

Palliative Care Services Plan

2013–2017



Foreword by Minister for Health

Palliative care is not often mentioned publicly and is generally treated as an 'out of sight - out of mind' aspect of our health system, however, it remains a significant and crucial part of medical treatment for a broad range of people in our community suffering from chronic or terminal medical conditions. Demand for palliative care will continue to increase as our population ages and we will need to respond to this to ensure that people receive the care and dignity they deserve at the end of their life. Palliative care plays such a key role in the health system and I am pleased to release the ACT Palliative Care Services Plan 2013-2017 to help direct the development and delivery of these services over the next five years.

It is easy to think that palliative care is only provided to the needs of the patient who has a chronic or terminal illness, but this is far from the truth. The family and friends of someone who is nearing the end of their life also require close assistance and support from the clinical professionals to better understand the issues facing their loved one and how best they are able to support their loved one. That is a key aspect of this plan.

This plan identifies six goals for the ongoing development of palliative care services in the ACT, along with associated strategies to work towards their achievement. In particular these goals relate to issues surrounding education and awareness of palliative care, access to services and continuity of care.

Wide ranging consultation was undertaken during the development of this strategy and involved palliative care service providers, non government organisations, consumers, carers, advocacy groups and clinicians. I would like to thank all those who commented on the draft plan as your feedback was critical in informing the coordinated and patient focused document we have today. Importantly consultation does not end here. Successful implementation will require ongoing dialogue between the government and all key stakeholders over the next five years to ensure it stays on tracks and delivers the end of life care results that Canberrans deserve and expect.

I would also like to acknowledge the contribution of the members of the ACT Palliative Care Services Plan Steering Committee who generously provided valuable time, expertise and guidance during the development of the plan.

The ACT Palliative Care Services Plan 2013-2017 provides a solid base to ensure that best practice care and treatment is provided to Canberrans in a respectful and dignified way.



Katy Gallagher MLA
Minister for Health

Overview

The ACT Palliative Care Services Plan 2013-2017 (the Plan) provides strategic direction for the development of palliative care in the ACT to best meet current and projected population needs. The Plan outlines the future directions and service requirements to 2017 for the palliative care services provided in the ACT and signals the need to develop greater capacity to respond to the needs of people and their families for end of life care in community settings.

The Plan represents the culmination of an extensive consultation process involving a broad range of stakeholders including palliative care services, consumers, community representatives, volunteer groups, peak bodies, service providers in the public and private sector, non-government organisations and researchers.

Accessing palliative care services

ACT Health provides palliative care services for the population of the ACT plus a tertiary inpatient service for parts of the surrounding Southern NSW Local Health District (SNSWLHD). Specialist palliative care services are provided from Clare Holland House (CHH), the Canberra Hospital (TCH), Calvary Hospital (CH), the Home Based Palliative Care (HBPC) team and Palliative Care ACT which trains and supports volunteers.

The demand for palliative care services is expected to increase substantially over the next five years due to population growth and ageing in this catchment region. The incidence of cancer in the ACT and Southern NSW is increasing at a rate of between 3-4% per annum which will have a cumulative impact of around a 20% increase in the population demand for a diagnosis that currently accounts for around 75-80% of total demand for palliative care services in the ACT.

Of equal importance is the recognition that patients with many other chronic conditions such as end-stage cardiac, respiratory and renal disease and neuro-degenerative conditions have a need for end of life care and access to appropriate palliative care services.

The majority of palliative care is provided by primary palliative care providers including acute hospital specialties, General Practitioners (GPs), community nursing and residential aged care facilities (RACF). Specialist palliative care services, provided for patients (and their families) requiring more complex care and support needs, also play a vital role in providing consultancy services. These services include advice, information and education to the primary palliative care providers.

Planning for the future

The ACT Palliative Care Services Plan 2013-2017 (the Plan) has identified six key goals with 16 associated strategies for achieving these goals, for possible implementation. These six goals are in close alignment with the four goal areas identified in the National Palliative Care Strategy (2010).¹

- The Plan recognises the need to **improve access** to palliative care services, including services to special needs groups, such as children, people with disabilities, people with a cognitive impairment, people from culturally and linguistically diverse backgrounds and people who identify as Aboriginal and Torres Strait Islander.
- **Increasing awareness of end of life issues**, both in the general community and amongst health professionals will facilitate more timely conversations about treatment options, the dying process, avoiding futile or unwanted treatments, advance care planning and awareness and control of symptoms.

¹ Department of Health and Ageing (2010) *National Palliative Care Strategy 2010*

- Improved awareness of end of life care issues, and **improved resourcing** of palliative care services, will enable the earlier engagement of appropriate palliative care services for patients with life-limiting illnesses. Research has demonstrated that this enables improved symptom management, knowledge of care and treatment options and overall improved health outcomes for patients as a result of the more holistic care that palliative care services are able to provide.²
- Smoother, more **seamless transitions** for patients between multiple care settings in which palliative care services may be provided including hospital inpatient care, palliative care services, GP practices, community based services, RACF and patients' homes is likely to improve patient's experience.
- Improved access to services and coordination with other clinical services can occur with the **introduction of new models of service delivery** including collaborative models of care between palliative care services and other services such as services for people with chronic conditions and those in RACFs, and the development of specialist palliative care outpatient clinics and Day Hospices.
- The Plan aims to enhance the resourcing of palliative services in the ACT in order to provide for the projected increase in population demand. The most important component is an **enhancement of workforce**, most notably in community-based settings. In terms of inpatient beds, an increase in the current capacity of designated palliative care beds from 19 beds to 25 beds in 2016/17 and 28-30 beds in 2021/22 is outlined in more detail on page 12.
- **Establishing a local body of evidence** with systematic data about patients' experiences and outcomes at the end of life will serve to underpin service improvement activities. The ACT will develop an integrated mechanism to incorporate patient activity and outcomes, care standards and consumer feedback that will inform service and workforce development and quality improvement.

Implementing the Plan

This Plan has been developed so that there is a clear understanding of what palliative care services currently exist, what the future palliative care needs are predicted to be and what strategies should be put in place to meet the growing need over the next five years.

An Implementation and Evaluation Framework has been developed to monitor and assess progress against the six goals and 16 supporting strategies of the Plan. A new Action Plan will also be developed each year. Progress will be monitored by the ACT Palliative Care Services Plan Steering Committee.

The ACT Palliative Care Services Plan 2013-2017 Technical Paper from the consultant is available on the ACT Health website and contains a greater level of detail on current palliative care services provided as well as demand projections. An associated 2 page summary of the Plan is also available.

2 Haines IE (2011) *Managing patients with advanced cancer: the benefits of early referral for palliative care*

Palliative Care is...

The term “palliative care” is used in a variety of contexts and can be used to describe specialist palliative care services, palliative interventions and the palliative care approach³. 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 accurate assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

A variety of definitions of palliative care are used across Australia. In line with the national Palliative Care Working Group, ACT Health has adopted the definition put forward by the World Health Organization as its working definition of palliative care. Palliative care:

- Provides relief from pain and distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor 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 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.⁴

With the continued ageing of the population the number of deaths is projected to increase substantially over the next 30-40 years, placing an increased burden on end of life services. The nature of dying is also changing. People are more likely to die in a hospital or other institutional setting. They are more likely to be elderly, to die as a consequence of the end stages of advanced chronic illness and be less likely to have family or community supports available to them. Projections of the demand for care at the end of life suggest that the trend towards institutional care will increase as the number of people dying each year grows in absolute terms, and as the proportion of elderly people in the community exceeds the availability of carers.⁵

3 Kristjansson LJ, Toye C, Dawson S (2003) New dimensions in palliative care: a palliative approach to neurodegenerative diseases and final illness in older people, *MJA*; 179 (6 Suppl) S41-S43

4 Palliative Care Australia. (2010). *Health System Reform and Care at the End-of-life: A Guidance Document*. National EOL Framework Forum

5 Ibid.

Service Vision and Principles

Vision

People with a life-threatening illness in the ACT and their families and carers will have timely access to quality palliative care that is consumer and carer focussed, respects their choices and is appropriate to their needs.

Principles

The key principles underpinning this vision are:

- **Empowered person centred care** – Individuals and families will be able to make informed decisions about their care choices with support from a system which focuses on the needs of the individual and works in partnership with individuals, families and carers.
- **Access and equity** – The palliative care system acknowledges the importance of equity in health care, prioritises services to those most in need and promotes accessible, acceptable, affordable and timely services.
- **Advocacy** – Palliative care services are provided based on the expressed wishes of the dying person, caregiver(s), families, and communities.
- **Skilled workforce** – There is a commitment to building a workforce that is skilled in the palliative approach and supported by specialist tertiary level services, home/family supports and volunteers.
- **Collaborative model of team based coordinated care** – Palliative care services provide collaborative team based services in consultation with patients to deliver an effective, appropriate and coordinated service appropriate to needs.
- **Integration and collaboration to support the patient journey** – Care is delivered in an integrated fashion with “seamless” transition across care settings so that patients and their families can easily gain access to the care or information they need through any entry point.
- **Best practice** – Care is open to innovation and informed by the latest best practice and research relevant to the local context.
- **Resource management** – Services are structured to make effective and efficient use of available resources that meet the needs of patients and families.



Palliative Care Services in the ACT



Goals and Strategies for the Future of Palliative Care

Goal 1

ACT Health plays a leadership role in ensuring reliable access to quality palliative care in the ACT, appropriate to needs and respecting the wishes of patients

a) Ensure that a range of modalities are offered in the provision of palliative care services in the ACT, consistent with the size of the catchment population and sustainable within available resources

The ACT community is seeking flexible, local care delivery of quality palliative care services for people at the end of life regardless of where they live, and that any barriers to delivery are addressed. In planning to best meet these community requirements, ACT Health has been guided by the National Palliative Care Strategy, best practice and other national guidelines and benchmarks. These services will aim to achieve the highest standards of safety and quality and value for money, and be sustainable in terms of the size of the population catchment being served and the available workforce.

The aim will be to provide services as close as possible to the community settings where clients reside, close to their carers and families, while recognising that many people will not have access to the same level of community support, and at times, many patients will require the level of acute care and/or symptom management that can only be provided in a hospital setting.

b) Develop an integrated, cohesive ACT Palliative Care Clinical Network

As part of the strategic development of health services in the ACT, ACT Government health services are being developed within strengthened and resourced clinical networks. These networks will involve ACT Health and Calvary clinicians working together across hospitals and with GPs and regional services using collaborative processes and models of care.

An integrated ACT Palliative Care Clinical Network headed by a Clinical Leader will involve clinicians working flexibly across the various service delivery settings to provide a cohesive service. As with other ACT Clinical Networks such a service would seek to provide a consistent quality of service for patients irrespective of where care is provided and timeliness of access to appropriate services irrespective of where a person requiring palliative care enters the health system. This Network would also include a problem resolution component to address other operational issues as they arise.



c) Ensure access to appropriate end of life care services for special needs groups including children, people from culturally or linguistically diverse backgrounds and people who identify as Aboriginal and Torres Strait Islander

End of life care will be tailored to the individual needs of the client and their families with the aim of achieving the best possible outcome for people needing palliative care and their carers. People requiring end of life care may have a poor prognostic indicator such as cancer, advanced organ failure such as chronic heart or renal failure, and neurodegenerative disorders such as motor neuron disease, multiple sclerosis, dementia or multiple co-morbidities.

People with dementia or other cognitive impairments have special needs when requiring end of life care, including communication difficulties, managing adequate nutrition, and ensuring that pain does not go unrecognised and under-treated. They will also require assistance in relation to guardianship issues (Power of Attorney) including advance care planning.

There is a need to ensure that palliative care services provided to people from culturally and linguistically diverse backgrounds are culturally appropriate and take into account any special needs that patients, carers and families may have.

There is a need to ensure that palliative care services provided to people who identify as Aboriginal and Torres Strait Islanders are culturally appropriate and respond to any special needs that individual people and families may have.



Goal 2

To ensure that palliative care services provide continuity of care and smooth transitions between settings

a) Improve current methods of service delivery with clear entry points and entry criteria and more seamless transitions between care settings

There is a need to clarify the role of the specialist palliative care service to ensure that consumers with life-limiting illnesses are able to receive the appropriate level of care in the right setting in a timely manner. Greater clarity would assist the specialist palliative care services to provide targeted care for patients with complex needs and would assist generalist health services in making referrals and in providing primary palliative care services for patients with less complex needs with the right level of support from the specialist service. In this regard, it is also noted that while many residents of Southern NSW LHD, such as those living in Queanbeyan are within the catchment of ACT bed-based specialist palliative care services, there is also a need to improve the coordination of palliative care across the State/Territory divide.

b) Enable earlier identification of patients who require end of life care and earlier engagement of palliative care services

The benefits of earlier engagement of palliative care services for patients with terminal illness include better knowledge of treatment options, symptom control and pain management and end of life care planning. Earlier engagement of palliative care services will be enabled through a number of the strategies outlined here, including increased workforce capacity in the specialist palliative care service, clearer entry points and entry criteria and the development of specialist palliative care early referral outpatient clinics.

c) Establish clearer pathways for consumers in accessing palliative care services in the ACT

In recognising the complexity of end of life care and the multitude of settings within which care may be provided, ACT Health needs to ensure clear pathways for consumers and their carers in accessing palliative care services. Most people are only involved in this type of care once and need guidance and some form of case management to ensure best outcomes and effective use of available services.

d) Introduce new and innovative modes of delivering end of life care in the ACT

Wherever possible new programs are being introduced based on new and emerging evidence and successful implementation in other jurisdictions. There are already a number of new models of care being introduced in the provision of palliative care services in the ACT.



Goal 3

The ACT community is well informed about all aspects of death and dying, and that individuals and their families are able to make an informed choice about their treatment options and the settings in which palliative care is provided

a) Ensure that the ACT community is well informed about palliative care service options and end of life issues including advance care planning

The importance of developing effective communication between patients, families and their care team is a core component of a quality palliative care service. Advance care planning is an important tool in these conversations for reviewing treatment options and goals of care in the context of patient and family wishes and considerations.

Another aspect of death and dying that the ACT community needs to be better informed of is the ability of people with terminal conditions to donate organs and/or tissue for medical use or research. It is important for these conversations to be initiated early so the patient's wishes are known. Medical suitability for donation can be determined at the time of death.

There is a need to review the use of advance care planning in the ACT including the use of the Respecting Patient Choices (RPC) Program®, and to identify any barriers to greater take-up, particularly for patients living at home and in RACFs and develop strategies to address these.

b) Ensure that health professionals working in all settings are well informed about palliative care services and end of life issues including advanced care planning

There is a need in the ACT, and nationally, to enhance the awareness of health professionals of the scope, and benefits of timely and appropriate access to, palliative care services. Within the acute care environment there is a need for a strategy for engaging clinicians hospital-wide in education and provision of information relating to advance care planning including the RPC Program® and the organ and tissue donation process.



Goal 4**To build capacity of palliative care services to meet the current and projected population demand****a) Develop specialist palliative care services in line with the projected increase in population demand to 2016/17 as outlined in this Plan**

The provision of quality palliative care services requires adequate capacity and capability and these need to grow to meet the projected increase in population demand. The current and future projected inpatient activity requirements for specialist palliative care services are summarised in Table 1 below.

Table 1: Current and Projected Palliative Care Inpatient Activity, ACT 2011-2021

Hospital	2010-2011	2016-2017	2021-2022	Per annum average growth
Canberra				
Separations	231	273	318	3.3%
Beddays	1,566	1,975	2,278	
ALOS* (days)	7.4	7.8	7.6	0.3%
@90% occupancy	5.2	6.5	7.4	
Calvary (CHH)				
Separations	398	471	546	3.2%
Beddays	5,782	5,905	6,657	-1.7%
ALOS* (days)	14.9	12.9	12.6	
@90% occupancy	18.1	18.5	20.9	
Total beds @90% occupancy	23.3	25.0	28.2	

*ALOS- Average Length of Stay

Source: ACTAIM V1.3, Status Quo Projections

Based on the projected growth and ageing of the population and trends in palliative care service provision in the ACT, a total of 25 designated inpatient beds would be required in 2016/17, increasing to 28.2 beds in 2021/22. This number of beds will be required to provide for the care and support of palliative care patients in the final stages of terminal illness and to provide the capacity for inpatient management of symptoms and some level of respite care.

The proportionate breakdown across facilities, based on the status quo service roles of TCH and CHH, is a projected demand for 21 inpatient beds at CHH and 8 beds at TCH. These projections also incorporate increased demand driven by population growth and ageing from SNSWLHD, accounting for 22% of palliative care separations at TCH and 11% of separations at CHH.

In addition to the increased bed capacity, allocation of resources should also be considered to support a range of other modalities including home based care, day hospice and respite care.

b) Build the capacity of primary care providers to support the increased demand for end of life care in the ACT

The majority of palliative care services will be provided by primary providers including GPs, other medical specialties, hospital and community nursing teams, together with volunteers, carers and families.

Strategies for achieving greater engagement of GPs are required to provide a sustainable palliative care service capacity. These are expected to include the provision of support and education to GPs and other primary health care providers including non government organisations and RACFs.

c) Provide support for volunteers and carers in their efforts to provide care and support for people with life-limiting conditions

Caring for a person with a life-limiting condition living at home is a demanding and stressful process for carers. As more people choose to receive end of life care in the community the impact on carers needs to be recognised and there will be a greater need to provide support for carers including overnight respite care services. It is often the time when a carer reaches the point of fatigue that alternative options, including residential aged care, hospital inpatient and/or hospice care are sought.

Volunteers play an important role in supporting people with life-limiting conditions and their carers. Strategies will be required to increase the number of volunteers and to provide education and training for them in this role.



Goal 5

To ensure an appropriately qualified and sustainable workforce to provide the projected level of palliative care services in the ACT

a) Develop a Workforce Plan to support the recruitment and retention of the projected increased workforce requirements

A summary of the projected specialist palliative care workforce requirements in the ACT in 2017 is summarised in Table 2 below. These projections should be seen as estimates and will be further considered as part of the development of the ACT Palliative Care Workforce Plan. However shortages exist in key areas including allied health and bereavement care that need to be addressed as a priority and there are national workforce shortages in some core specialist palliative care professions including medical and allied health.

Table 2: Current and Projected Staffing – ACT Specialist Palliative Care Services[†]

Profession	Total Current Staffing 2012 (FTE#)	Total Projected Minimum Staffing Requirement 2017 (FTE#)
Medical	5.8	8
Nursing	21.6	25.9
Allied Health		
Social Work	1.0	2.0
Occupational Therapy	0.8	1.8
Physiotherapy	0.6	2.0
Psychology	1.5	1.5
Speech Pathology	0.0	1.0
Pharmacy	0.3	1.0
Dietetics	0.0	0.5
	4.2	9.8
Bereavement Support	1.0	2.0
Volunteers		
Coordinators	1.6	3.0
Volunteers (registered)	130	150
Administration	3.8	4.5

[†]Includes all ACT specialist palliative care services

[#]FTE- Full time equivalent

b) Build the competence of primary care providers involved in the provision of palliative care services

As indicated earlier, the development of capacity and competencies in primary care providers can have a major impact in ensuring a sustainable palliative care service by taking some of the pressure off specialist palliative care services. Collaboration with institutions is required to include basic training in the palliative care approach.

Goal 6**To develop a knowledge base to inform service and workforce development and quality improvement****a) Develop an integrated database incorporating patient activity and outcomes, care standards and consumer feedback that can inform service development and quality improvement activities**

A quality palliative care service is driven by information which includes data, research, evidence and consumer feedback that can be used to support decision-making, guide service development and drive quality improvement. Therefore there is a need to develop an integrated database incorporating patient activity, care standards and outcomes etc that can support the review and evaluation of service development and quality improvement.

b) Conduct research for the ACT based on major service priorities and knowledge gaps

An important step has been taken with the establishment of the Calvary Centre for Palliative Care Research. The next step is the development of a palliative care research program for the ACT based on major service priorities and needs. One of the most important steps in developing this research agenda is for the Centre to build collaboration and research partnerships with local service providers including TCH and RACFs, with other palliative care research teams and with academic institutions including the universities within the ACT.



