

# Supporting Australians to Live Well at the End of Life

Draft National Palliative Care Strategy 2010

Prepared for  
Department of Health and Ageing

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## Table of Contents

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Introduction .....	3
The Strategy .....	8
Awareness and Understanding.....	12
Appropriateness and Effectiveness .....	13
Leadership and Governance .....	15
Capacity and Capability .....	16
Bibliography .....	18

## Introduction

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### Introduction

The pattern of life, disease, dying and death has changed dramatically in Australia over the last several decades. The mean age of death in Australia in 1907 was 41. In 2000, it was 73, and six years later, it was 74. In 1900 in Australia 45,306 people died. In 2000, this number had increased to 128,291, and in 2006, there were 133,739 deaths<sup>1</sup>.

The increased number of deaths is not merely the result of an increase in population as the age-specific mortality rate per 100,000 has fallen dramatically over the same time from 1085 in 1907, to 644 in 2005.

Increased life expectancy has brought with it much higher rates of chronic disease. Many people carry non life-threatening chronic conditions such as arthritis, hearing and vision loss, and mental illness with them into their final years. These conditions don't threaten life expectancy, but can significantly affect a person's well being and health care needs.

More serious life limiting chronic diseases such as dementia, cardiovascular and respiratory diseases, and cancers are also on the rise and have changed the pattern of death.

Most healthy Australians, when asked where they would prefer to die, nominate their home as their preference. However, the statistics on place of death indicate that this is relatively uncommon — only 16% of people die at home. Twenty per cent of people die in hospices and 10% in nursing homes. The rest die in hospitals<sup>2</sup>. This results in a high cost burden for the health system<sup>3,4</sup> and potentially a poorer quality of death<sup>5</sup>.

Of the 130,000 people who die annually in Australia, the proportion whose death is anticipated is variously reported between 25 and 50%<sup>6</sup>. That means the remainder are people with potential palliative care needs. Not all people approaching the end of life need specialist palliative care. The provision of appropriate, high quality care for people at end of life occurs every day across Australia through a palliative approach. However, there is evidence of unmet need of those with complex needs, those from defined population groups and those with specific conditions<sup>7</sup>. There exists the opportunity to improve approaches to ensure all Australians receive quality needs based care at the end of their life.

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<sup>1</sup> Australian Institute of Health and Welfare (AIHW) 2008. GRIM (General Record of Incidence of Mortality) Books. AIHW: Canberra.

<sup>2</sup> CareSearch Preferred Place of Death accessed 14 April 2010 [www.caresearch.com.au](http://www.caresearch.com.au)

<sup>3</sup> Kardamanidis K, Da Cunha C, Taylor L, Jorm L. Hospital costs of older people in New South Wales in the last year of life. MJA 2007; 187 (7): 383-386

<sup>4</sup> Lynn J, Adamson D. 2003 Living well at the end of life. RAND Health White paper.

<sup>5</sup> Finlay I, Higginson I, Goodwin D, Ann Oncol. Palliative care in hospital, hospice, at home: results from a systematic review. 2002;13 Suppl 4:257-64. PCA DYING WELL Palliative Care Australia submission outlining ideas and priorities for the 2010-11 Federal Budget

<sup>6</sup> Palliative Care Australia. 2005 A Guide to Palliative Care Service Development: A population based approach.

<sup>7</sup> This may include Aboriginal and Torres Strait Islander People, people from culturally and linguistically diverse backgrounds, people living in rural and remote locations, people who are socially or financially disadvantaged, veterans and their spouses, people living on their own, people in the justice system, children and adolescents, people with mental health issues and people with disabilities.

## Introduction, Continued

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### **Palliative Care Services in Australia**

Palliative care services have had a long history in meeting the needs of those approaching the end of their life. The 1960's saw the beginnings of 'modern' palliative care services. Over the last 20 years in Australia the specialisation of palliative care has advanced considerably. Palliative care is provided in almost all settings where health care is provided including neonatal units, paediatric services, acute hospitals, general practices, residential and community aged care services, and generalist community services.

Specialist palliative care services operate from a variety of settings including specialist inpatient consulting services, specialist inpatient settings, hospices and community based specialist services. With the advent of improved specialisation has come the willingness of generalist providers to want to 'hand over' the responsibility of palliative care for their clients to specialist providers. However like few other areas in health care, palliative care is both a phase of care and a specialty service.

Specialist palliative care services have a vital role in providing specialist clinical advice – particularly for those with complex symptoms requiring palliation, as well as the provision of direct care for a small number of overall patients and more broadly the provision of capacity building and support services to the broader health and human services sectors.

Palliative care is also an intrinsic part of all health and human services in their overall responsibilities in providing comprehensive care to their clients. Integration and collaboration with specialist palliative care services can then ensure capacity building and enhanced quality of care.

It will be important in the life of this Strategy to ensure that both these aspects of palliative care continue to be strengthened.

Most palliative care services have developed in parallel with oncology services to meet the needs of cancer clients in complex symptom management at the end of their lives. With the increasing number of clients with a range of complex disease patterns and an increase in the number of cancer clients, new approaches to care and service models are required. The trajectory of various disease types is depicted in Diagram 1. Unlike cancer clients who experience considerable decline in a short period of time prior to death and where the need for palliative care services may be more obvious, chronic clients have a much longer disease trajectory with difficult prognostication. The need for palliative care may not be obvious and may involve multiple, shorter encounters.

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## Introduction, Continued

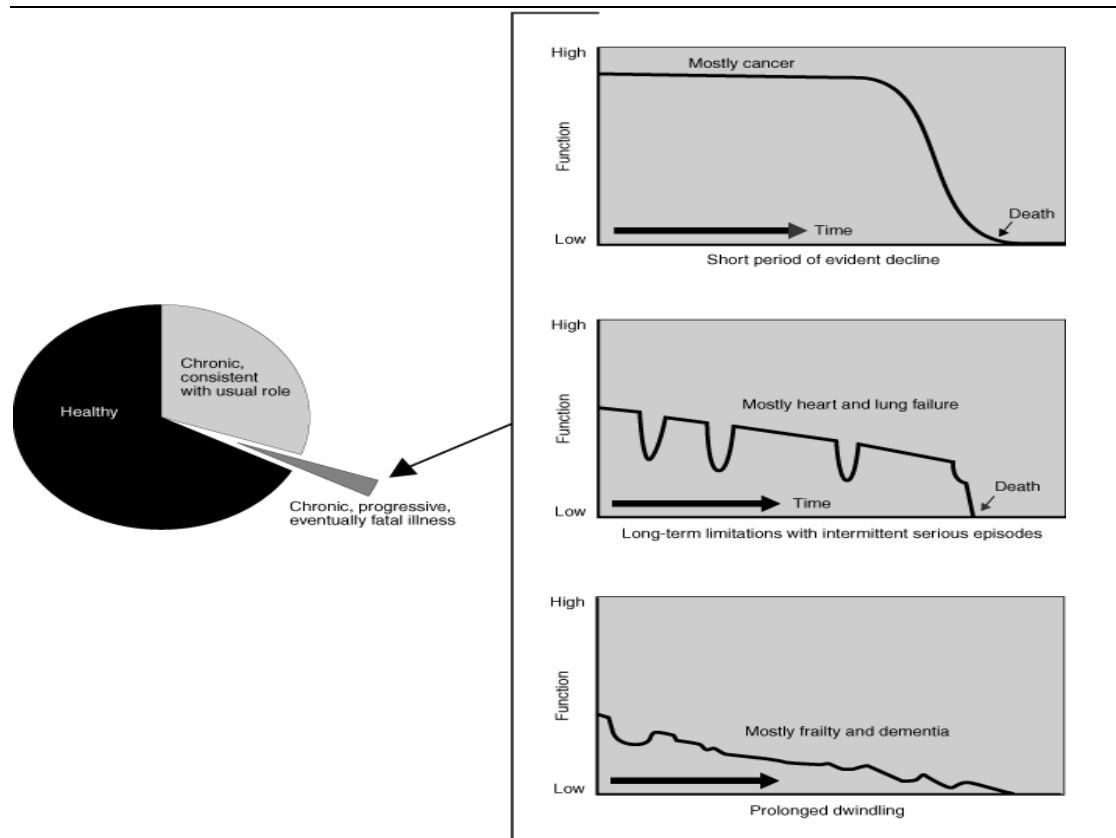


Diagram 1:

### The disease trajectory of chronic illness<sup>8</sup>

#### Scope of Palliative Care

The scope and definition of palliative care is by its very nature broad and problematic. Defining palliative care has become confused with trying to specifically define the scope of palliative care services. This confusion arises when trying to differentiate between the services provided by generalist health professionals, specialist services and the needs of people approaching the end of their life.

The term 'end of life care' has started to be used by several organisations and jurisdictions as an overarching term<sup>9</sup>. Others use the term 'end of life' to refer to the last days of life, whilst a third term 'terminal care' is used by some to attempt to specifically identify the care needs in the last days of life.

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<sup>8</sup> Lynn J, Adamson D. 2003 Living well at the end of life. RAND Health White paper.

<sup>9</sup> Palliative Care Australia, United Kingdom NHS

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## Introduction, Continued

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### Scope of Palliative Care (continued)

During the consultations in the development of this document views regarding terminology were canvassed with little consensus being reached. Stakeholders have fairly firm views of the differences of these terms depending on their personal perspectives.

Palliative care is defined by the World Health Organisation<sup>10</sup> as:

*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 patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counseling, 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.*

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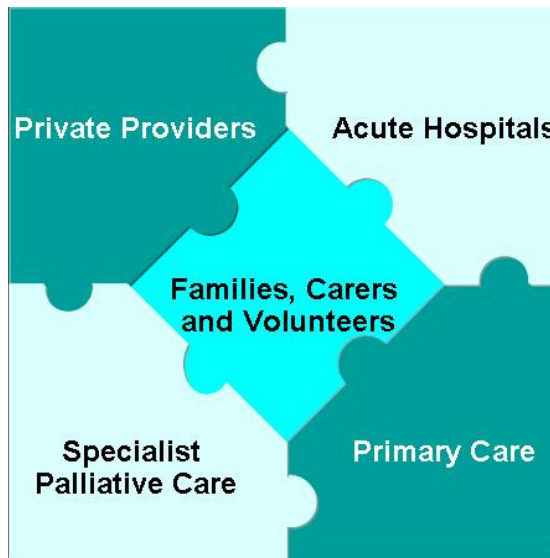
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<sup>10</sup> <http://www.who.int/cancer/palliative/definition/en/>

## Introduction, Continued

### Scope of Palliative Care Service System

Within Australia palliative care is provided across the health and human services spectrum by: public hospitals, private hospitals, general practitioners, justice health services, disability services and specialist palliative care services – public and private, in both inpatient and community based settings as depicted in Diagram 2.



**Diagram 2: The Palliative Care Service Picture**

Given the issues with the defining the scope of palliative care, the term palliative care when used in this document is intended in its broadest sense to encapsulate both specialist and generalist care. The term end of life is used to indicate issues broader than care needs and services.

Whilst there is a National Palliative Care Program that supports national approaches, most palliative care service provision occurs within the remit of the State and Territory health systems. Each State and Territory has an articulated approach to palliative care in their jurisdiction. This Strategy then must enhance and build on the work occurring at the jurisdictional level, not duplicate or contradict it.

## The Strategy

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### **The National Palliative Care Strategy**

The development of the National Palliative Care Strategy (NPCS) commenced in 1998 and was endorsed in October 2000 by Australian Health Ministers Advisory Council. The NPCS represents the combined commitments of the Commonwealth, State and Territory Governments, palliative care service providers and community-based organisations to the development and implementation of palliative care policies, strategies and services that are consistent across Australia.

The NPCS (2000) is a stand-alone document which set objectives and strategies intended to inform policy and service development across Australia, and guide States and Territories in their planning for the development of palliative care services and in supporting patient care agencies in this development.

It was also intended to provide the framework for the Commonwealth, States and Territories to work together cooperatively and collaboratively in ensuring that resource allocation occurred in concert with the development of palliative care services, and that palliative care policy, planning and service delivery would be directed towards common and agreed goals.<sup>11</sup>

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### **The Impact of the Strategy**

The National Palliative Care Strategy *Activity Implementation Report (2005)*, subsequent literature scan and stakeholder consultation undertaken as part of the development of this Updated National Palliative Care Strategy, clearly demonstrates there has been a wealth of important activity which has occurred at all levels around the development of palliative care services (see Phase 1 Report for more detail).

The NPCS 2000 has been key in advancing the sector's capacity through:

- increased understanding of palliative care in the health sector
- providing a focal point for State and Territory activities
- providing the overall direction for the National Palliative Care Program.

Ten years on, whilst much has happened and there are demonstrable achievements, some gaps and deficiencies still remain in the provision of high quality palliative care service provision to all Australians, when and where they need it.

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<sup>11</sup> National Palliative Care Strategy, 2000, Commonwealth Department of Health and Aged Care

## The Strategy, Continued

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### The Updated National Palliative Care Strategy

The National Palliative Care Strategy - Supporting Australians to Live Well at the End of Life has been developed following extensive consultation and research. Eight workshops were held across Australia in March 2010 and an extensive on line survey was undertaken by 320 people. This provided a significant amount of data on the views of various stakeholders on the directions, priorities and potential strategies for inclusion in this update.

The scope of the Updated National Palliative Care Strategy 2010 is broad, addressing both palliative care provided in all specialist and general settings as well as end of life issues.

This update arose at a time of far reaching health care reform in Australia. In some regards, the future shape of palliative care service provision is unknown. What is clear is that the demand for high quality palliative care across Australia will increase, and that to meet this demand all parts of the health and human services sector will need to focus on the following four goal areas:

- Awareness and Understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability.

Each of these goal areas are further defined in this Strategy with goal statements, objectives and action areas. Note that there is a high degree of interrelatedness of these goals and, as such, some strategies could sit under more than one goal. Some suggested measures of success are listed for each goal area. These measures will require refinement and translation into measurable performance indicators. They are not intended to be comprehensive but rather indicative of overall improvements in the delivery of quality palliative care to all Australians who need it.

The Consultation Report produced as part of the update of the Strategy contains many useful suggestions regarding specific approaches to the action areas listed in the Strategy. It is recommended that this document be reviewed in the planning of specific work areas.

The need for palliative care and the diversity of service settings across Australia is enormous. It is not possible for a national strategy to highlight or address all areas. This Strategy aims to focus on those improvements that will give the most sustained benefit. That does not mean that other activity that is occurring is neither important nor useful.

The clear message of demand emerging from the stakeholder consultation process in the development of this strategy is that Australians want a system that *supports Australians to live well at the end of life*.

Progressing the action areas identified in this Strategy will ensure Australia continues to be a world leader in the provision of first class palliative care services.

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## Overview of Goal Areas

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### Goal Areas

Four goal areas have been identified for the National Palliative Care Strategy 2010, namely:

- Awareness and Understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability.

This section provides a brief overview of the context for each goal areas and a table of the specific goals for each.

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### Awareness and Understanding

Access to any service is predicated on awareness of the need for, and the existence of, the service or services. There is a need to significantly enhance the understanding of dying, death, grief, bereavement and loss of the Australia population, including health professionals and carers, to enable better access to appropriate, timely services across the end of life continuum.

Any approach to building awareness and understanding must be undertaken in a culturally respectful way. Death and dying is an extremely personal matter. For some cultures there are explicit norms around how these issues are approached. Given that one-quarter<sup>12</sup> of Australians come from a culturally and linguistically diverse background, awareness campaigns and services themselves must ensure they are culturally safe and appropriate.

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### Appropriateness and effectiveness

Appropriateness is about ensuring the right approach, in the most suitable setting in a timely manner. Appropriateness requires good systems and processes to support access to information and services. This is critical to the provision of high quality palliative care.

Effective care is also about providing those interventions which are supported by an evidence base and providing them effectively and efficiently.

Appropriate and effective care systems need to be supported by a strong research base and services that have good systems of quality control and cultures of quality improvement.

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### Leadership and Governance

The governance of any system is key to the improvement and implementation of strategy. This is particularly so given the diversity of the service system for palliative care. The investment of resources at the national, state and territory and local levels will be enhanced through stronger, more visible and accountable leadership and governance of national palliative care approaches.

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<sup>12</sup> Australian Bureau of Statistics 2009. A Picture Of The Nation: The Statistician's Report On The 2006 Census.

## Overview of Goal Areas, Continued

### Capacity and Capability

High quality palliative care requires adequate capacity and capability. In essence that means sufficient numbers of appropriately skilled people in the right place with adequate systems to support safe, quality care.

There has been significant investment in palliative care resources – training, facilities, workforce numbers, equipment and clinical resources. Building capacity and capability is not simple and requires more than just investment. It is important to recognise that capacity building initiatives often have long lead times. Any investment will need to be targeted, particularly with regards to education and training to ensure sustainable outcomes.

Action should be explored as a matter of urgency to mitigate the combined effects of workforce, shortages, ageing of the palliative care workforce and increasing demand.

### Goal Summary

The following table summarises the goals in each goal area. The following pages detail the action areas under each goal.

GOAL AREA	NUMBER	GOAL
Awareness and Understanding	Goal 1	To significantly improve the appreciation of dying and death as a normal part of the life continuum.
	Goal 2	To enhance community and professional awareness of the scope of, and benefits of timely access to, palliative care services.
Appropriateness and Effectiveness	Goal 3:	Appropriate and effective palliative care is available to all Australians based on need.
Leadership and Governance	Goal 4	To support the collaborative, proactive, effective governance of national palliative care resources and approaches.
Capacity and Capability	Goal 5	To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

**Table 1: National Palliative Care Strategy 2010 Goals**

## Awareness and Understanding

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### Goals

#### Goal 1:

To significantly improve the appreciation of dying and death as a normal part of the life continuum.

#### Goal 2:

To enhance community and professional awareness of the scope of, and benefits of timely access to, palliative care services.

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### Action Areas

Action will be undertaken to:

- Develop a comprehensive, evidence based, multi-modal and targeted national public awareness strategy to promote death as a normal part of living and the services and options available for people nearing the end of life.
  - Work with various parts of the health and human services sector to increase the visibility of end of life issues, palliative care and roles and responsibilities.
  - Provide mechanisms to ensure palliative care providers across the continuum are aware of, and provide, culturally appropriate palliative care and end of life support including care preferences, spiritual requirements and bereavement expression.
  - Support the national roll out of Advance Care Planning including addressing any barriers to uptake.
  - Continue to support the integration of palliative care training within all health undergraduate and relevant post-graduate curricula.
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### Measures of Success

Measures of success for this goal will be to identify:

- Changes in public awareness
  - Improvements in appropriate referral rates to palliative care
  - Improvements in palliative care training.
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## Appropriateness and Effectiveness

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### Goals

#### Goal 3:

Appropriate and effective palliative care is available to all Australians based on need.

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### Action Areas

Action will be undertaken to:

- Resolve definitional issues surrounding palliative care.
  - Support the evolution of appropriate models of palliative care service provision. This may include:
    - nurse led units of both home based and in-patient services where nursing care is the predominant need of a client and/or need for specialist medical services are limited
    - expansion of the role of Nurse Practitioners within palliative care
    - expansion of the palliative care special interest role for Aboriginal Health Workers
    - development of palliative care special interest workers (medical, nursing, allied health and volunteers) in all chronic disease services to act as central resource and collaborating agents between chronic care services, their clients and specialist palliative care. This will increase the capacity and self sufficiency of chronic care units to better meet the needs of their clients as they reach the end of their lives
    - evolution of models proven to be effective in meeting the needs of those clients with particular palliative care needs such as children and adolescents, people living at home, and people within the justice system.
  - Develop a national template for palliative care pathway with triggers for referral for specialist palliative care services. Specialist services for specific diseases (renal, motor neurone disease, Parkinson's disease, dementia, mental illness, disability) can then customise this template for their own setting.
  - Implement a national roll out of an end of life care pathway in all acute care settings.
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## Appropriateness and Effectiveness, Continued

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### Action Areas (continued)

- Incorporate specific references to palliative care and the end of life phase in all relevant national and state plans, frameworks and clinical guideline documents.
  - Develop a national bereavement care framework.
  - Continue to support a continuous quality improvement approach through the use of national standards and an appropriate review mechanism.
  - Develop an appropriate mechanism to review national outcome data from this process to drive further improvements across specialist palliative care services.
  - Work with national standards bodies to incorporate appropriate standards to reflect quality palliative approach based care and address other end of life issues.
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### Measures of Success

Measures of success will include:

- Outcome data and trends from relevant data collections
  - Adoption of palliative care specific standards by other standards and accreditation systems
  - An Australia-wide roll out of:
    - end of life care pathway
    - palliative care referral pathway
  - The development of a national bereavement care framework.
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## Leadership and Governance

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### Goals

#### Goal 4:

To support the collaborative, proactive, effective governance of national palliative care resources and approaches.

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### Action Areas

Action will be undertaken to:

- Strengthen the role of the Palliative Care Intergovernmental Forum (PCIF) by establishing a work plan and formal reporting responsibilities through to the Health Policy Priorities Principal Committee (HPPPC) a principal committee of the Australian Health Ministers Advisory Council (AHMAC).
  - Establish mechanisms for formal communication, engagement and linkages throughout the sector to address:
    - Research collaboration, funding, priorities and dissemination of outcomes
    - Clinical leadership
    - Consumer engagement
    - Leadership across all areas of health and human services for end of life issues
    - Implementation of this strategy including coordination between national program providers and priority setting and tracking of any project funding with a focus on consolidating outcomes from previous projects
    - National measurement of both palliative care service provision and quality, and the implementation and outcomes of this Strategy
    - Workforce
    - Palliative care in the health reform context.
- 

### Measures of Success

Measures of success for this goal will include:

- The inclusion of PCIF in formal reporting requirements to HPPPC
  - The implementation of a formalised communication and engagement mechanisms.
  - The development and attainment of a formal PCIF workplan.
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## Capacity and Capability

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### Goals

#### Goal 5:

To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

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### Action Areas

Action will be undertaken to:

- Identify and implement funding models that explicitly promote flexibility to meet the needs of the patient and their family. This may include:
    - Funding based on assessed need
    - Funded care packages, including rapid access / rapid response options
    - Fund holding by appropriate providers, including aged care services, to be able to navigate and source appropriate care regardless of location.
  - Explore new and enhanced roles for aged care providers in palliative care.
  - Undertake further research and ongoing monitoring of the relative cost of care and cost effectiveness of care models in the last year of life, particularly savings to be gained through appropriate hospital avoidance for clients approaching the end of their life
  - Undertake further work to identify, classify and cost specialist palliative care clients and their care.
  - Provide enhanced, coordinated support for carers, volunteers, communities of carers and carer respite. Continue to support carers through established networks, use of appropriate assessment tools and appropriate resource material and education.
  - Remove structural and funding barriers to coordinated, flexible local care delivery for people at the end of life regardless of where they live.
  - Further improve the skill and confidence of the generalist workforce to work with clients at the end of their life.
  - Enhance online palliative care support and resources through the development of 'communities of interest.
  - Promote the existence of online palliative care resources to all health and human service providers with links to service specific and disease specific websites.
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## Capacity and Capability, Continued

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### Action Areas (continued)

- Work with Health Workforce Australia to ensure adequate numbers of skilled palliative care specialist providers across all disciplines.
- Enhance and legitimise the role of specialist consultancy services to support generalist providers with direct clinical advice and education and training, advocate for end of life issues and provide training places
- Work with NeHTA and other relevant agencies to ensure that the capacity exists to record and track Advance Care Planning within electronic health records
- Work with the Community Services and Health Industry Skills Council to include end of life and palliative care competencies in all care worker training packages
- Work with private health insurers to develop sustainable models of quality palliative care in the private sector
- Continue to develop the role of the general practitioner in palliative care through supportive approaches including:
  - the development of those with a special interest
  - the development of practice nurse roles in palliative care
  - incorporation of Advance Care Planning in enhanced primary care planning and “over 45” medical checks
  - appropriate support for GPs who are providing an active role in a client’s palliative care, including providing telephone support and home visits
- Work to ensure appropriate and adequate capacity to manage the storage and release of the deceased body<sup>13</sup>.

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### Measures of Success

Measures of success for this goal will include:

- Improvements in the number of full time equivalents working in specialist palliative care services
  - Improvements in the number of people dying in their place of choice.
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<sup>13</sup> This is particularly required for certain cultural groups and settings. For example, there are significant issues in the Northern Territory wet season with the inability to undertake burials in some areas, and with the pressure on hospitals and aged care providers to free up beds.

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