

# National Palliative Care Strategy 2017 Draft 2.1

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## Acknowledgements

The Department and Urbis acknowledge and thank all those who have taken the time to contribute to the consultation process to inform the development of this draft updated National Strategy.

## Definitions

Four terms frequently used in the text of this National Strategy are defined below. Definitions of these and other terms can be found in the Glossary at the end of the document. There are other definitions of palliative care and end-of-life care in use across Australia and in some related sectors, such as aged care.

### Palliative Care

For the purposes of this National Strategy, the definition for palliative care is that developed by the World Health Organization:

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

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.<sup>1</sup>

### End-of-life care

While there is not complete consensus on the relationship between palliative and end-of-life care, there is a recognition that palliative care may be required throughout an illness trajectory and not just at the end of life, while care at the end of life may incorporate palliative care. The definition of end-of-life care used throughout this draft National Strategy is that included within the National Consensus Statement on End-of-Life Care:

*End-of-life care 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>2</sup>

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<sup>1</sup> World Health Organization, 2017

<sup>2</sup> Australian Commission on Safety and Quality in Health Care 2015, page 33

## **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>3</sup>

## **Palliative approach**

“A palliative approach is an approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the holistic needs of patients and caregiver/s that is reflected in assessment and in the primary treatment of pain and in the provision of physical, psychological, social and spiritual care.”<sup>4</sup>

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<sup>3</sup> Australian Commission on Safety and Quality in Health Care 2015, page 35

<sup>4</sup> Palliative Care Australia, 2005, page 11

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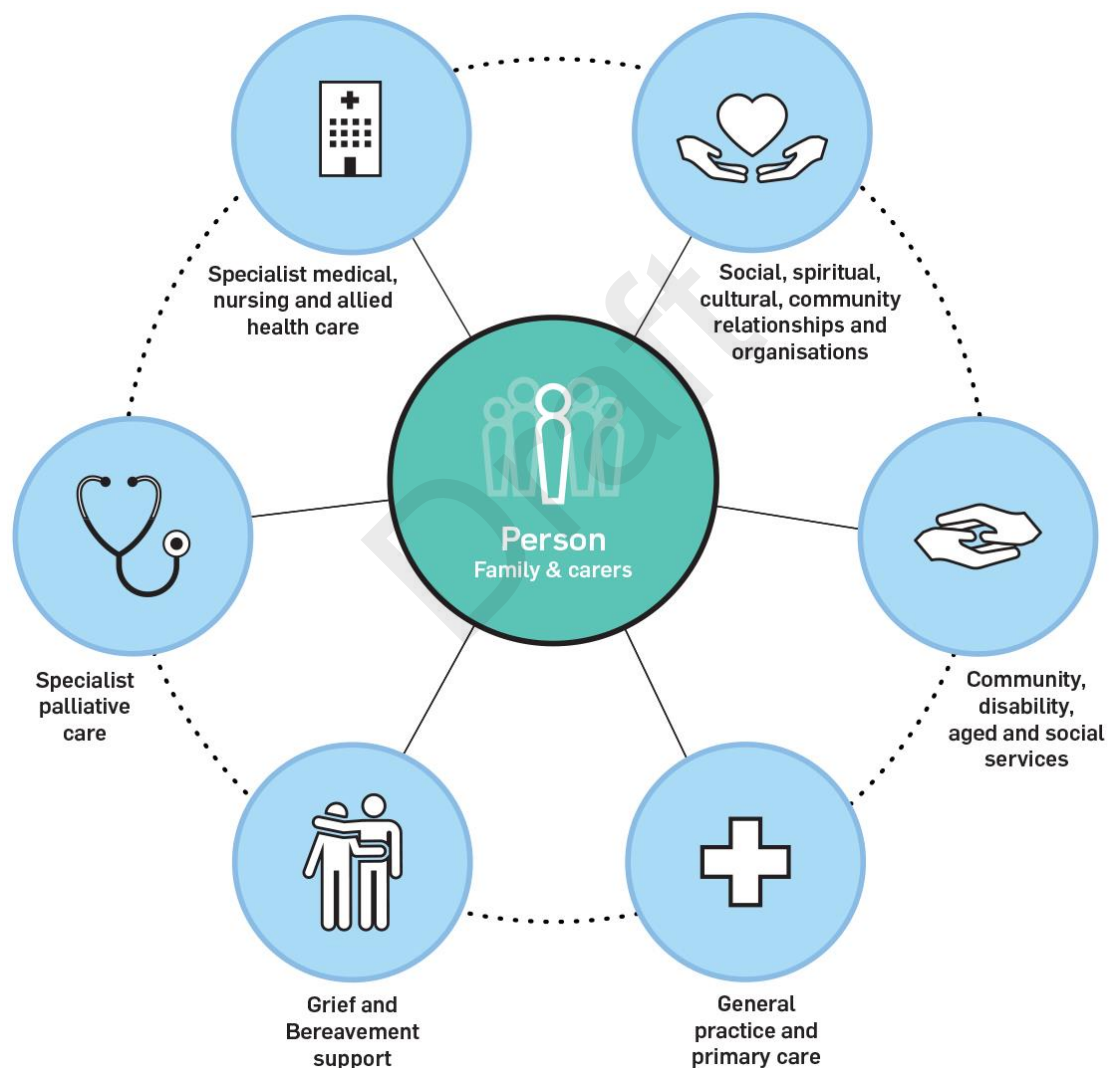
# The updated National Palliative Care Strategy

## Purpose

Palliative care plays a vital role at the end of life for many Australians, reducing the physical and emotional distress of dying, and optimising quality of life for individuals and the carers, family and friends supporting them.

The purpose of this National Strategy is to provide an over-arching vision for palliative care in Australia so that ***all Australians with a life-limiting illness live well until the end of life.***

The National Strategy affirms that palliative care is a person-centred approach provided in a range of settings by a variety of clinical and non-clinical, professional and non-professional service providers. The types of palliative care support that may be experienced by an individual, their families and carers is illustrated in the diagram below. Care may be provided in a range of settings depending upon the individuals' choice, the availability of services, and the type of care required.



# Audience

This National Strategy is designed as a document that can be used by people and organisations at all levels of the community and the service system. It is intended to be used by all Australian governments; primary, community-based, and tertiary health services; community-based social services; residential aged care facilities; and organisations seeking to improve the experience of palliative care in Australia.

For the general public, including people receiving palliative care and their families and carers, the National Strategy is intended to articulate the priorities for palliative care in Australia in order to set expectations for the experience of quality palliative care in all settings.

## Palliative care in Australia

In the 2015 Economist Intelligence Unit's Quality of Death Index, Australia was one of the highest-ranking countries in the quality of services provided to people at the end of life, affirming the significant progress that has been made over many years.<sup>5</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>6</sup>

The discipline of specialist palliative care has grown in Australia since the 1980s, and every state and territory government health department funds and delivers palliative care services for its residents. In the last few decades, palliative care has become available within almost every health care setting, including neonatal units, paediatric services, general practices, acute hospitals, residential and community aged care services, 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>7</sup>

Since the 1990s, the Commonwealth Government has supported the National Palliative Care Projects as well as the national peak body for palliative care, Palliative Care Australia. 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 end-of-life care planning. These projects have had a major influence on the palliative care sector as well as the broader health system, and have contributed significantly to the achievements of the first two National Palliative Care Strategies.

### Demand for palliative care is increasing

- In 2015-2016, almost **14,300** patients received a Medicare Benefits Scheme-subsidised palliative medicine specialist service<sup>8</sup>, an increase of **84.8%** from 2010-11.<sup>9</sup>
- In 2015-2016, Medicare Benefits Scheme-subsidised palliative medicine specialist services were estimated at **\$5.6 million**, an increase of nearly **60%** over the previous five years.<sup>10</sup>
- In 2014-15, there were **65,000** palliative care-related hospitalisations, an increase of **19.2%** since 2010-11.<sup>11</sup>
- It is anticipated that by 2066 around **25%** of the population will be **over 65**. 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>12</sup>.
- Australia has one of the highest rates of institutionalised death in the developed world, with **80%** of people dying in hospital or residential aged care facilities<sup>13</sup>.

<sup>5</sup> The Economist Intelligence Unit, 2015

<sup>6</sup> Urbis, 2016

<sup>7</sup> Australian Institute of Health and Welfare, 2016a

<sup>8</sup> Australian Institute of Health and Welfare, 2017

<sup>9</sup> Australian Institute of Health and Welfare, 2012

<sup>10</sup> Australian Institute of Health and Welfare, 2016b

<sup>11</sup> Ibid

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

<sup>13</sup> Broad et al, 2013, quoted in Ibid

In the community, palliative care is provided by a range of practitioners, including general practitioners, community nurses, aged and social care workers, and allied health professionals (including physiotherapists, pharmacists, occupational therapists, speech pathologists, dieticians, social workers and psychologists).

While all Australians are entitled to effective and appropriate palliative care, evidence suggests there continues to be unmet need among some segments of the community.<sup>14</sup> This may include Aboriginal and Torres Strait Islander people; people from culturally and linguistically diverse backgrounds; people who identify as lesbian, gay, bisexual, transgender, or intersex; people living with a disability; people experiencing homelessness; people in incarceration; children and young people; people with cognitive impairment (including dementia); and people living in rural and remote areas. There is a need for further research to understand the access and uptake barriers for under-served populations, and to develop new and flexible models of service delivery to tailor services to individuals' needs.

## **An updated National Palliative Care Strategy**

The first National Palliative Care Strategy was endorsed in October 2000 by the Australian Health Ministers' Advisory Council. The first National Strategy represented the combined commitments of the Commonwealth, state and territory governments, palliative care service providers and community-based organisations to the development and implementation of the highest standard of palliative care services and policies.

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 2013 the Australian Commission on Safety and Quality in Health Care undertook scoping and consultation work "in an effort to understand the complexity of issues and barriers affecting the delivery of safe and high-quality end-of-life care in acute facilities".<sup>15</sup> In the resulting background paper, *Safety and Quality of End-of-life Care in Acute Hospitals*, the Commission emphasised the need for a national consensus statement to articulate the standard of end-of-life care that patients, carers and families should expect in acute hospitals. While the subsequent 2015 *National Consensus Statement on End-of-life Care* has been developed for the acute care setting, the elements of the Consensus Statement are applicable to a range of settings in which palliative and end-of-life care might be provided.

Concurrently, most jurisdictions have either updated or produced new policy frameworks for palliative and end-of-life care. Since the previous National Strategy was released in 2010, there has been ongoing discussion regarding the language used to refer to care at the end of life. This National Strategy has maintained the term 'palliative care' but notes that there is not a national consensus regarding terminology and that there is overlap between concepts of palliative and end-of-life care.

Also since 2010, significant change has taken place in related service sectors such as aged care, chronic disease, and disability, as well as an increasing recognition of the need for services to be person-centred. This update of the National Strategy has sought to align with strategic frameworks in the primary, community and aged care sectors, and other components of the health system.

## **The development of this updated National Strategy**

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>16</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 an implementation plan and a monitoring and evaluation framework.

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<sup>14</sup> Senate Community Affairs Committee, 2012

<sup>15</sup> Australian Commission on Safety and Quality in Health Care, 2013, Page 2

<sup>16</sup> Urbis, 2016, Page i

This draft National Strategy reflects an update of the 2010 National Strategy, rather than an entirely new document. Evaluation participants considered that the goals within the 2010 National Strategy remained appropriate. Within this draft, the language of the goals has been revised to reflect areas of strategic focus underpinned by goal statements and priorities. These, in turn, will be supported by an implementation plan that will outline the intended outcomes, performance indicators, and accountability for monitoring and results. Finally, an evaluation framework will be developed to assist with future assessments of the National Strategy's impact, and to contribute to the evidence base for ongoing development and delivery of palliative care services nationally.

In preparing this update, a period of desktop research was undertaken and over 50 stakeholders were interviewed, followed by the current period of public consultation which includes an online submission process as well as workshops in every capital city.

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## Guiding principles

The following six principles are considered to be fundamental to the provision of high-quality palliative care services, and should be demonstrated in all service improvement, policy and research development activities. These principles are reflected in all the Strategic Focus areas of this National Strategy.



### Palliative care is person-centred care

The delivery of palliative care should be respectful of, and responsive to, the needs, preferences and values of the person receiving care and their families and carers. Individuals and their families and carers should be included in decision-making regarding service provision. The individual should be at the heart of planning and delivery of services at every level. Over time, this should include the ability for service funding to 'follow the individual', increasing their choice in determining where and how they receive care.



### Death is a part of life

Palliative care services are delivered in a larger social context. Individuals and families may have 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. Early and documented planning with formal and informal care providers can ensure that individuals, carers and families are supported physically, emotionally, culturally, and spiritually.



### Carers are both providers and recipients of care

Carers have a unique role in supporting someone at the end of their life. The importance of their role should be acknowledged and respected and their health and wellbeing needs considered as a component of holistic palliative care, including bereavement support.

The role that caring communities may play in a person's life and decision making is also important, as care at the end of life will include recognition of all aspects of an individual's life, including social, cultural, spiritual and family networks and relationships.



### Care should be equitable

All Australians should be able to access quality palliative care. There are population groups that are currently underserved, 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 homeless
- living in rural and remote areas.

Services need to be flexible and responsive to ensure that care is accessible and appropriate.



## **Services should be integrated across the wider service system**

Palliative care may be required in a wide range of settings across the health, social services and community sectors. Building interactions and integration across sectors should assist in ensuring that Australians have access to the right level of palliative care when they need it, and that transition across care settings does not interrupt the provision of appropriate care. This should include addressing any barriers due to structural funding mechanisms across primary, community-based and tertiary care settings.

Specialist palliative care has a unique contribution to make within the health sector, and specialists can assist by providing education, advice and support to other health professionals where full specialist care is not required but a palliative approach would be beneficial.



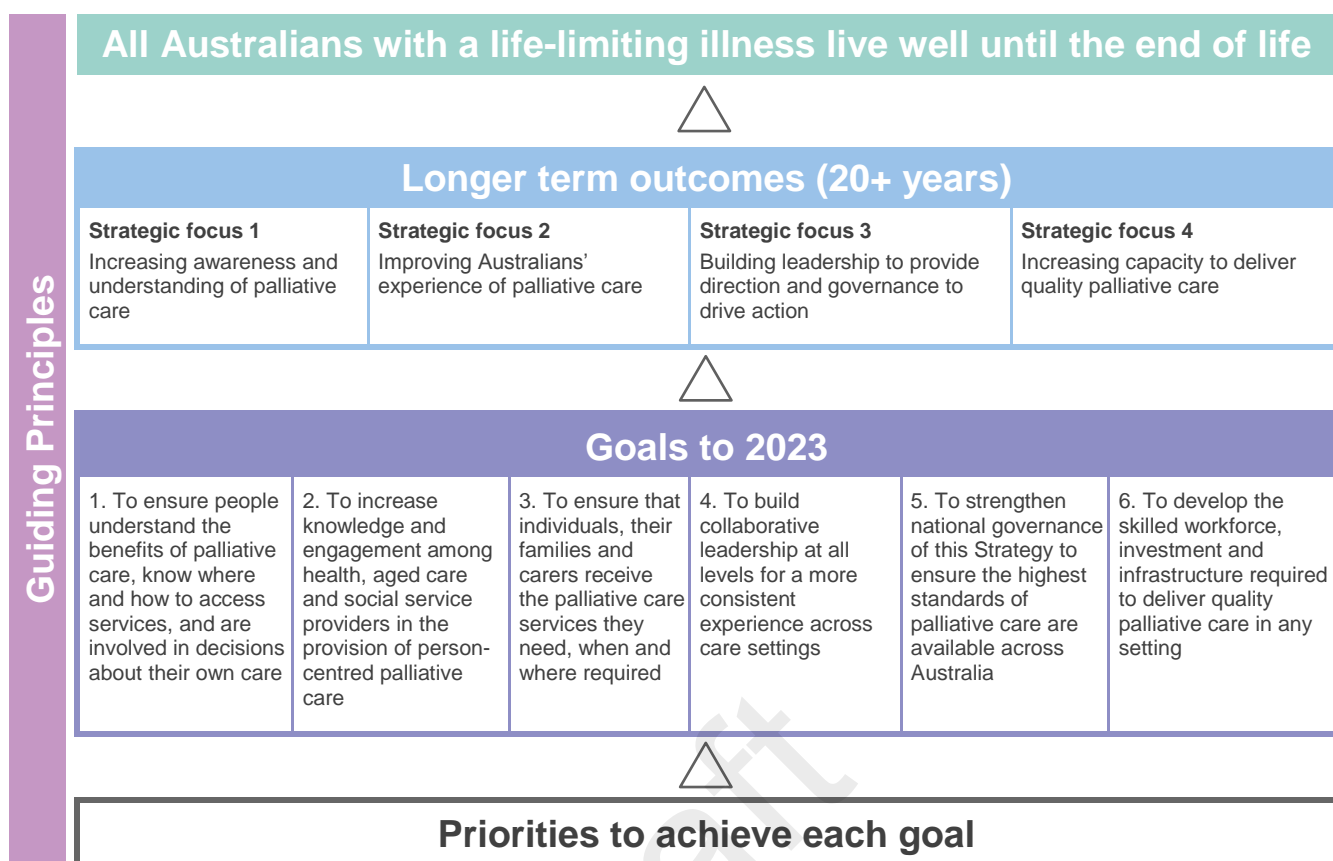
## **Care should be high quality and evidence-based**

There is a need for continued investment in research and knowledge sharing to provide an evidence base to drive the delivery and continuous improvement of quality palliative care, with service delivery demonstrably grounded in the evidence. Greater sharing of knowledge and experience across health sectors and care settings will expand the potential for high quality care to be provided across a range of settings.

There is a need for greater focus on the design and collection of meaningful data to provide a more complete picture of the provision of palliative care across jurisdictions, and greater consistency of service across the country.

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# Structure of the National Strategy



The implementation of the National Strategy will be guided by an Implementation Plan, to be developed once the goals and priorities of the updated National Strategy have been agreed. The Plan will identify the stakeholders involved as well as the timing and accountability for activities.

A Monitoring and Evaluation Plan will also be developed that will identify how the National Strategy's progress will be measured and reported.

A process of consultation will be undertaken with jurisdictions and other stakeholders with key responsibilities for the provision and development of palliative care services, to inform the framework for implementation, monitoring and evaluation of the National Strategy.



# Strategic focus – increasing awareness and understanding of palliative care

Goal 1 – To ensure 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?

*“The quality of care provided to people at the end of life is one of the key indicators of the values of a community.”<sup>17</sup>*

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. 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; gatherings such as [the Compassionate Communities Network](#), the [Dying to Talk](#) project, the [GroundSwell Project](#), and [Death Cafes](#) provide opportunities for people to discuss death and its meaning, and to express what is of value to them.

The first goal of the National Strategy is about the public – all of us – because the experience of dying will affect all of us. Raising awareness and helping people understand the importance of palliative care will create more opportunities for people to talk about their wishes for their own end of life, and this in turn should help individuals, their families and carers to seek and find the support required to live well till the end of life.

Acknowledging the importance of the end of life will also help communities to advocate for accessible, high quality palliative care from specialist and generalist health services, aged care and social services. Raising awareness of palliative and end-of-life care will also raise awareness of the needs of those who care for those who are dying, and those who are bereaved.

## Priorities

- Promote, contribute to and support community-level discussions about death and dying and end-of-life care preferences
- Undertake a targeted series of information and marketing campaigns to promote the benefits of palliative care, build capacity within the community and highlight the needs of individuals and families at the end of life
- Develop and implement surveys to monitor levels of palliative care literacy and understanding within the Australian public
- Improve data collection on the uptake and consistency of use of advance care plans and advance care directives, including analysis on where and how these are being developed and used

*[Please note: the Implementation Plan, to be developed once the National Strategy and its priorities are agreed, will outline the indicators, data sources, timeline and responsibility for achieving the priorities identified here.]*

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<sup>17</sup> Queensland Government, 2015, Page iv

## Goal 2 – To increase knowledge and engagement among health, aged care and social service providers in the provision of person-centred palliative care

### Why is this important?

*“Clinicians have a responsibility to initiate and facilitate honest discussions with patients earlier in their illness trajectory and to assist them to make decisions about how they want to live for the rest of their lives.”<sup>18</sup>*

People die in a range of care settings, from home to hospital, and from residential aged care facilities to hospices. At all stages of the illness trajectory, and in all settings, specialist palliative care or a palliative approach may be required to maintain an individual’s comfort and quality of life.

Specialist palliative care providers have an essential role both in providing evidence-based palliative care and in advising other health providers in a palliative approach to care. At the same time, not everyone will have complex needs requiring specialist palliative care and there is significant potential to increase the capacity for other health professionals in the primary, community and acute settings, to take a palliative approach to providing symptom management.

There is a great need for increased knowledge of palliative care among people providing care and support to those at the end of their life, including the ability to recognise when an individual is ready to discuss and make choices about palliative care. Service providers in all settings also need to be able to recognise clinical deterioration and dying, and be able to provide or access services that will keep people living as well as they can for as long as they can. The more that service providers can initiate these conversations and facilitate end-of-life care planning, the easier it will be for individuals and their families and carers to make the choices that are right for them.

### Priorities

- Ensure that compulsory palliative care education is included in undergraduate and post-graduate medical, nursing and allied health curricula and in vocational training programs
- Provide palliative care education and training, including communication skills as a core competence, as part of professional development in all health services including general practice, primary and community-based services, hospitals, residential aged care facilities, and other environments where service providers may be called upon for a palliative approach to care
- Increase the number of clinical and non-clinical service providers who are skilled in assisting individuals and their families and carers to have discussions on end-of-life care including the development of advance care plans
- Promote training and educational resources to broaden the understanding of palliative care for service providers with respect to the needs of people from different ethnic, cultural and faith traditions
- Promote understanding among health professionals of the benefits of early referral to palliative care for all people with life-limiting conditions, including complex, chronic illnesses as well as cancer
- Increase the use of validated screening and assessment tools across all settings, including assessment of carer and family needs

*[Please note: the Implementation Plan, to be developed once the National Strategy and its priorities are agreed, will outline the indicators, data sources, timeline and responsibility for achieving the priorities identified here.]*

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<sup>18</sup> Government of Western Australia, 2016, Page 10



# Strategic focus – improving Australians' experience of palliative care

Goal 3 – To ensure that individuals, their families and carers receive the palliative care services they need, when and where required

## Why is this important?

*"Integrated care is seamless care. It enables patients, carers and families to be central to their own care planning and to receive the right care, in the right places, at the right times."*<sup>19</sup>

At the heart of palliative care is the goal of ensuring that people may live as well as possible for as long as possible. 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. All states and territories have structures in place to provide palliative care in a range of settings, including the home.

At the same time, barriers remain to ensuring that all Australians have access to palliative care services. These include the limited number of specialist palliative care services; concentration of specialist services within metropolitan areas; lack of specialist and trained generalist providers; siloed funding mechanisms; and cultural or language barriers for some population groups.

Illness trajectories will differ widely depending on diagnosis. Children and young people may have a long engagement with palliative care services and need varying levels of assistance during that time. Likewise, people who are frail and aged, including those with dementia, may not require specialist palliative care until the very end of life, if at all, but may benefit from a palliative approach to care. Improving the use of care pathways, including pathways for transitions between settings and in the course of the dying process, will assist people to receive more coordinated and integrated care tailored to their needs, and reduce unnecessary transfers between care settings.

Primary Health Networks and local hospital or health networks as well as Aboriginal 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.

Individuals, their carers and families require access to services – primary, community-based, and specialist – that are flexible and comprehensive to respond to changing needs over time. It is also essential that individuals, their carers and families are engaged in discussions about their care preferences early on in their illness, and that advance care plans or other mechanisms are in place to communicate an individual's preferences regarding their care.

## Priorities

- Embed a patient-centred approach to all palliative care planning so that individuals, carers and families are involved in care planning and ongoing needs assessment
- Improve access to palliative care services through greater integration with existing services for specific population groups, such as MyAgedCare and the National Disability Insurance Scheme
- Conduct research to establish a baseline and monitor unmet need for population groups where palliative care access and uptake is known to be low, including Aboriginal and Torres Strait Islander people; people who identify as lesbian, gay, bisexual, transgender or intersex; people experiencing homelessness; people living in rural and remote areas; and people who are incarcerated
- Promote the use of existing Medicare Benefit Schedule item numbers that can be used for palliative care planning and coordination

*[Please note: the Implementation Plan, to be developed once the National Strategy and its priorities are agreed, will outline the indicators, data sources, timeline and responsibility for achieving the priorities identified here.]*

<sup>19</sup> NSW Agency for Clinical Innovation, 2017, Page 9



## Strategic focus – building leadership to provide direction and governance to drive action

Goal 4 – To build collaborative leadership at all levels for a more consistent experience across care settings

### Why is this important?

*“For many organisations, significant cultural change will be necessary to develop successful and sustainable systems for delivering safe and high-quality end-of-life care, and to effect improvements in the experiences of patients, families and carers. To achieve this, a systematic approach and committed leadership are necessary.”<sup>20</sup>*

Many people living with life-limiting illness will move between a variety of care settings as they approach the end of life. Increasingly, services recognise the benefits for individuals and families in remaining at home as much as possible. This is particularly true for children and young people with a life-limiting condition who may have contact with a palliative care service for many years. In many parts of Australia, local networks have been established between primary and tertiary health providers, home care providers, palliative care specialists, residential aged care facilities, volunteers and other community-based providers to assist people to receive care in their place of choice and to ensure consistency of care when transferring between care settings.

Strengthening the level of information sharing and collaboration at local levels should assist in improving transitions of care, including enhancing care pathways and shared care arrangements. At all levels, including 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 underserved population groups previously identified in this National Strategy.

The National Palliative Care Projects and Palliative Care Australia have an important role to play in sharing innovation and excellence as well as strengthening the evidence base for new treatments and approaches. In addition, greater collaboration between general practice and state/territory health services may reduce duplication of effort and assist in providing greater consistency of service experience. Greater information sharing across jurisdictions should also help to increase consistency of services for people who may move to different states or regions. Strengthening existing networks for information sharing should be linked to the governance of the National Strategy (Goal 5) to ensure that, nationally, services can learn from each other regarding the best ways to address barriers to access and to improve the quality of care.

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, including people living in residential aged care facilities, people with disability, and people living with chronic disease. Improving coordination and information sharing with other sectors will help to improve the consistency of experience of palliative care for people across Australia.

### Priorities

- Strengthen information transfer between national, state/territory, and local networks to drive collaboration
- Promote action at local and regional levels to ensure that all health and social care provider organisations, including residential aged care facilities and home care providers, are aware of local options for palliative care and understand the benefit of early referral to palliative care services
- Invest in joint initiatives that improve the consistency of service experience across jurisdictions

*[Please note: the Implementation Plan, to be developed once the National Strategy and its priorities are agreed, will outline the indicators, data sources, timeline and responsibility for achieving the priorities identified here.]*

<sup>20</sup> Australian Commission on Safety and Quality in Health Care, 2015, Page 22

## Goal 5 – To strengthen national governance of this Strategy to ensure the highest standards of palliative care are available across Australia

### Why is this important?

*“The committee considers that some flexibility needs to be retained as to how each state and territory allocates its funding [for palliative care] given their differences in terms of geographic size, dispersion, population, and demographics. However, the committee regards accountability as critical and calls on the government to ensure sufficient governance structures are in place”<sup>21</sup>*

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. This National Strategy is intended to provide a shared direction and an authorising environment for the continual improvement of palliative care services in all states and territories. At the same time, the absence of formal governance and accountability structures has been noted as a barrier to improving access as well as the quality and consistency of care provision across the country.

A formal national structure with links to the Australian Health Ministers’ Advisory Council will ensure that palliative and end-of-life care are recognised and resourced as integral components of the health system, while retaining the independence of states and territories to decide how best to invest in palliative care services. It will also provide a structural mechanism to support information sharing between the Commonwealth (which funds general practice and aged care services) and states/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. Embedding palliative care further within the national governance structures of the health system will facilitate the effective integration of specialist palliative care and a palliative approach to 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.

### Priorities

- Establish and maintain a national governance structure with a formal link to the Australian Health Ministers’ Advisory Council
- Provide oversight for the implementation and monitoring of this National Strategy
- Strengthen existing mechanisms for enhancing collaboration and knowledge transfer across the sector
- Establish data collection mechanisms to enable linked, nationally consistent monitoring of access to and uptake of palliative care services
- Strengthen the inclusion of palliative care standards in accreditation of primary and acute settings, residential aged care facilities, home care services and hospices

*[Please note: the Implementation Plan, to be developed once the Strategy and its priorities are agreed, will outline the indicators, data sources, timeline and responsibility for achieving the priorities identified here.]*

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<sup>21</sup> Senate Community Affairs Committee, 2012





## Strategic focus – increasing capacity to deliver quality palliative care

Goal 6 – To develop the skilled workforce, investment and infrastructure required to deliver quality palliative care in any setting

### Why is this important?

*“Current end of life and palliative care models are unsustainable and will not meet future demand without significant redesign.”<sup>22</sup>*

The need for palliative care will continue to increase as the Australian population ages and people live longer with chronic disease and disability. Current models for palliative care services 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. In addition, an ageing workforce and shortages of medical and nursing staff trained in palliative care is placing increased pressure on services to meet rising demand. Investment is needed into community-based models that are flexible to accommodate increased demand and public expectations.

As a result, innovation is required to develop new, efficient models for service delivery to meet the needs of all Australians living with life-limiting illness. This will require increased investment in workforce development and training, as well as an increase in resources and infrastructure for both home-based and in-patient care provision. Further service design is required to identify and mitigate the critical incidents which lead to inappropriate or unnecessary emergency department presentations at the end of life. This includes recognition of the range of care settings and the development of flexible service models appropriate for greater in-home and community-based care.

Goal 6 is closely linked to Goal 2 (to increase knowledge and engagement among health, aged care and social service providers). There will be an increasing need for both specialist and non-specialist palliative care providers in all care settings and hence an increased need for developing new ways of making the most efficient use of resources. Recognising the constraints of current service models in the face of rising demand also includes recognition of the potential for well-trained, non-clinical roles in palliative care services, particularly in home-based palliative care. There is also great potential to work more closely with community organisations, volunteers and non-government service providers to build a holistic service approach that recognises the multi-faceted needs of people living with life-limiting illness. To realise these opportunities, investment will be required in infrastructure, service development and workforce planning and development.

### Priorities

- Develop new and innovative service delivery models which are able to deliver care flexibly according to the individual's needs and across service settings, including after hours
- Develop a national workforce development framework for palliative care, to include a competency framework suitable for all care settings
- Undertake service mapping to determine where gaps in service provision occur, and for whom, and develop responses to improve service accessibility

*[Please note: the Implementation Plan, to be developed once the Strategy and its priorities are agreed, will outline the indicators, data sources, timeline and responsibility for achieving the priorities identified here.]*

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<sup>22</sup> Department of Health and Human Services, 2016, Page 1

# Glossary of terms

**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>23</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>24</sup>

**Bereavement** – “refers to the event of death of a person with whom there has been an enduring relationship.”<sup>25</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>26</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>27</sup>

**Carers** – “people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.”<sup>28</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>29</sup>

**End-of-life care** – “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>30</sup>

**Grief** – “is how bereavement affects us personally, with effects across several domains – emotional, cognitive, social, physical, financial and spiritual.”<sup>31</sup>

**Integrated care** – “Integration is a coherent set of methods and models on the funding, administrative, organizational, 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>32</sup>

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<sup>23</sup> Australian Health Ministers’ Advisory Council, 2011, Page 9

<sup>24</sup> Australian Health Ministers’ Advisory Council, 2011, Page 10

<sup>25</sup> CareSearch, 2017

<sup>26</sup> National Strategic Framework for Chronic Conditions 2017

<sup>27</sup> Ethnic Communities’ Council of Victoria, 2012, Page 1

<sup>28</sup> Carers Australia, 2017

<sup>29</sup> Australian Commission on Safety and Quality in Health Care, 2015., Page 33

<sup>30</sup> Australian Commission on Safety and Quality in Health Care 2015, page 33

<sup>31</sup> CareSearch, 2017

<sup>32</sup> World Health Organization 2016, page 3

**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>33</sup>

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

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”<sup>34</sup>

**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>35</sup>

**Palliative approach** – “A palliative approach is an approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the holistic needs of patients and caregiver/s that is reflected in assessment and in the primary treatment of pain and in the provision physical, psychological, social and spiritual care.”<sup>36</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>37</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>38</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 nonspecialist clinicians who are providing palliative care.”<sup>39</sup>

**Terminal** – “the stage of an illness when death is likely within days.”<sup>40</sup>

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<sup>33</sup> Department of Health and Human Services, 2016, Page 29

<sup>34</sup> World Health Organization, 2017

<sup>35</sup> World Health Organization, 2017

<sup>36</sup> Palliative Care Australia, 2005, page 11

<sup>37</sup> Australian Government, n.d

<sup>38</sup> Australian Government, 2017

<sup>39</sup> Australian Commission on Safety and Quality in Health Care 2015, page 35

<sup>40</sup> Australian Institute of Health and Welfare, n.d.

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Draft



## How will this National Strategy be implemented?

*An Implementation Plan will be developed following the public consultation of the draft National Strategy, and the final approval of the document. This Plan will include actions to address the priorities, responsibilities, and progress and outcome indicators.*

Draft



## Monitoring and evaluation plan

*A Monitoring and Evaluation Plan will be developed following the public consultation of the draft National Strategy, and the final approval of the document. This Plan will identify key outcomes to assess the achievements of the Strategy, as well as the evaluation questions, performance indicators, data sources, and timeframes for data collection and analysis.*

Draft



Urbis' Public Policy team has received ISO 20252 Certification for the provision of Social Policy Research and Evaluation

*All information supplied to Urbis in order to conduct this research has been treated in the strictest confidence. It shall only be used in this context and shall not be made available to third parties without client authorisation. Confidential information has been stored securely and data provided by respondents, as well as their identity, has been treated in the strictest confidence and all assurance given to respondents have been and shall be fulfilled. (Template Version 2017.1.0)*



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