliver services to align with the needs of our community</p> <p>5d We provide palliative care at the time and in the place that a person requires</p> <p>5e All people involved in palliative care have the appropriate skills</p> <p>5f We provide palliative care that is culturally safe and culturally responsive</p> <p>5g We support the wellbeing and resilience of people working in palliative care</p> <p>5h We develop and strengthen the Aboriginal and Torres Strait Islander health workforce in all areas of the health system, both clinical and non-clinical</p> <p>5i We develop a culturally skilled and responsive workforce in all areas of the health system, both clinical and non-clinical</p>	<p>5j We continue to support research to identify gaps in service provision and implement responses to address those gaps</p> <p>5k We continue to ensure that there is the appropriate skilled workforce to deliver palliative care both now and in the future across primary, community-based and tertiary services</p> <p>5l We support the delivery of palliative care in all care settings to ensure that people can access the care they need when and where they need it</p> <p>5m We support the development and use of technology to deliver palliative care</p> <p>5n We support strategies to increase engagement by Aboriginal and Torres Strait Islander people in Palliative Care Services</p>

---

## Goal 6: Data and evidence

**Robust national data and a strong research agenda strengthen and improve palliative care.**

### **Why is this important?**

The lack of consistent collection and reporting of data on palliative care has been identified as an area for improvement at both state and territory<sup>67,68</sup>, and national levels.<sup>69,70</sup>

Many jurisdictional and national data collection mechanisms do already exist, including those supported through the National Palliative Care Projects; in addition, work continues at national, state and territory levels to improve data development, collection and interpretation activities. However, further work is required to enable linked and nationally consistent data collection to improve both routine monitoring and evaluation reporting. This can be strengthened by effective and accurate processes to routinely ask patients and record responses if they identify as being of Aboriginal and/or Torres Strait Islander origin.<sup>71</sup>

The evaluation of the National Palliative Care Strategy 2010 resulted in several recommendations related to the collection of data across all care settings and the development of nationally consistent data. People who contributed to the evaluation argued strongly that data improvement is critically important to strengthen the evidence base regarding the provision, quality and effectiveness of palliative care across Australia.<sup>72</sup>

A key goal for this National Strategy is to improve the ability to evaluate palliative care at a population level and to monitor outcomes across Australia. This will allow the quality and processes of care to be assessed and improved across all care settings. It will also assist to expand the understanding of where people are able to access palliative care, who is providing the care, and the frequency and effectiveness of different treatments or services. Central to this evaluation will be the voices of those who are recipients of care, in both the design and collection of data and in research processes.

Australia has benefited for many years from a focussed national research agenda, which has created a large network of clinicians, academics, researchers and policy makers; the outcomes of this large-scale investment in research have contributed significantly to the quality of palliative care provided in Australia.<sup>73</sup> Maintaining a strong national commitment to research and evidence will benefit Australia as well as help to improve services internationally by increasing the global knowledge base.

<sup>67</sup> Audit Office of New South Wales, 2017

<sup>68</sup> Victorian Auditor-General's Office, 2015

<sup>69</sup> Productivity Commission, 2017

<sup>70</sup> Senate Community Affairs References Committee, 2012

<sup>71</sup> AIHW, 2010

<sup>72</sup> Urbis, 2016

<sup>73</sup> Ibid

## Priorities

- 6.1 Nationally consistent data collection is used to monitor, evaluate and report on access to and outcomes of palliative care
- 6.2 Palliative care providers contribute to data collection, monitoring and reporting activities
- 6.3 Data collection and reporting informs continuous quality improvement of palliative care
- 6.4 A robust national research agenda informs sector development and improvement
- 6.5 Research includes the experience of individuals affected by a life-limiting illness and these experiences inform the continuous improvement of palliative care
- 6.6 Systematic processes are in place for asking all patients and recording responses to the standard Aboriginal and Torres Strait Islander status question, 'are you [is the person] of Aboriginal or Torres Strait Islander origin?'<sup>74</sup>

## What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
<p>6a My feedback informs improvements to care</p> <p>6b I can access quality, evidence-based information that helps me make informed decisions</p>	<p>6c We collect and share data on the palliative care we provide and the outcomes of that care</p> <p>6d We continuously improve the care we provide to reflect the evidence on quality palliative care</p> <p>6e We learn from the feedback we receive from people affected by life-limiting illnesses</p> <p>6f We know where to find data and evidence to improve the care we provide</p> <p>6g We routinely ask all people and record responses if they identify as being of Aboriginal and/or Torres Strait Islander origin</p>	<p>6h We continue to support the improvement of nationally consistent data collection and reporting for palliative care</p> <p>6i We support data infrastructure that informs the continuous improvement of palliative care</p> <p>6j We continue to support research to maintain a strong evidence-base for palliative care</p> <p>6k We support the translation of research into practice</p>

<sup>74</sup> AIHW, 2010



---

## Goal 7: Accountability

**National governance of this Strategy drives action.**

### **Why is this important?**

A key finding of the evaluation of the National Palliative Care Strategy 2010 was the value placed on national governance structures to improve collaboration and accountability across jurisdictions. The absence of formal governance and accountability structures was noted as a barrier to improving access as well as the quality and consistency of palliative care provision across Australia.<sup>75</sup>

A formal national governance structure with links to the Australian Health Ministers' Advisory Council will ensure that palliative care is recognised and resourced as an integral component of the health system, while retaining the independence of states and territories to decide how best to invest in palliative care services. Such a governance mechanism will be strengthened by including people with lived experience of palliative care and by ensuring that the voices of people affected by life-limiting illnesses are considered in service and research development.

This governance structure will be responsible for the development of the Implementation Plan for this Strategy (refer to page 26) as well as reporting on progress made towards achieving the goals within this Strategy. It will also provide a structural mechanism to support information sharing between the Commonwealth (which funds general practice and aged care services) and states and territories (which fund community, tertiary and specialist services).

As Australians live longer, and more people live with chronic and life-limiting conditions, the need for palliative care will continue to increase.<sup>76</sup> Embedding palliative care further within the national governance structures of the health system will facilitate the effective integration of palliative care across all service settings. This governance structure can also provide a platform for dialogue and integration with other service sectors including aged care, disability, and social services, and for promoting the use of quality standards and accreditation processes.

<sup>75</sup> Urbis, 2016

<sup>76</sup> Productivity Commission, 2017

## Priorities

- 7.1 A national governance structure for this Strategy maintains a formal link to the Australian Health Ministers' Advisory Council
- 7.2 Oversight for the implementation and monitoring of this National Strategy includes annual reporting on progress
- 7.3 People with lived experience of palliative care are consulted in national policy development
- 7.4 The national governance structure facilitates closer integration with other policy and service sectors
- 7.5 Indicators for quality palliative care are reflected in the accreditation processes of all care settings

## What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
<p>7a I see changes being made to improve palliative care</p> <p>7b My voice is represented and informs decision making</p>	<p>7c We are involved in and knowledgeable about changes being made to improve palliative care</p> <p>7d We provide care that is aligned to best practice</p>	<p>7e We work towards fulfilling our commitments in this Strategy</p> <p>7f We regularly monitor and report on the priorities in this Strategy</p> <p>7g We include people with a lived experience of palliative care in the implementation of this Strategy</p> <p>7h We promote the inclusion of palliative care indicators in accreditation standards across all care settings</p> <p>7i We commit to strong collaborative partnerships within and across governments to improve quality and consistency of palliative care</p>

# Implementation Plan

The responsibility for the implementation of the National Strategy rests with the Commonwealth, state and territory governments, with the Commonwealth providing national leadership and policy direction as well as supporting national research and other programs, and the state and territory governments providing quality palliative care and policy development within their jurisdictions.

The implementation of the National Strategy will be guided by an Implementation Plan, to be developed by Commonwealth, state and territory governments within the year following endorsement of the Strategy. The Plan will identify activities, accountability and timing for progress within a five-year timeframe. Annual reporting on the activities within the Plan will feed into the Monitoring and Evaluation Plan.

An indication of what the Implementation Plan might include is outlined in the table below.

Goals	Priorities	Activities
Goal 1: Understanding— People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care	1.1 More people are aware of the benefits and the local availability of palliative care	The specific actions at regional, state or national levels that will be undertaken to support achieving the goal
Responsibilities	Timing	Data sources
The organisation(s) accountable for implementing the activity	The expected timeframe for undertaking this activity	The evidence that will be used to report the progress made towards achieving the goal



# Monitoring and Evaluation Plan

A Monitoring and Evaluation Plan will be developed to identify how progress on the priorities in the National Strategy will be measured and reported. Data collection should contribute to annual monitoring and reporting as well as to longitudinal evaluation of achievements over the five-year timeframe for the Implementation Plan. Many indicators are already available in existing datasets; however, the National Strategy contains some aspirational priorities which will require the development of new, or enhancement of existing, datasets.

An indication of what the Monitoring and Evaluation Plan might include is outlined in the table below.

Outcomes	Evaluation questions	Indicators
1a. I can access information on palliative care and end-of-life issues and can make informed decisions about the care that I want to receive	Question(s) to assess the extent to which the outcome has been achieved	The measure(s) used to assess progress towards achieving the outcome
Data source	Timeframe	
The evidence that will be used to assess the progress made towards achieving the goal	The time period within which the outcome is expected (long, medium or short-term)	



---

# Glossary of terms

**Aboriginal** (adjective): A person of Aboriginal descent who identifies as Aboriginal and is accepted as such by the community in which he[or she] lives (the original inhabitants of the Australian continent and surrounding islands).

**Advance care plan:** states “preferences about health and personal care and preferred health outcomes. They may be made by, with, or on the person’s behalf, and are prepared from the person’s perspective to guide decisions about care.”<sup>77</sup>

**Advance care directive:** “a type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult.”<sup>78</sup>

**Bereavement:** “refers to the event of death of a person with whom there has been an enduring relationship.”<sup>79</sup>

**Chronic conditions:** “have complex and multiple causes; may affect individuals either alone or as comorbidities; usually have a gradual onset, although they can have sudden onset and acute stages; occur across the life cycle, although they become more prevalent with older age; can compromise quality of life and create limitations and disability; are long-term and persistent, and often lead to a gradual deterioration of health and loss of independence; and while not usually immediately life threatening, are the most common and leading cause of premature mortality.”<sup>80</sup>

**Culturally and linguistically diverse:** “a broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characteristics.”<sup>81</sup>

**Carers:** “people who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age. Carers include family members, friends, relatives, siblings or neighbours. Grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers.”<sup>82</sup>

**End of life:** “the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.”<sup>83</sup>

<sup>77</sup> Australian Health Ministers’ Advisory Council, 2011, Page 9

<sup>78</sup> Australian Health Ministers’ Advisory Council, 2011, Page 10

<sup>79</sup> CareSearch, 2017c

<sup>80</sup> Australian Health Ministers’ Advisory Council, 2017 Page 6

<sup>81</sup> Ethnic Communities’ Council of Victoria, 2012, Page 1

<sup>82</sup> Australian Government, 2011

<sup>83</sup> Australian Commission on Safety and Quality in Health Care, 2015, Page 33

**End-of-life care**<sup>84</sup>: “includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.”<sup>85</sup>

**Grief**: “is how bereavement affects us personally, with effects across several domains—emotional, cognitive, social, physical, financial and spiritual.”<sup>86</sup>

**Integrated care**: “Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings. Where the result of such multi-pronged efforts to promote integration leads to benefits for people, the outcome can be called integrated care.”<sup>87</sup>

**Life-limiting illness**: “a person with life-limiting illness may die prematurely. This term is often used for people living with a chronic condition that may seem life-threatening but can continue for many years or even decades.”<sup>88</sup>

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

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”<sup>89</sup>

<sup>84</sup> The Aged Care Funding Instrument (ACFI) enables a claim for a palliative care program involving end-of-life care for a resident of a Residential Aged Care Facility. Within this context end-of-life care is defined as care provided in the last week or days of life. See [https://www.caresearch.com.au/caresearch/Portals/0/PA-Toolkit/Resources\\_2016\\_Update/Fact\\_Sheet\\_10\\_End\\_of\\_Life\\_Terminal\\_Care\\_Pathways.pdf](https://www.caresearch.com.au/caresearch/Portals/0/PA-Toolkit/Resources_2016_Update/Fact_Sheet_10_End_of_Life_Terminal_Care_Pathways.pdf)

<sup>85</sup> Australian Commission on Safety and Quality in Health Care 2015, page 33

<sup>86</sup> CareSearch, 2017c

<sup>87</sup> World Health Organization 2016, page 3

<sup>88</sup> Department of Health and Human Services, 2016, Page 29

<sup>89</sup> Based on World Health Organization, 2017b



**Paediatric palliative care:** "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited."<sup>90</sup>

**Person-centred care:** Person-centred care "is a philosophy that sees doctors, nurses and health services treating people the way they want to be treated. It allows people to make choices about the type of health services and care they access, and how and when it is delivered.

With person-centred care, each person is treated as a complete human being with their own life story, values, culture, interests and beliefs. Support from others is tailored to meet the person's individual situation, unique needs and goals."<sup>91</sup>

**Quality of care:** "the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care must be safe, effective, timely, efficient, equitable and people-centred."<sup>92</sup>

**Respite:** "Respite care refers to the provision of care for a person with a disability, severe medical condition or who is frail aged, by an organisation or another person other than the carer for a temporary period so the carer can have a break from caring."<sup>93</sup>

**Specialist palliative care:** "Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care."<sup>94</sup>

**Terminal:** "the stage of an illness when death is likely within days."<sup>95</sup>

**Torres Strait Islander:** A person of Torres Strait islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he [or she] lives (the original inhabitants of the Torres Strait Islands).

<sup>90</sup> World Health Organization, 2017a

<sup>91</sup> Australian Government, n.d

<sup>92</sup> World Health Organization, 2017c

<sup>93</sup> Australian Government, 2017

<sup>94</sup> Australian Commission on Safety and Quality in Health Care 2015, page 35

<sup>95</sup> Australian Institute of Health and Welfare, n.d.



---

# References

- Aoun, S, Breen, L, Howting, D, Rumbold, B, 2015. *Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need*. PLOS ONE, 10.1371.
- Audit Office of New South Wales, 2017. *New South Wales Auditor-General's Report – Planning and evaluating palliative care services in NSW*. Sydney.
- Australian Bureau of Statistics, 2016. *Causes of Death, Australia, 2015*. ABS Cat No. 3303.0 Canberra.
- Australian Commission on Safety and Quality in Health Care, 2015. *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*. ACSQHC, Sydney.
- Australian Commission on Safety and Quality in Health Care, 2013. *Safety and Quality of End-of-life Care in Acute Hospitals: A Background Paper*. ACSQHC, Sydney.
- Australian Commission on Safety and Quality in Health Care, 2016. *Overview: Guide to better care for Aboriginal and Torres Strait Islander communities*. ACSQHC, Sydney.
- Australian Government, 2017 1.1.R.250 *Respite care*. <http://guides.dss.gov.au/guide-social-security-law/1/1/r/250>. Accessed 28 July 2017.
- Australian Government, 2011. *National Carer Strategy*. Canberra.
- Australian Government, n.d. *Person-centred caring*. <https://www.carergateway.gov.au/person-centred-caring>. Accessed 28 July 2017.
- Australian Health Ministers' Advisory Council, 2017. *National Strategic Framework for Chronic Conditions*. AHMAC, Canberra.
- Australian Health Ministers' Advisory Council, 2011. *National Framework for Advance Care Directives*. AHMAC, Canberra.
- Australian Institute of Health and Welfare, 2017a. *Palliative care services in Australia – Service provided by palliative medicine specialists*. AIHW, Canberra.
- Australian Institute of Health and Welfare, 2017b. *Deaths*. <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/leading-causes-of-death>. Accessed 9 October 2017.
- Australian Institute of Health and Welfare, 2016a. *Australia's health 2016*. Australia's health series no. 15. Cat. no. AUS 199. AIHW, Canberra.
- Australian Institute of Health and Welfare, 2016b. *Palliative care services in Australia – Palliative care outcomes*. AIHW, Canberra.
- Australian Institute of Health and Welfare, 2012. *Palliative care services in Australia 2012*. Cat. no. HWI 120. AIHW, Canberra.
- Australian Institute of Health and Welfare, 2010. *National best practice guidelines for collecting Indigenous status in health data sets*. Cat. No. IHW 29. AIHW, Canberra.
- Australian Institute of Health and Welfare, n.d. *Palliative care phase code N*. <http://meteor.aihw.gov.au/content/index.phtml/itemId/639015>. Accessed 8 June 2017.



- CareSearch, 2017a. *The Role of Specialist Palliative Care*. <https://www.caresearch.com.au/caresearch/tabid/1006/Default.aspx>. Accessed 10 October 2017.
- CareSearch, 2017b. *Continuity of Care*. <https://www.caresearch.com.au/caresearch/tabid/2438/Default.aspx>. Accessed 10 October 2017.
- CareSearch, 2017c. *Bereavement and Grief*. <https://www.caresearch.com.au/caresearch/tabid/1345/Default.aspx>. Accessed 28 July 2017.
- Chan, WH, Fong, A, Wong, KY, Tse, DW, Kam Shing, L, & Lai Ngor, C 2016, *Impact of Death Work on Self: Existential and Emotional Challenges and Coping of Palliative Care Professionals*, Health & Social Work, vol. 41, no. 1, pp. 33-41.
- Connolly, A, Allingham, S, Clapham, S, Quinsey, K, Mastroianni, F, Foskett, L, 2017. *Patient Outcomes in Palliative Care in Australia, National Compendium Report, July to December 2016*. Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong.
- Department of Health and Human Services, 2016. *Victoria's end of life and palliative care framework*. DHHS, Melbourne.
- Dy, S, Apostol, C, Martinez, K, & Aslakson, R 2013, *Continuity, Coordination, and Transitions of Care for Patients with Serious and Advanced Illness: A Systematic Review of Interventions*. Journal Of Palliative Medicine, 16, 4, pp. 436-445.
- Ethnic Communities' Council of Victoria, 2012. *ECCV Glossary of Terms*. ECCV, Melbourne.
- Gomes, B., Calanzani, N, Gysels, M, Hall, S, Higginson, I, 2013. *Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers*. Cochrane Database of Systematic Reviews (6), 1-285.
- Hardy, J, Haberecht, J, Maresco-Pennisi, D, & Yates, P, 2007, *Audit of the care of the dying in a network of hospitals and institutions in Queensland*. Internal Medicine Journal, vol. 37, no. 5, pp. 315-319.
- Horsfall, D, Noonan, K, & Leonard, R, 2012, *Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities*. Health Sociology Review, 21, 4, pp. 373-382.
- Kellas, J, Castle, K, Johnson, A, & Cohen, M, 2017, *Communicatively Constructing the Bright and Dark Sides of Hope: Family Caregivers' Experiences during End of Life Cancer Care*. Behavioral Sciences (2076-328X), 7, 2, pp. 1-12.
- Mason, B, Buckingham, S, Finucane, A, Hutchison, P, Kendall, M, McCutcheon, H, Porteous, L, & Murray, SA 2015. *Improving primary palliative care in Scotland: lessons from a mixed methods study*. BMC Family Practice, vol. 16, pp. 1-8.
- McIlfatrick, S, Hasson, F, McLaughlin, D, Johnston, G, Roulston, A, Rutherford, L, Noble, H, Kelly, S, Craig, A, & Kernohan, W, 2013. *Public awareness and attitudes toward palliative care in Northern Ireland*. BMC Palliative Care, 12, 1, pp. 34-40.
- McNamara, B, Rosenwax, L, Murray, K, & Currow, D, 2013. *Early Admission to Community-Based Palliative Care Reduces Use of Emergency Departments in the Ninety Days before Death*. Journal of Palliative Medicine, vol. 16, no. 7, pp. 774-779.
- McNamara, B, Hegney, D, 2016. *Conversations – Creating Choice in End of Life Care*. Australian Centre for Health Research, Melbourne.

- Mitchell, G, 2011. *Palliative Care in Australia*. The Ochsner Journal. 2011;11(4):334-337.
- Palliative Care Australia, 2017. *The Economic Value of Palliative Care and End-of-Life Care*. PCA, Canberra.
- Palliative Care Australia, n.d. *What is Palliative Care?* <http://palliativecare.org.au/understanding-palliative-care-parent-menu/what-is-palliative-care/>. Accessed 10 October 2017.
- Productivity Commission, 2017. *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Draft Report. Canberra.
- Senate Community Affairs Committee, 2012. *Community Affairs References Committee – Palliative care in Australia*. Senate Community Affairs Committee, Canberra.
- Stajduhar, KI, 2013. *Burdens of Family Caregiving at the End of Life*. Clinical & Investigative Medicine, vol. 36, no. 3, pp. E121-E126.
- The Economist Intelligence Unit, 2015. *The 2015 Quality of Death Index*. The Economist, London.
- The Groundswell Project, n.d. *The Groundswell Project – Our Mission*. <http://www.thegroundswellproject.com/mission/>. Accessed 4 October 2017.
- Urbis, 2016. *Evaluation of the National Palliative Care Strategy 2010 Final Report*. Urbis, Sydney.
- Virdun, C, Brown, N, Phillips, J, Luckett, T, Agar, M, Green, A, Davidson, P, 2015, *Elements of optimal paediatric palliative care for children and young people: An integrative review using a systematic approach*. Collegian, vol. 22, pp. 421 - 431.
- Victorian Auditor-General's Office, 2015. *Palliative Care*. Melbourne.
- World Health Assembly, 2014. *Strengthening of palliative care as a component of comprehensive care throughout the life course*. WHA, Geneva.
- World Health Organization, 2017a. *Palliative Care fact sheet*. <http://www.who.int/mediacentre/factsheets/fs402/en/>. Accessed 10 October 2017.
- World Health Organization, 2017b. *WHO Definition of Palliative Care*. <http://www.who.int/cancer/palliative/definition/en/>. Accessed 6 June 2017.
- World Health Organization, 2017c. *What is Quality of Care and why is it important?* [http://www.who.int/maternal\\_child\\_adolescent/topics/quality-of-care/definition/en/](http://www.who.int/maternal_child_adolescent/topics/quality-of-care/definition/en/). Accessed 9 October 2017.
- World Health Organization, 2016. *Planning and implementing palliative care services: a guide for programme managers*. WHO, Geneva.
- Zweig, S, & Oliver, D, 2009. *Returning from the Total Institution to a Home Environment: A Journey for Birthing and Dying*. Journal of Housing For The Elderly, 23, 1/2, pp. 116-129.





