



Palliative Care Services Plan 2009-2016

May 2009

Acknowledgements

We offer sincere thanks to the many contributors whose commitment and knowledge have informed the development of the Palliative Care Services Plan 2009-2016.

The Palliative Care Plan Steering Committee, the Palliative Care Plan Reference Group and Plan Development Project Team

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Minister's Foreword



South Australia's Health Care Plan 2007-2016 included a commitment from the South Australian Government to develop a new statewide palliative care plan. The State Government wants to see a heightened awareness that not only will there be more people requiring end of life care in the years ahead, but that the provision of this care is as much a responsibility of the whole health care system as it is for palliative care services.

The first report of the National Health and Hospitals Reform Commission also recognised end of life care as a priority area for health system reform.

SA Health's Palliative Care Services Plan 2009-2016 outlines the South Australian Government's plan to expand and reshape services, in light of increasing demand for end of life care across the health system.

The Palliative Care Plan:

- > sets out a new structure for palliative care services within SA Health
- > outlines the steps that will be taken to reorganise existing palliative care services through a mixture of consolidation and expansion to ensure they continue to play their crucial part in the care of those people at end of life with the most complex needs
- > describes the initiatives that will be taken to ensure that wherever possible, people who want to receive their end of life care at home can do so, even when they have complex or emergent care needs
- > details the work ahead to build the capacity of all end of life care providers to ensure high quality end of life care to all South Australians who need it, regardless of age, disease or location
- > seeks to draw families, communities, neighbourhoods and workplaces together in caring for people at end of life, and after death, to better support those who experience grief and loss
- > promotes the widespread uptake of advance care planning through an 'Informed Choices Program'.

The Palliative Care Plan builds on the vision set out in South Australia's Health Care Plan and links with a series of other statewide plans that focus on the health needs of country South Australians, older people and those living with, or at risk of developing chronic illnesses.

The Plan has been developed in consultation with key partners and the implementation of the plan will be undertaken by regional Health Services.

Hon John Hill MP
Minister for Health

Introduction

South Australia's Health Care Plan 2007-2016 identified an increasing demand for palliative care services in the coming years.¹ Planning to meet this increase in demand presents a series of challenges which include the community's expectations of access to quality end of life care services, particularly for the growing population of older people who increasingly are living alone and with fewer available family members able to provide support. Compounding this challenge, is a workforce that is itself ageing and retiring, and cannot be readily replaced.

South Australia has a well established and well regarded palliative care sector. Palliative care services for many years have championed holistic approaches to care and delivering integrated services across in-hospital and out-of-hospital settings.

In developing this new plan for palliative care, emerging knowledge about caring for the dying has been merged with the strengths of SA current palliative care service delivery program.

The Plan positions the work of palliative care services within the broader context of all the end of life care needed and provided across the state. It recognises and responds to both the growing demand for end of life care and a noticeable trend toward an increasing proportion of all end of life care being directed toward palliative care services.

Further, it promotes a shift in the level of reliance on palliative care services and directs palliative care services towards those people with the most complex end of life care needs. It expands the focus on building the capacity of generalist providers to ensure continuity and their active participation in care through to the end of life.

The Plan itself is structured in two sections. The main body of the plan sets out the strategies, key enablers and initiatives that SA Health will put in place over the next eight years to shape the future role and impact of palliative care services. Background and contextual detail to explain the decisions and steps planned have been incorporated in a series of Appendices.

Terminology

The terms 'palliative care' and 'end of life care' require definition and their use within this Plan needs careful clarification.

The term palliative care is used to refer to specialty clinical practice and service delivery.

End of life care is used to describe care that is planned for, negotiated with, or provided to a person at the end of their life. It is used without specific reference to timeframes and hinges instead on the orientation toward providing care appropriate for a natural life event and the ordinary place of death within a person's lifespan.

The use of the terms in this way is not intended to value one over the other but to assist in differentiating the roles of specialist and generalist providers of end of life care in ways that clarify the contributions of each, while allowing for consistent use of terms. Appendix 1 sets out the use of these terms in more detail, and a more general glossary of terms has also been provided in Appendix 10.

Care at end of life

Whenever a person dies in South Australia, a range of effects can be felt across families, communities and workplaces.

Dying is a normal part of the life cycle and affects people of all ages. The impact of a death can also have a profound effect on the health and wellbeing of close family members, friends and co-workers. The experience of caring for someone at end of life can be made more difficult when needs go unmet, symptom control is inadequate or care is fragmented or lacks coordination. Just as poor quality care can have a profound and lasting impact on those left behind, the effect of high quality end of life care can ripple across generations. In this respect, the quality of care provided to every South Australian at the end of their life is everyone's business. Death should not be hidden away; nor should care of the dying be completely handed over to professionals.

Caring for those who are dying can serve to:

- > deepen the bonds within families
- > build communities across neighbourhoods; strengthen friendships and collegial networks
- > foster compassion and resilience
- > enhance respect for health and life
- > reduce community anxiety about death.^{2,3,4}

Responding to people's concerns

End of life care ends in death, but begins at a point that varies according to a range of factors. In some instances people make the transition to end of life care when diagnosed with an incurable illness. For others, end of life care is triggered by subtle clinical changes, an event, a revision of prognosis, or a simple recognition that death is coming. In some circumstances end of life care can last for years, and in others only days, or even hours, as can sometimes be the case in an Intensive Care Unit with the withdrawal of life-support.

Listening to people's concerns about the care and services they need at end of life brings into sharp focus the themes that must be central in planning service delivery.

Their expectations include that:

- > a range of care options will be available
- > the workforce delivering care will be skilled
- > there will be continuity of caregiver and resultant capacity to form a 'therapeutic' relationship with the care team
- > there will be around the clock access to support and advice
- > social supports are as important as symptom management
- > grief and bereavement support will continue beyond the immediate post death period.

People in South Australia expect access to comparable levels of care and support regardless of their location in the state. Services need to be positioned in ways that spare people the need to move between multiple sites for the services they need.

They need to be able to have timely conversations that 'walk them through' their likely end of life pathway. Most people want to be actively engaged as a key decision maker about the type and extent of care they receive, where they receive that care and when the time comes, where they would prefer to die. For families, understanding the physical nature of the dying process provides important contextual information that helps avoid crisis-induced decisions at critical moments, particularly during the last days of life. Emotional, social and spiritual symptoms are acknowledged as being of as much importance as the physical symptoms in achieving quality living at the end of life.

The Palliative Care Council of South Australia has played a key role in promoting community awareness of the palliative care philosophy and has contributed to the increasing awareness of the needs of people who are dying and those who care for them. Their continuing work in advocacy, community representation and health promotion align with and support the directions of this Plan.

End of life care challenges

South Australia's Health Care Plan 2007-2016⁵ identified an increasing demand for end of life care in the coming years. The challenges of the future that shape the Plan involve the need to manage a substantial increase in demand for and community expectations of quality end of life care services;

- > to a growing population of people that will be both older, increasingly living alone, with fewer available family caregivers
- > by an ageing workforce, many of whom are soon due to retire, and will not easily be replaced.

Ageing population

Australia has an ageing population and South Australia has the highest proportion of older people in the nation with regional South Australia recording a higher percentage of older residents than metropolitan areas.

Over the next 15 years, the number of South Australians aged over 65 is expected to almost double from its current figure of one in six as the 'baby boomer' generation moves into older age. In the next 10 years it is also expected that the percentage of the population living beyond the age of 65 will rise from the current figure of 15% to 22%.

Ageing workforce

Like the rest of the nation, South Australia is facing a health care workforce crisis as its workforce ages. Many of today's health workers will be retiring in the foreseeable future and the health care sector is competing against many other industries for the small pool of young people and migrants entering the workforce.

There is no immediate or 'quick fix' solution to this major workforce planning challenge. SA Health modelling of future workforce supply indicates a complete inability to maintain workforce groups at current numbers into the future. For example, it is predicted that the number of Registered Nurses in SA will drop from approximately 16,000 to around 12,000 by 2020.

The crisis in the country workforce is of even greater concern:

- > Nurses in the country are on average older than the state mean, and the nursing workforce in country SA is anticipated to shrink by up to 30% in the next 20 years.
- > Increased turn over of General Practitioners in country South Australia will continue to be a problem; currently 40% of General Practitioners have less than five years experience working in rural SA and over the next five years international medical graduates are expected to constitute around 40% of the rural medical workforce.

Profiling death and its causes

This Plan anticipates an overall increase in the amount of end of life care that will need to be provided in South Australia over the years to come. Some trends are also evident in the changing prevalence of diseases that cause death. The major causes of death by disease currently seen across Australia are listed in the table below.

The top 10 causes of death account for 53.2% of all deaths registered in 2006. Cardiovascular diseases remain the leading cause of death in South Australia, accounting for 37.5% of all deaths in 2002-2003.⁶

Table 1

Major causes of death in Australia by disease⁷

Rank	Cause of death and ICD code	Number	%
1	Ischaemic heart diseases - (I20-I25)	22 983	17.2
2	Strokes (I60-I69)	11 465	8.6
3	Trachea and lung cancer (C33-C34)	7 348	5.5
4	Dementia and Alzheimer's disease (F01-F03, G30)	6 542	4.9
5	Chronic lower respiratory diseases (J40-J47)	5 443	4.1
6	Colon and rectum cancer (C18-C21)	3 858	2.8
7	Blood and lymph cancer (including leukaemia) (C81-C96)	3 693	2.7
8	Diabetes (E10-E14)	3 662	2.7
9	Diseases of the kidney and urinary system (N00-N39)	3 192	2.4
10	Prostate cancer (C61)	2 952	2.2

Source: South Australian Cancer Registry, Epidemiology Branch, SA Health 2008

In 2005, South Australian age-adjusted cancer mortality rate was 228.7 deaths per 100,000 for males and 135.9 for females, comparable to national averages.⁸ Taking into account the current age/sex patterns of cancer and projected population growth over the years ahead, the overall cancer patterns show a slight, but not significant, decline in incidence and mortality rates in both males and females. However the effect of ageing will see a projected rise in the overall number of both new cases of cancer as well as in the number of cancer deaths in South Australia in the years ahead. Table 2 sets out these projections.

Table 2

Summary of projected number of new cases of cancer and mortality in SA

Year	2008	2011	2016
Projected number of new cancer cases	8,816	9,326	10,265
Projected cancer deaths	3,609	3,759	4,062

Estimating the size of the total population of people for whom end of life care could be required and the proportion of those who require the input of a palliative care service is not straightforward. Methodologies differ widely and have evolved out of varying presumptions and proxy measures.^{9,10,11,12,13,14} The approach and rationale taken in the Plan is set out in the following section.

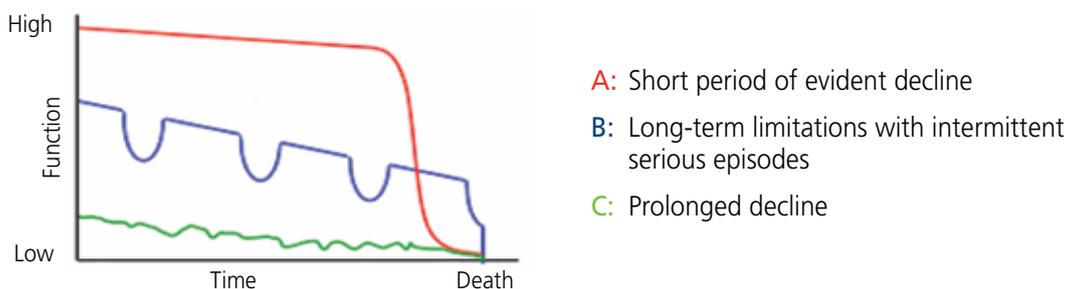
Planning end of life care

Historically the focus of the palliative care sector has been weighted towards those people with a diagnosis of cancer. An appreciation of the features of a person's end of life trajectory as a significant determinant of need has emerged from current palliative care literature. This is helpful in planning service responses at a whole-of-system level and across all age groups, including for infants, children, adolescents and young adults. Consideration of end of life trajectories helps broaden the scope of planning beyond a focus on the relatively small proportion of people who die with involvement from a palliative care service.¹⁵

This palliative care plan recognises three typical or characteristic end of life trajectories (excluding sudden death) and seeks to appropriately position palliative care services across these trajectories to ensure the input and resources of services are most effectively utilised. It should be noted that they are not intended for use as a fixed template to be applied to individual people.¹⁶

Figure 1

Typical end of life trajectories.

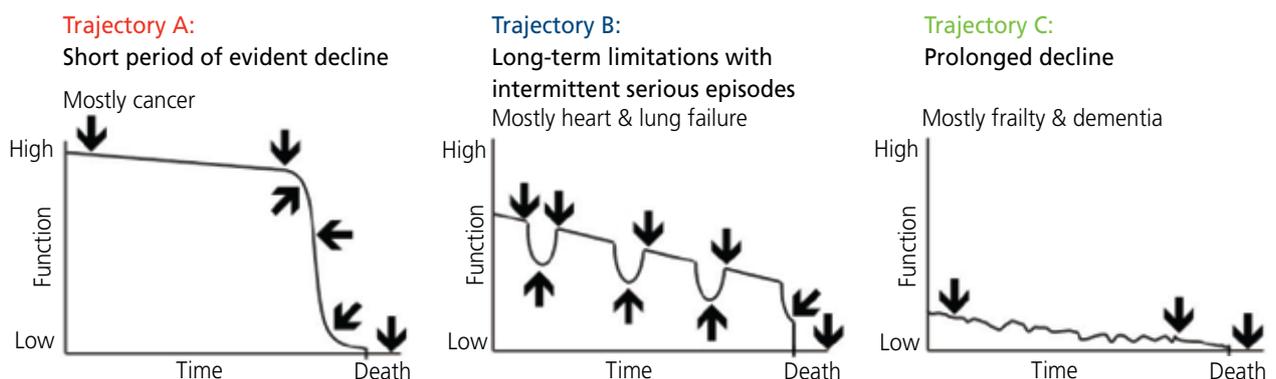


Taken from Lynn & Adamson (2003)

Along these trajectories, a series of key points or triggers representing interventional opportunities that can change the nature, direction and outcomes of care can be anticipated. Triggers come in many forms and may include a new diagnosis or revision of prognosis, the advent of a frightening or overwhelming symptom, an escalation of symptoms or an indication of increasing distress or despair. Across these end of life trajectories, a number of triggers can be predicted. The following figure indicates examples of where triggers may occur along the typical trajectories.

Figure 2

Triggers and trajectories

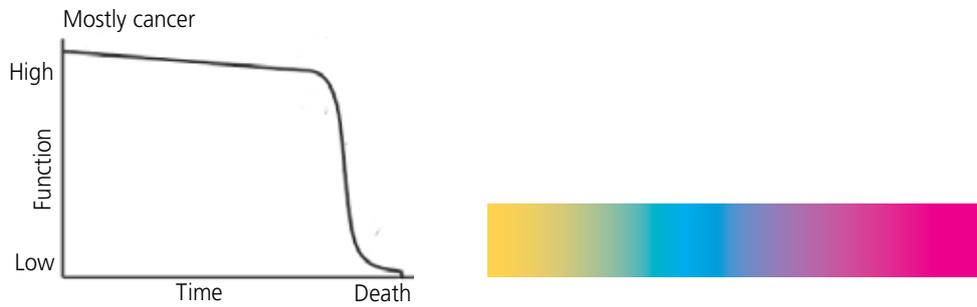


Clarifying the scope of palliative care also requires a determination of the most appropriate distribution of work along the specialist-generalist service provider continuum. This lays the foundation for understanding the roles and responsibilities required of the broader health sector in supporting the end of life care needs of their clients and their intersection with the speciality of palliative care. A more detailed explanation of end of life trajectories and triggers is provided in Appendix 2.

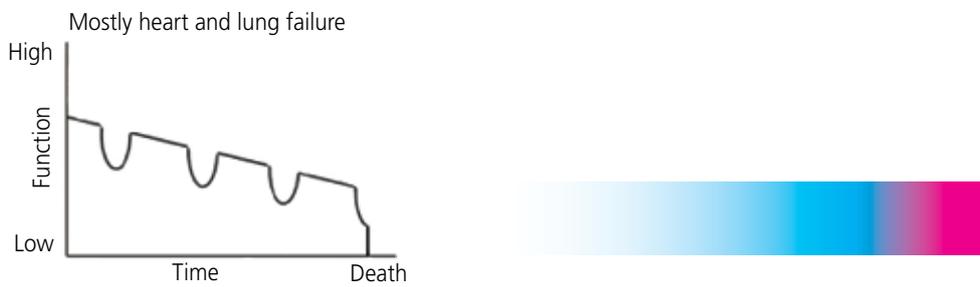
Figure 3

Relationship between the specialist-generalist continuum and trajectories

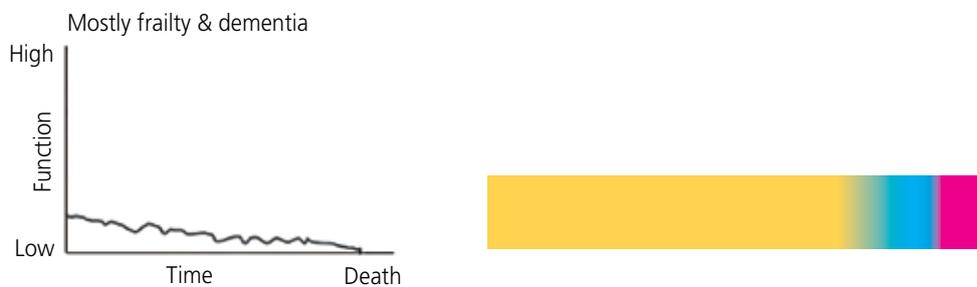
Trajectory A: Short period of evident decline



Trajectory B: Long-term limitations with intermittent serious episodes



Trajectory C: Prolonged decline



End of life care provided by generalist providers without assistance from specialist providers of palliative care.



End of life care led by generalist providers with some level of continuing or occasional direct input from specialist providers of palliative care.



End of life care led by generalist providers with some level of continuing or occasional direct input from specialist providers of palliative care.

Expanding and reshaping palliative care services

To expand and reshape palliative care services to meet the demand and workforce challenges ahead the following directions have been identified:

- > Consolidation of palliative care services into regionalised teams for enhanced integration and sustainability
- > Formalising links and partnerships between metropolitan and country services
- > Recasting the balance of end of life care that takes place in the in-hospital and out-of-hospital settings to give increased opportunity for people who want to receive end of life care at home
- > Building the capacity of generalist providers to effectively contribute to high quality end of life care
- > Developing a palliative care quality agenda which supports understanding, planning for, and reporting on the needs and the outcomes of care for all those at end of life across each service catchment and across the state
- > The regionalised palliative care services will provide an integrated service for people and their families across in-hospital and out-of-hospital sites.

Appendix 3 provides more detail of directions to expand South Australian palliative care services.

Service delineation

The delineation of services identifies the scope of practice and the services provided within these levels and provides important planning, resource allocation and accountability functions. The development of the service delineation profile for palliative care services in SA reflects a local adaptation of the national palliative care service delineation framework.¹⁷ While this national framework describes palliative care services using a three tiered framework, the *Clinical Service Delineation for SA Health Facilities*¹⁸ uses a 6 tiered model to describe patient complexity and the minimum level of support required to resource these needs. To integrate these two frameworks, and thus preserve the capacity for service comparison at a national level, this Plan positions the palliative care services of SA Health at three of the local levels of delineation (Levels 6, 4 and 2). These levels correlate with Level III, II and I services respectively within the national service delineation framework. An expanded description of delineated service profiles is contained in Appendix 4.

Table 3

South Australian service delineation, resource and capability matrix^a

Level	Capability	Typical resource profile
Acute, chronic, aged and community providers of end of life care.	<p>Quality end of life care including assessment, triage, care coordination and clinical management, bereavement risk assessment and bereavement care for patients with uncomplicated needs associated with end of life care.</p> <p>Has formal links with a palliative care services for purposes of referral, consultation and access to specialist care as necessary.</p>	<p>General medical practitioner, nurse practitioner, practice nurse, generalist community nurse, Aboriginal health worker, allied health staff.</p> <p>Health care providers from a range of community and acute specialties and disciplines would be included at this level.</p>
Level 2 palliative care service (PCA Level I)	<p>Provide palliative care for patients, primary caregivers and families whose needs exceed the capability of primary care providers.</p> <p>Provides assessment, & community & clinical education.</p> <p>Care consistent with needs and provides consultative support, information and advice to primary care providers.</p> <p>Has formal links with primary care providers and a formal partnering relationship with a Level 6 service as well as with a local Level 4 service (through clustering arrangements if present) to meet the needs of patients, caregivers and families with complex problems.</p> <p>Has quality and audit programs.</p>	<p>A rural palliative care nurse coordinator with local support from general medical practitioner, allied health staff, pastoral care and volunteers.</p> <p>A designated staff member if available coordinates a volunteer service.</p>
Level 4 palliative care service (PCA Level II)	<p>As for Level 2, able to support higher resource level (due to population base or the presence of a Country General Hospital that brings with it additional responsibility to a cluster of smaller services), or the presence of a hospice associated with an adjacent Level 6 service.</p> <p>Provides inpatient care; within satellite hospice unit beds (in periurban centres) or a small cluster of (non-dedicated) palliative care beds within each Country General Hospital.</p> <p>Has formal links to primary care providers and a formal partnering relationship with a Level 6 service as well as with Level 2 services (within a cluster if present) to meet the needs of patients, caregivers and families with complex problems.</p>	<p>A rural palliative care nurse coordinator with addition of dedicated GP with a special interest, NP position and or advanced practice nurse with relevant specialist qualifications.</p> <p>Includes designated allied health and pastoral care staff.</p>
Level 6 palliative care service (PCA Level III)	<p>Provides comprehensive care for the needs of patients with complex need, and support for their caregivers and families.</p> <p>Provides inpatient care: Mostly in hospice units with some capacity within acute care beds of metropolitan hospitals based on need.</p> <p>Has formal links with primary care providers and formal partnering agreements with a number of Level 4 and Level 2 services across the state to meet the needs of patients, caregivers and families with complex problems.</p> <p>Contributes to high quality specialist research, advanced clinical training and graduate education programs and has integrated links to relevant academic units including professorial chairs where available.</p>	<p>Interdisciplinary team including a service director, palliative medicine specialists, a clinical nurse leader, advanced practice nurses, nurse practitioners and an expanded range of clinical and allied health staff with specialist qualifications and dedicated consultant roles in palliative care.</p>

^a Adapted for the South Australian context from the Palliative Care Australia service delineation matrix (2005)

Palliative care services in metropolitan Adelaide

Metropolitan Adelaide will be served by three public adult Level 6 palliative care services. Consistent with the health system architecture underpinning the SA Health Care Plan, these Level 6 services will be based at the metropolitan General Hospitals: The Queen Elizabeth Hospital, the Repatriation General Hospital and the Modbury Hospital. Existing palliative care services will be consolidated within these services to ensure the long-term viability and sustainability of the palliative care sector in the state. This will mean that the four separate palliative care services in the Central Northern Adelaide Health Service will be consolidated into two integrated services. Level 6 palliative care services will provide services across spine and other hospitals/health care facilities within their catchment area.

The three Level 6 services will each serve as a tertiary level resource to a designated number of Level 4 and Level 2 services based in country South Australia to ensure equitable access and consistent specialist coverage across the whole state.

The paediatric palliative care service based at the Women's and Children's Hospital will maintain and develop its focus as a Paediatric Level 6 service providing quality end of life care of infants, children and adolescents across the state. This requires partnering with all adult services across metropolitan, periurban and rural South Australia. The partnering relationships between delineated palliative care services are outlined below and are described in more detail in the following section.

Palliative care services in country South Australia

The service architecture of the SA Health Plan provides for expanded clinical services at four Country General Hospitals and with this comes an enhanced capacity to develop end of life care services at these sites. Palliative care services based in the four population centres of Mt Gambier, Pt Lincoln, Berri, and Whyalla will be developed to become Level 4 palliative care services by 2016. Over time, and with analysis of trends in demand and flow, this may include expanded inpatient capacity and incorporate a cluster of specialist inpatient medical and nurse-led care options in these four hospitals.

A statewide centre for Aboriginal and Torres Strait Islander Health will be established in Pt Augusta. Leadership in the provision of culturally safe end of life care for Aboriginal people will be an important function of this centre. This will be particularly valuable to address the needs of Aboriginal people wanting to 'return to country' to die.

Periurban areas of the northern Adelaide plains, the Adelaide hills and the Fleurieu Peninsula are all facing rapid and extensive population growth. The Strategy for Planning Country Health Services in SA recognises that service planning and service delivery in these areas will increasingly integrate with that of the metropolitan area. Over time this will facilitate the coordinated distribution of resources to the growth areas of greater Adelaide. Consistent with the trends in urban growth and consolidation, these periurban services will move toward Level 4 palliative care service delineation by 2016.

The development of small hospices at Mt Barker and at Gawler Hospitals are in recognition of population size and demand flowing from outer metropolitan and periurban areas. This will include expanded inpatient care capacity, and may include a cluster of nurse-led beds within the compliment of dedicated palliative care beds.

The development of a similar unit for the Southern Fleurieu remains an option for the future and will be reviewed in the light of population demand and inpatient flow data in 2012.

Consistent with cluster arrangements developed by Country Health SA, each Level 4 service will serve as an area resource to Level 2 services in those parts of the state in which they are located. Like Level 4 services, Level 2 services are characteristically small (in terms of team size) and operate across very large catchments containing scattered rural and remote population centres.

Statewide access to specialist expertise and support

The considerable resources invested in palliative care services are utilised to maximum effect through a system of relationships called 'service partnering'. With varying degrees of formality, these partnerships ensure that every primary care provider involved in the care of a person at end of life can access a local palliative care provider if required. If the local specialist service is resourced at Level 2 or Level 4, then that service can access support from their Level 6 partner, if required. By such means, the expertise and clinical knowledge of specialists concentrated in the metropolitan Level 6 services can be made (directly and indirectly) available to all on the basis of need. The development of a statewide clinical network for palliative care has been identified as the most appropriate mechanism to enable this and other outcomes.

The initial partnering arrangements that cover all palliative care services funded by SA Health are outlined in table 4. These partnering relationships may be revised in the years ahead as the clinical service profiles of some services change in line with the planning directions of Country Health SA.

Table 4

SA palliative care service partnerships

L6 partner (and service base)	Rural and peri-urban Level 4 and Level 2 service partners (and service base)
Northern Adelaide Palliative Services (based at Modbury Hospital)	Gawler & Districts (<i>Gawler</i>) Barossa & Districts (<i>to be determined</i>) Pt Pirie Regional (<i>Pt Pirie</i>) Yorke Peninsula (<i>Wallaroo</i>) Lower North (<i>Clare</i>) Riverland (<i>Berri</i>)
Central Adelaide Palliative Services (based at TQEH)	Adelaide Hills (<i>Mt Barker</i>) Mallee Coorong (<i>Murray Bridge</i>) Whyalla (<i>Whyalla</i>) West Coast (<i>Ceduna</i>) Pt Augusta & Far North (<i>Pt Augusta</i>) Eyre Peninsula (<i>Pt Lincoln</i>)
Southern Adelaide Palliative Services (based at RGH)	Southern Fleurieu (Victor Harbor) Kangaroo Island (Kingscote) South East (Mt Gambier) Naracoorte (Naracoorte)
SA Paediatric Palliative Care (based at WCH)	Whole of state (<i>all adult level 6, 4 and 2 services</i>)

Moving from institutional to integrated regionalised service models

The history of palliative care service development in Australia and elsewhere records that many services were established out of an impetus to improve end of life care for cancer patients in the interventional acute care setting. The size of the hospital (traditionally measured in terms of total number of inpatient beds), the presence and size of a tertiary cancer treatment service, along with the generation of referral-based demand shaped the way resources were allocated to palliative care services.

The design and focus of palliative care services has increasingly moved toward more seamless operation and influence across settings and sites of care. Increasingly it has come to be recognised that:

- > a considerable number of remediable factors that contribute to the level of demand for inpatient care are located in the community settings
- > unmet needs exist in the community setting that are independent of institution orientated service performance or reform.

In response to these and other system-level changes, specialist services are becoming increasingly deinstitutionalised and regionalised in both their focus and in their corporate identity. This trend has and will continue to see a shift in planning focus toward the population within the service catchment in an effort to better understand and respond appropriately to people's needs.

The right balance between in-hospital and out-of-hospital care

In 2004 a representative sample of South Australians were asked about their preferred place of death if they were dying of 'a terminal illness such as cancer or emphysema'.¹⁹ Seventy percent indicated a preference to die at home.^b This contrasts sharply with the actual incidence of death at home for people with cancer of 14% in 2000-2002. This difference is consistent with the experiences of other comparable countries and a range of systemic barriers to achieving higher rates of death at home have been identified.²⁰

Palliative care services actively work to support the choices of people at end of life and their caregivers to receive the care and support they need in the place of their shared preference. However, more can and needs to be done to support care at home, not just for the last days of life, but over the whole end of life period. For many people and their families, anxieties about their capacity to manage dying at home and the extent and responsiveness of services often shape attitudes about whether home is a safe and appropriate place to be as death approaches.^{21,22,23,24,c} It is important to note that for the growing proportion of people with advanced disease who live alone, the option of continuing care at home until death may be unrealistic.

Despite predicted increases in demand for end of life care over the next decade, the community will be able to rely on responsive clinical teams capable of anticipating and/or responding effectively to emergent and complex care needs of people dying at home. As a result more people will feel confident in the choice of care at home. A whole-of-system effort will be required to meet community expectations about support for end of life care at home.

The palliative care plan has been informed by the outcomes achieved through system-wide redesign of palliative care services across a number of Canadian provinces. These jurisdictions report using a single regionalised integrated service model of service delivery to achieve substantial and sustained shifts in the amount and quality of end of life care provided in the community setting.^{25,26,27,28,29,30,31}

Elements of these Canadian strategies, along with features of the Marie Curie Delivering Choice Programme in the UK^{32,33,34} and others from Sweden³⁵, have been incorporated into this palliative care plan to enhance community-based end of life care in South Australia. Collectively these changes will assist in achieving a doubling in the rate of death at home of palliative care service referred patients by 2012. Reports from the international experience suggest that the rate of death at home in South Australia can be further increased by 2016.

^b When this figure is adjusted to take into account the distribution of cancer deaths by age and gender, the preferred incidence of death at home for people who might be expected to die of cancer was 58%.

^c For a comparable UK example see 'Patients wanting home death fear they won't get the help they need'. Retrieved 1 June 2008 from: deliveringchoice.mariecurie.org.uk/news_and_events/press_releases/delivering-choice-programme.htm

Model of palliative care in SA

Palliative care will be provided through a service model that operates across a geographical catchment area, integrates the provision of care across in-hospital and out of hospital settings, involves collaborative links with other primary care providers and includes partnering arrangements between Level 6, 4 and 2 services across the state. Within this model, palliative care retains its integral relationship with the acute care sector in recognition of the complex care needs of its patient base and the importance of its role in assisting those patients transitioning from curative care streams.

The model is structured to facilitate the person on an end of life care pathway to access the range of services available. Complexity of need should not be the primary factor in determining the setting of care at end of life. Most people who have complex needs can be cared for in a community setting if they so wish, provided they have around the clock access to expert advice and support.

While the bulk of care at end of life occurs in peoples' own homes, hospice care plays a crucial role by providing short episodes of inpatient care for symptom control, rehabilitation, terminal care, respite, and continuing care in instances where care at home cannot be sustained.

An important challenge in this Plan has been to strike the right balance between resource allocation that adequately supports inpatient care and also ensures optimisation of care in out-of-hospital settings.

A regionalised service model and a consistent approach to palliative care will be adopted across the state.

This will be supported by:

- > A single palliative care Unique Record Number to support once only referral.
- > The statewide development and uniform use of common tools, medical history & clinical record, standardised instruments, protocols and admission, discharge and referral criteria to increase efficiency and uniformity of care.
- > Increased use of evidence-based guidelines and the tailored use of standardised and optimised clinical pathways.
- > A consultation-liaison service construct with active partnerships with direct care providers.
- > The provision of the bulk of inpatient palliative care in dedicated hospice units.
- > the incorporation of Advanced Practice roles across disciplines contributing to the palliative care team
- > enhanced capacity for the regional team to work across multiple sites, providing an in-reach service to other health facilities in the catchment area
- > improved performance measurement through shared use of quality indicators and a shared quality framework for service outcome measurement and reporting
- > consolidated coordinated training and support to volunteers and paid staff across services
- > shared education and research programs.

Streamlining access and referral

A number of steps will be required to consolidate and streamline access to palliative care services and enhance their profile amongst service users and referrers.

They include:

- > Development of a centralised point of contact process, to ensure 'once only' referral
- > Ready access to after-hours phone support and advice
- > The promotion of the new and established online service directories, including the Palliative Care Australia services directory, the Palliative Care Council of SA directory of services, the Divisions of General Practice, the Directory of Cancer Services in South Australia, and the Health Provider Registry, to enhance community awareness of and access to relevant information about providers and services for those at end of life
- > Direct promotion of new regionalised services to all referrers and via webpage and other existing forums or media.

The Plan also incorporates the development of a self-sustaining SA Palliative Care Community Pharmacy Network to facilitate a quality use of palliative medicines approach across community, aged care settings, ensure the optimal prescription and dispensing of palliative care medications around the clock to those who need them, and the safe disposal of those drugs when no longer required. Accessibility to medications after hours in the community setting remains a continuing challenge that undermines successful care at home for people with complex or fluctuant symptoms.

Palliative care services in the out-of-hospital setting

From international experience and with the benefit of the GP Plus Health Care Strategy, it is anticipated that South Australia can achieve a much higher rate of supported death at home. By 2012, between 30-40% of those people referred to a palliative care service should be supported to die at home. A key element of a 2012 mid-point review will be the refinement of service-level strategies and initiatives that can increase this rate further and support dying at home for between 45 and 55% of people referred to a palliative care service.

The extent to which services are able to achieve these rates of care and death at home will depend on a range of factors. The principle enabler of success will be the optimal use of the expanded palliative care teams through the consistent application of the model of care set out in this plan. The numbers of palliative care patients cared for in the community will be expected to rise over time, and modelling of projected activity in the community suggests the following levels of home or community-based activity.

Table 5

Projected numbers of people supported at home by a palliative care service and deaths at home. ^d

	Number of people receiving support at home (Deaths at home)		
	2008-09	2011-12	2016-17
Northern Adelaide Palliative Service	900 (135)	940 (330)	970 (480)
Central Adelaide Palliative Service	1200 (180)	1220 (425)	1240 (620)
Southern Adelaide Palliative Service	925 (140)	955 (335)	980 (490)
Total	3025 (455)	3115 (1090)	3190 (1590)

Whole-of-service responses will be required to achieve a number of ambitious but realistic performance indicators that support this shift from hospital to community care. Within and across health regions, appropriate service-level reporting and performance evaluation mechanisms will be required to support a shared reporting and review cycle through which service leaders will be able to identify enablers, refine strategies and overcome barriers to achieve these outcomes. A number of key initiatives will support this redesign.

The community palliative care team

To support the shift to increased numbers of people supported to die at home, more will be asked of palliative care community teams and more resources will be provided to support them. Palliative care services provide a range of clinical services and programs across their respective service catchments. They are provided:

- > to people requiring care at end of life and their caregivers and families when the level of nursing, medical and psychosocial care needed exceeds the capacity of primary care teams and community-based chronic care and aged care services
- > based on need and informed by a comprehensive palliative care assessment
- > in homes and in residential aged care, transition care and community disability support facilities
- > at an agreed and consistent level across the state, as delineated by the resources and capabilities of each level of specialist service (Level 2, 4 and 6).

In the community setting, palliative care services will provide:

- > palliative care assessment, care planning, advice and support for people and their families/kinship groups
- > around the clock, consultative advice to providers of primary and community-based chronic end of life care services to support them in their work and systematically build and extend their skills, confidence and clinical capacity in the care of people at end of life
- > around the clock advice and support to palliative care patients and their caregivers, either remotely or at the point of care, based on need

^d Modeling in Table 3 uses current SAPS referrals and rate of death at home and projects this data across each new palliative care service catchments. The SAPS catchment has been used as the reference point because it will remain unaffected by the new service configuration.

- > ongoing assessment of risk from complicated grief from time of referral, early therapeutic intervention to positively alter grief trajectory and timely referral to primary and specialist loss and grief services, wherever possible
- > a range of high quality and regularly evaluated programs of clinical teaching and capacity building to all providers of community-based end of life care, across health and disabilities sector.

Palliative care services often 'share' the care of people with complex needs with community agencies such as Royal District Nursing Service who also employ palliative care nurse consultants to provide advice and support in the home. To avoid duplication of services, providers will work together to ensure a quality, coordinated, sustainable approach to care. As demand increases, opportunities will arise for existing and new services to enter the services provider market. Careful mapping of care needs and service roles will clarify agencies roles and contributions and avoid duplication.

Palliative care packages

One of the new components of service arising from statewide reforms in health will be a targeted suite of palliative care packages to support community based care of people at end of life, their caregivers and their families. The scoping and development of these packages for use across South Australia will be undertaken as a priority and funding for these packages will be identified through a number of state and federal health reform initiatives.

This suite of packages may include:

- > a 'final days' package, designed for use in the terminal phase of care
- > a 'stabilisation' package, used as a short-term strategy in response to a rapid escalation of symptoms or shift in the burden of disease or in response to a family psychosocial crisis
- > a 'caregiver respite' package, for short periods of both planned and unplanned caregiver respite
- > a 'complex continuing care' package, for the continuing care of a person at end of life at home who would otherwise require overnight admitted care in a hospice
- > a package specific to meeting needs of Aboriginal people.

On the basis of need, these packages will also be accessible to support home-based care at end of life provided by generalist providers. A critical enabler will be the availability of the right mix of Registered Nurses and personal care workers required to perform this work, particularly at short notice, after hours and over night. The development of this personal care worker role for use in palliative care packages will require planning and a comprehensive workforce strategy.

Day hospice

The Plan makes provision for the piloting and evaluation of a variety of 'day support' options, for use by clients of Level 6 and 4 services. The day hospice setting may prove a suitable venue for a range of planned activities such as the performance of therapeutic procedures and interventions, assessment and rehabilitative activities, carer education, carer respite and support and to mitigate social isolation.^{36,37,38} This reflects the need to organise services in response to demographic and social trends that see an increasing proportion of older people living alone, and/or without a primary caregiver³⁹.

Rapid response teams

In recognition of the impact of managing increasing numbers of people with complex care needs in the community, Level 6 palliative care services will develop and pilot the use of rapid response teams. These teams will bring expanded emergency and out of hours multidisciplinary response to the home or site of care at short notice and may comprise, nursing, palliative medicine and allied health staff depending on need. These teams will respond to situations that would otherwise result in presentation and management in the Emergency Department, or admission to an acute care bed or hospice.

Out-of-hours interventions performed by rapid response teams are likely to include:

- > a comprehensive clinical reassessment
- > revision of the plan of care and changes to the therapeutic regimen
- > communication of changes and the initiation of follow up 'in hours' by routine care providers.

They may also include the activation of a short-term palliative care stabilisation package, and if required, hospital or hospice admission. An evaluation of the efficacy and effectiveness of rapid response team initiatives will be required and will inform the midpoint review of the Plan.

Ambulatory care services

Across the GP-Plus Health Care Centres and in the outpatient settings of public hospitals within their service catchments, palliative care services will provide a range of ambulatory care services including:

- > multidisciplinary palliative care outpatient consultation and review clinics
- > contribution to multi-specialty clinics (eg multidisciplinary cancer and Motor Neurone Disease clinics)
- > psychosocial assessment and individual, family and group counselling services
- > bereavement support and counselling services.

A number of innovative clinics may also be piloted and evaluated including:

- > symptom specific clinics (eg dyspnoea, anxiety/depression and cachexia/asthenia)
- > discipline-specific clinics (eg physiotherapy, occupational therapy, pharmacy, nursing).

Palliative care services in the hospital setting

The place of hospices in integrated service delivery

Dedicated hospice units play a critical role in meeting the needs of people at end of life who require periods of intensive inpatient care. The bulk of inpatient care provided by palliative care services will take place in hospices. Admission to all publicly funded hospice beds is based on need as determined by a palliative care assessment.

Admission to palliative care beds will assist people who require:

- > optimal control over complex or difficult symptoms
- > therapeutic investigations, interventions or care focused on rehabilitation and restoration of functional independence
- > terminal care in instances where this cannot be provided elsewhere.

The beds of a hospice are quarantined for this purpose and service the needs of people across the service catchment and the state, rather than the immediate catchment of the host hospital in which they are located. Hospices require a minimum cluster of 16 beds to ensure a critical mass of patients and skilled staff with qualifications and expertise. Where possible these units should be located on a ground floor environment with easy access to outdoor areas and easy on-site access to investigatory and treatment technologies.

Dedicated hospice units will be located in each of the Level 6 palliative care services. To meet the needs of South Australians requiring overnight admitted care in a hospice setting through to 2016, a reconfiguration and expansion of hospices beds is needed.

The changes outlined below represent a general configuration and timeframe, the final details of which will be determined at regional health level through the development of integrated health plans.

The establishment of the Level 6 palliative care services will require a transitioning period where the elements of the model are expanded. This transitioning period will involve both the sites where the Level 6 services will be based and those services where palliative care is currently being provided.

The following section makes provision for increasing the number of palliative care beds across metropolitan and greater Adelaide areas to 104 by 2016.^e Palliative care bed numbers in country areas are more difficult to quantify but this Plan identifies the need for 8-16 beds spread across the country General hospitals, at least two beds in the centre for Aboriginal health in Pt Augusta, supported by further beds in smaller country hospitals based on population size and need.

^e Made possible only by using a combination of differentially resourced and costed nurse-led hospice beds and medical-led hospice beds. The uptake of supported care in community-based shared housing options will also impact on the total number of beds needed across greater Adelaide for the life of this plan. The 2012 midpoint review will result in adjustments to these projections.

For the greater northern Adelaide area

- > Based in the Modbury Hospital, this unit will serve as the main centre of inpatient care in the Northern suburbs of Adelaide. The current hospice at Modbury Hospital will need to increase from its current 14 to 22 beds over the next few years.
- > A second hospice will soon need to be established at Gawler Hospital, configured initially as a small satellite unit of the Modbury hospice with a cluster of 4-6 palliative care beds. The size and the capacity of this unit will then need to be expanded to reach a sustainable unit of 10 beds by 2016.^f
- > The development of the hospice in Modbury Hospital will involve transitioning of some inpatient care from Lyell McEwin Hospital.

For the western, inner and eastern Adelaide areas and the Mt Lofty Ranges

- > The development of a hospice unit at The Queen Elizabeth Hospital is a priority. This unit will be part of the Level 6 palliative care service based at QEH and will need to have the capacity to provide 24 palliative care beds within the next 4 years. This hospice will serve as the main centre of inpatient palliative care in the western, central and eastern suburbs of Adelaide.
- > Some hospice care for public patients will continue to be accessed from Mary Potter Hospice in North Adelaide.
- > A small satellite hospice unit will need to be established at Mt Barker Hospital in the immediate future with an initial cluster of 4-6 palliative care beds. The size and the capacity of this unit will be expanded to reach a fully sustainable unit of 10 beds by 2016.
- > The development of the hospice at The Queen Elizabeth Hospital will include transitioning some of inpatient palliative care provided at the Royal Adelaide Hospital and the Phillip Kennedy Centre Hospice. The nature of palliative care services provided at RAH will change to better reflect its role as a Major Metropolitan Hospital. Similarly the role of Phillip Kennedy Centre will also change. While it will continue in its role as a provider of end of life care the planned expansion of services across the continuum of end of life care will ensure additional community based options are also available. The nature of service provision at Phillip Kennedy Centre will need to be considered within this expanded context.

For the southern Adelaide areas

- > Hospice facilities at Repatriation General Hospital will need to expand to a 22 bed unit. This unit will continue to serve as the main centre of hospice care in the southern suburbs of Adelaide.
- > Additional planned bed capacity will also be required at Repatriation General Hospital to absorb demand until the 22 bed unit is established.
- > The development of a hospice at Noarlunga Hospital with a base capacity of 10 beds by 2016, configured initially as a small satellite unit with a cluster of 4-6 palliative care beds.

Within the catchment of the paediatric palliative care service

- > Paediatric palliative care service has a commitment to supporting children and younger adolescents with palliative care needs to remain at home.
- > The need for paediatric palliative care in SA is too small to warrant a dedicated paediatric hospice unit. Paediatric inpatient palliative care will continue to be provided at Women's and Children's Hospital in hospital wards relevant to the child's underlying diagnosis or in adult hospices.

Within the catchments of Country General Hospitals

- > The volume of inpatient palliative care needed across country areas varies according to population demographics.
- > Each Country General Hospital will be developed to have a 2-4 bed capacity in purpose-designed single palliative care rooms.
- > The Palliative Care Coordinator will lead each rural and peri-urban palliative care service. These positions will serve to ensure:
 - the provision and coordination of high quality care for palliative care patients in each service catchment
 - the continuing provision of education and capacity building to primary and acute care providers of end of life care within the service catchment
 - a close and ongoing relationship with the Level 6 service partner.

^f Subject to the assessment of sustainability, workforce, palliative care bed demand as set out in the findings of the 2012 midpoint evaluation of the Plan.

- > Drawing on the role of Country General Hospitals as outlined in the Strategy for Planning Country Health Services in SA, Level 4 services will have greater capacity to support one or more neighbouring Level 2 services that operate within their cluster arrangement.
- > The Nurse Practitioner role will be a key element in the provision of expert palliative care by Level 4 services across the state. Within the framework set out by the Nurses Board of South Australia, Nurse Practitioners working in Level 4 palliative care services would be banded as 'rural and remote' with either a palliative care-specific scope of practice, a dual specialty scope of practice (that includes palliative care and for example an aged care or chronic disease scope of practice). These Nurse Practitioners will need access to palliative medicine specialists and to regular periods of clinical time in a Level 6 service through their candidature and on an ongoing basis.
- > To meet the end of life care needs of people who will increasingly be receiving care for advanced disease at local Country General Hospitals, the plan anticipates the need for designated medical roles within rural Level 4 services. In the absence of staff medical officers employed at Country General Hospitals, the role of the General Practitioners with a Special Interest in palliative care will be explored .
- > To work as a General Practitioner with a Special Interest in palliative care will require a Clinical Diploma of Palliative Medicine. Along with Nurse Practitioners and other members of the Level 4 service, they will be supported to locally manage the care of people at end of life with complex needs through a partnering arrangement with a Level 6 service that includes a program of regular visiting and the use of telemedicine as outlined below.

Within the catchment of country hospitals/health care centres

- > Inpatient end of life care will continue to be available in other country hospitals, in particular those hospitals that already have developed purpose-designed 'palliative care rooms'.
- > As Pt Augusta develops as a centre for Aboriginal Health, the inpatient care requirements at Pt Augusta will need to be identified. Palliative care in-patient facilities will need to have capacity to support cultural and spiritual end of life care needs of Aboriginal peoples.

Palliative care services in the residential aged care setting

Palliative care services currently provide a consultancy service to residents in aged care facilities. This service will continue and be expanded as the community palliative care teams are increased. The development of community packages of care will further assist aged care providers in meeting the care needs of their residents.

As part of the older peoples' health reform agenda in SA, the new Health Service Framework for Older People includes a range of initiatives that will further support aged care providers in meeting the health care needs of their residents. One element of this wide-ranging reform will be the advent of Regional Older People's Health teams working across aged care services and settings.

Through close partnerships, the Regional Older People's Health teams and Palliative Care services will work together to optimise their respective contributions to the care and support needs of older people at end of life. This will include round the clock access to advice and support from a local palliative care service, and access to overnight admitted care in a hospice on the basis of need. Consistent with sector standards and community expectations residential aged care facilities across South Australian will continue to provide quality end of life care to residents so that they may 'live in place' and 'die in place'.

Working within the new care model

Types of palliative care beds

The Plan also develops the concept of differentiated types of palliative care bed. Nurse-led care options will be explored and developed to enhance the flexibility of services as they strive to be more responsive to the needs and preferences of people who require admitted overnight care or supported community residential care.

The co-location of a cluster of nurse-led beds within each public hospice will depend on a number of factors including:

- > the piloting, evaluation and costing of this option
- > the availability of advanced practice nurses and Nurse Practitioners to facilitate the care.

A mid-point review will be undertaken in 2012 to examine the overall demand for overnight admitted care in hospices, taking into account trends in demand, length of stay, inpatient activity profiles and the outcomes of investment in community-based care. This will inform the further consolidation of hospices in the outer northern and southern suburbs and in the Adelaide Hills. The impact of the expansion of private cancer services at Calvary Hospital on demand for palliative care services will be monitored and will also inform planning for inpatient care.

Acute palliative medicine in hospitals

Through the provision of an Acute Palliative Medicine Service, Level 6 adult palliative care services will maintain a presence in the all metropolitan hospitals within their respective catchments. The predominant component of this work will be consultancy and liaison in character.

This includes the provision of:

- > Consultancy and liaison services to a range of specialty clinical teams to contribute to coordinated, seamless care for inpatients based on agreed referral criteria and referral mechanisms. This component of service is not an emergency service or an adjunct discharge planning service
- > Timely and sensitive exploration and negotiation of transfer to community based care options or inpatient care at a hospice or other appropriate facilities (including other hospices across the greater Adelaide area, residential aged care facilities, and community-based shared housing options if available)
- > Input to multidisciplinary case conferences and clinics where appropriate
- > The first line referral point for triage and the initial elements of the palliative care assessment will be provided in most instances by a Level 3 or 4 specialist or advanced practice nurse.

A significant emphasis of the work of an Acute Palliative Medicine Service provided at metropolitan hospitals will take place through the use of 'critical conversations' with and between treating teams, inpatients and their caregivers and families at key trigger points along the end of life illness trajectory. In anticipation or in response to these triggers, palliative care services will:

- > contribute to decision-making forums [through family and clinical case conferences] to enhance shared end of life care planning
- > ensure that timely, appropriate and coordinated palliative care inpatient transfers between metropolitan hospitals and hospices across the greater Adelaide area are facilitated.

Given the changing emphasis and the differing target profiles for metropolitan general and major hospitals within the health service architecture of SA Health, it will become increasingly important that people are admitted to the *right hospital* which may not necessarily be the *nearest hospital*.

Optimising the influence of palliative medicine

The model of care supports palliative medicine specialists to achieve high levels of integration and influence in a range of medical specialty services (including oncology, neurology, renal, thoracic and general medicine) to ensure that each acute specialty service integrates quality end of life medical care into their clinical practice.

Palliative medicine specialists will work across clinical services and actively engage with the junior and resident medical staff and with advanced trainees of those services to maximise their capacity to provide quality end of life care to inpatients in the acute care setting.⁹

The team providing the Acute Palliative Medicine Service will include palliative medicine specialists, nurse practitioners, clinical practice consultants and coordinators and where available, advanced trainees in palliative medicine, general practice trainees and sessional general practitioners with a special interest in palliative care.

⁹ Their target population is often referred to as those identified via the 'surprise-question':
"Would you be surprised if this patient were to die in the next 6-12 months?"

These teams will help facilitate acuity-based care planning and timely responses to need in the Acute Medical Units of Adelaide's three adult major metropolitan hospitals. They will collaborate with other contributing medical specialist services and nursing and allied health staff working in this setting. The Paediatric Palliative Care service will provide this function at the Women's and Children's Hospital.

On the basis of a comprehensive palliative care assessment, they will provide an appropriate level of consultation or continuing clinical involvement using standardised protocols, individually tailored and negotiated to meet the needs of inpatients who have been identified as transitioning from an acute care pathway focusing on cure or disease modification to a palliative care pathway that focuses on quality of life and active symptom control.

In some instances the Acute Palliative Medicine Service may be the best team to assume managing care during an episode of admitted overnight care in an adult major metropolitan hospital. To facilitate appropriate investigations or treatment the Acute Palliative Medicine Service may arrange a planned admission to acute or sub acute beds of these hospitals for this purpose. This will necessitate a daily presence and access to advice and support on an around the clock basis.

The acuity model^h will change many aspects of management and the flow of inpatients across the metropolitan hospitals of Adelaide. Equally, the enhanced capacity of country general hospitals to meet the needs of people undergoing treatment for advanced or end-stage disease will also impact on the palliative care inpatient profile of adult major metropolitan hospitals. The quantity of palliative care service resources required to support quality end of life care in the major metropolitan hospitals and the amount of direct care provided by the Acute Palliative Medicine Service teams will be need to be monitored and refined as these changes take effect.

Equipping teams for change

A considerable emphasis of this plan hinges on the use of a single shared model of palliative care to support the quality and consistency of service delivery across the state. Expanding the capacity and the disciplinary diversity of the specialist team to enhance the sustainability of services over the long-term presents as both a challenge and an opportunity.

To achieve the vision of a dynamic modern palliative care service structured for long-term efficacy, flexibility and sustainability requires an integrated strategy of team diversification and role design, within a team culture characterised by 'interdisciplinary' rather than 'multidisciplinary' approaches and 'collaborative' rather than 'cooperative' work practices.^{40,41,42}

The strategy rests firstly on matching the right skills and expertise to best meet the needs of people at end of life. Broadly speaking this includes a range of biomedical, psychosocial, spiritual and cultural care expertise. It then requires that the right configuration of fully optimised disciplinary roles be brought together to function as an integrated collaborative interdisciplinary team. Exploring the impact of new and emerging roles will also be an important feature of the workforce strategy.

The three Level 6 adult palliative care services in metropolitan Adelaide will be expanded by the inclusion of a number of new and emerging roles, each designed to add to the capacity of services to achieve enhanced community care outcomes for people at end of life, their caregivers and families. A significant emphasis will also be placed on extending the concept of 'advanced practice roles' beyond nursing into other areas including social work, pharmacy, and a range of allied health and other psychosocial support roles.

When the new adult Level 6 services are launched they, along with the SA Paediatric Palliative Care Service, will have expanded clinical teams to assist their efforts to achieve the service and patient-level outcomes described in this plan. As a consequence of the presence of new roles, and in response to the enhanced focus on community-based care, some of those working in long-established roles within palliative care teams will be called on to work differently. Level 6 services will also be additionally resourced commensurate with their respective out-of-region responsibilities to Level 4 and Level 2 partners across the state.

The healthy functioning and long term sustainability of these teams rests in part on the optimisation of shared learning opportunities, a culture of adaptability and reflective practice, exemplary leadership, and structured access to both individual and group clinical supervision. A number of contemporary challenges are also apparent.

They include:

- > the need to embed new and emerging roles within services and develop the methodologies to evaluate the impact and efficacy of each role, and by so doing contribute to the evidence that validates new team configuration and supports long-term workforce planning
- > the implementation of the nursing career structure, and a lack of similar career path for social workers
- > the need to generate and maintain a viable workforce of community-based careworkers with specific training in quality end of life care.

Additional information on new ways of working together is contained in Appendix 5.

^h As outlined in the relevant SA Clinical Senate model of care documentation (2008)

Supporting end of life care providers

To further improve the quality of this care, in the face of an overall increase in the demand for end of life care requires:

- > an informed community
- > an informed health sector the 'right' support for generalist providers of end of life care by the palliative care sector
- > a particular focus on supporting living-in-place/dying-in-place in the residential aged care setting
- > the whole of population evaluation of end of life care.

Underpinning the directions for palliative care is an end of life health literacy program. Advance Care Planning and Advance Directives play an important role in enhancing the health literacy of South Australians. The key strategy in this area involves the roll out of an Informed Choices Program across primary, chronic and aged care services in each health region. This program will train and equip key frontline workers positioned to respond to triggers along patient pathways to optimise the timely initiation of advance care planning and the completion and utilisation of advance care plans.

The Palliative Care Council of SA has a significant role in advancing health literacy for people at the end of life. The Council is recognised as an effective community representative peak-body advocating quality end of life care for all, supporting caregivers, and promoting health and health literacy.

Appendix 6 sets out additional information on supporting end of life care providers.

Improving access and equity

Like South Australia's Health Care Plan, this Plan recognises a 'social gradient' where the needs of marginalised or disadvantaged communities require particular attention to ensure equity of access and comparable care outcomes.

There are a range of planning issues and service delivery challenges associated with the end of life care needs of a number of specific populations including:

- > people living in rural and remote areas of the state
- > infants, children and adolescents
- > Aboriginal people
- > people from diverse cultural backgrounds or linguistic traditions
- > older people and those in residential and community aged care settings
- > younger people needing supported care in the community
- > those experiencing grief and bereavement
- > those receiving care in the private sector
- > those with interventional pain management needs.

Additional information outlining key initiatives and enablers associated with improving access and equity has been provided in Appendix 7.

Opportunities for collaboration

Health in grief and loss is an area that extends well beyond palliative care and will require a statewide and whole of health approach. Equitable access to primary care bereavement support for all, based on need, can be achieved by working with:

- > GP Plus Health Care Networks and other providers of primary care across the state to configure appropriate community-based primary care support and interventions strategies.
- > key stakeholders and champions within a range of health services (such as peri-natal, intensive care, mental health, and a range of chronic disease as well as trauma and emergency response teams) to explore and optimise system-wide responses.
- > range of community agencies and educators to raise awareness of the need for and enablers of community-wide health in grief and loss.

A statewide Health in Grief and Loss Plan will be developed. The expected long-term outcomes from of this plan will include:

- > enhanced equity of access to appropriate interventions for all people at risk of complicated grief regardless of the service pathway they take
- > a reduction in the incidence and severity of bereavement related mortality and morbidity across SA
- > reduced reliance on palliative care services to meet the bereavement needs of people who would not otherwise need or benefit from referral to a palliative care service
- > the repositioning of palliative care service focus back onto consultative, educational and direct service for complex bereavement in palliative care clients only.

The South Australian Paediatric Palliative Care Service will require expansion. To better meet the psychosocial support and bereavement care needs of infants, children, adolescents and their parents, families and communities, an additional role will need to be incorporated into the service. The nurse practitioner role will be further consolidated within the team complement, as will investment in specialist paediatric palliative medical expertise. End of life pathways for older adolescents and young adults with continuing care needs will need to reflect the transition into adult-oriented services.

Supporting regional older people's health services

Key members of each palliative care team will work with the new Regional Older People's Health Services to systematically establish and refine referral pathways, clinical support protocols, shared learning opportunities, and quality and evaluation of care at end of life in the aged care sector (both residential and community). Mechanisms will need to be in place to ensure formal relationships and referral pathways between tertiary level aged care services and palliative care services are optimized and lead to integration, coordination and continuity of contributions by these teams in both community and residential aged care settings.

Working alongside pain teams

Palliative care and pain services will work with other key stakeholders to support population-based improvement in outcomes related to prevention, intervention and control of acute, chronic and complex pain across South Australia. This suggests a need for a close clinical working relationship between procedural pain teams and palliative care teams. Formal relationships between Level 6 palliative care services and tertiary pain services will facilitate this.

Enhancing quality

A series of national standards governing the provision of palliative care services has been established through Palliative Care Australia.⁴³ These standards cover a range of service activities and practices and form the basis of a nationally consistent framework for service evaluation and quality improvement.

The quality of care provided to South Australians at end of life is dependent on many factors not least of which is a system-wide application and understanding of the common model of care, a degree of consistency in day-to-day use of language, practice and treatment guidelines, outcome assessment and performance improvement strategies.^{44,45} It also hinges on a cultural commitment to teaching and learning and to continuous quality improvement.

Demonstrating performance and continuous improvement

There will be a number of elements that together form a comprehensive quality framework for all palliative care services funded through SA Health.

These elements include:

- > the fostering of innovation and practice improvement, clinical and health service research, and a culture that seeks always to learn from mistakes, expand and share knowledge and improve the safety and quality of care
- > the performance of audit, quality feedback loops, and 'plan-do-study-act' cycles by individual practitioners, teams and services
- > regular service self-assessment against the national standards using a suite of validated assessment tools, with an emphasis on the experience of people at end of life, their caregivers and family as they traverse the health system
- > the adoption of the Competency Standards for Specialist Palliative Care Nursing Practice⁴⁶ as a shared statewide approach in the recruitment, professional practice development and performance management of specialist palliative care nurses
- > service benchmarking and peer assessment – each Level 2, 4 and 6 Service will undergo benchmarking with comparable benchmark partners identified locally or nationally and utilise peer assessment to critically review all aspects of service delivery to ensure quality
- > national palliative care specific accreditation. All Level 6 services will undergo specialty-specific accreditation by 2012 and all Level 4 services by 2016.

To support service evaluation, planning and reform a statewide reporting cycle will be developed to yield a consistent report of activities and outcomes across palliative care services. This Plan anticipates a continuing program of whole-of-end-of-life-outcomes surveillance will be in place to:

- > evaluate population-level end of life care outcomes across services, health regions, and the state
- > assist in the evaluation of service-level programs or pilots designed to enhance the care choices or improve the quality of end of life care provided across services, health regions and the state
- > assist in the revision and refinement of palliative care service planning, workforce and funding arrangements.

Appendix 8 sets out in more detail key aspects of the data, reporting and surveillance agenda that will support enhanced quality and care outcomes arising from the Plan.

Implementation

Strengthening partnerships

The integrated service delivery model described in this Plan draws on a whole of population approach and develops a sharper focus on the outcomes of people receiving end of life care across a range of care settings. The partnering relationships between palliative care services of varying levels across the state will be systematically consolidated over the life of the Plan. Each service will report on the development and the status of their partnering relationships including:

- > regular report on the development and implementation of programs of visiting and support
- > periodic audit and evaluation of the uptake and impact of remote telemedicine facilities.

Managing the transition

The formation of the regional services will require a period of transition as components of the model are expanded and reshaped. For the palliative care sector, this will include developing the Level 6 and Level 4 services at the General Hospitals, the reconfiguration of beds within hospitals and the expansion of teams working in the community setting.

The changes inherent in the model of care will require supported renegotiation of the roles of generalist providers of end of life care in the acute, residential and community setting. This will take place at a time when the effects of a range of other significant reforms designed to improve the provision of health care are also impacting positively on the system.

The Regions have established processes and mechanisms to manage this complex implementation. Service providers are actively participating in the design of the new service arrangements consistent with reform plans.

The transition is further supported by the new Aged Care Funding Instrument (ACFI) which has been implemented by the Australian Government in recognition of the increasing level of care required to meet the needs of some aged care residents. This instrument specifically recognises the increasing complexity of people's care needs at end of life and allows the aged care sector to maximise the resources available to them to more adequately these needs.

Leadership and change

Further planning at the regional level will lead to the development of integrated service plans for each region and it will be through this mechanism that the directions of this and other statewide services plans will be operationalised.

Underpinning this will be a framework of statewide quality improvement, reporting, information technology, workforce and population-based surveillance programs. South Australia's Health Care Plan makes use of statewide clinical networks, eight of which are currently in place. This approach represents the preferred clinical leadership mechanism for the palliative care sector in South Australia.

A Statewide Palliative Care Clinical Network will support the development of a single model of care and a standardised approach to service delivery across the state and also have oversight of a number of key statewide projects that will contribute to the roll out of this Plan.

Expanding the vision

Health Promotion

The palliative care sector has an evolving interest in the promotion of health through the normalisation of death. Through a range of targeted public health promotional approaches designed to shift the level of community anxiety about death and dying palliative care services seek to redress the concerns of those that feel that assisted suicide is a more dignified response to impending death than the path that lies through illness and dependence on others.⁴⁷

Developing and supporting the workforce

A statewide palliative care workforce strategy will be developed. Using a systematic approach to recruitment, retention and role innovation, a workforce strategy will be implemented to build the capacity and the sustainability of palliative care teams, including the early incorporation of a range of specialist roles in each adult Level 6 service including consultant physiotherapists, occupational therapists, pharmacists, clinical psychologists and the caregiver network facilitator. A 2009-2010 palliative care workforce profile will be produced as a priority.

Additional detail about the workforce strategy has been included in Appendix 9.

The Plan anticipates the need for a workforce of approximately 23 Nurse Practitioners by 2016. Consistent with the County Health workforce strategy some of the nurse practitioners working in Level 4 palliative care services may have a scope of practice that incorporates aged care or chronic disease care and work in roles that focus on a dual speciality population.

Growing this workforce will require the preparation of Nurse Practitioner candidates using a staggered cohort approach. The first cohort will be drawn from the interested specialist nurses with experience and post-graduate qualification. Nurse Practitioner role development positions will need to be incorporated within each Level 6 service in 2008/09 and the appointment of the first cohort of 6 palliative care nurse practitioners within 18 months. A Nurse Practitioner workforce development program will be put in place to facilitate coordinated training and clinical supervision opportunities across the state. It will play a key role in extending the focus of Level 6 services as centres of advanced training for all those disciplines that contribute to palliative care.

The cost effective incorporation of salaried sessional General Practitioners with a Special Interest in Palliative Care will be explored. Based on service need and level of uptake by general practitioners the role will be incorporated into Level 4 and Level 6 services across the state.

Other key role innovations include:

- > A repositioning of palliative medicine roles within the acute sector and a workforce replenishment strategy to ensure the supply of palliative medicine specialists.
- > The recruitment of accredited pharmacists for each adult Level 6 service in 2009 and the launch of a community pharmacy network in 2009.
- > The emergence of the palliative psychological medicine specialist role within the specialist medical complement of each adult Level 6 service.
- > The incorporation of a welfare officer in each integrated Level 6 service to provide information and assistance to families with welfare, legal, financial, housing, placement and transport issues.
- > The utilisation of a business manager in each adult Level 6 service to assist in the executive, financial and administrative functioning of each regionalised, integrated service.

Widening the concept of advanced training in Level 6 services

Each adult Level 6 service will meet the criteria for and maintain accreditation as a training site for advanced training in palliative medicine and will also serve as training sites for the clinical diploma in palliative medicine and the specialist skill attachment for general practice training.⁴⁸ While the training of paediatric palliative medicine specialists is not available in South Australia, opportunities for a combination of local and interstate advanced training will be explored and developed.

Advanced training positions will be allocated by analysis of statewide need through the workforce strategy.

All Level 6 services will take up a principle role in support of the role transition and clinical supervision of Nurse Practitioner candidates, and advanced training roles in social work, pharmacy and key allied health disciplines. Supporting the advanced practice training of others will be a key distinguishing feature of all specialists working in Level 6 services.

Service level leadership and accountability

The expanded scope of the three adult Level 6 palliative care services as outlined in this Plan will require skilled executive leadership oversight and capacity.

The challenges and transitions outlined in this Plan commend the use of service director positions in each adult Level 6 service with appropriate job and person specifications that reflect the need for high quality health service leadership and executive administration.

An adequate level of business manager support for each Level 6 service will also be required. Health regions will develop, through review and revision of all job and person specifications, a shared clinical governance structure for each adult Level 6 service that accounts for a contemporary construction of medico-legal liability and accountability within collaborative interdisciplinary practice models.

Equipping and integrating clinical teams through information technology

To enable palliative care services to work effectively and efficiently across acute and primary care settings, significantly enhanced information technology and data management support and is necessary.

To achieve the anticipated community-based care outcomes that have been outlined in this plan, team members will need to be supported to:

- > simultaneously work across the breadth of their service catchments while maintaining the ability to communicate with other clinicians, and collaborating agencies
- > input and extract clinical patient information in real-time while away from the office, in homes, hospitals, residential aged care facilities, GP Plus Health Care Clinics and outpatient departments
- > dispense with profoundly inefficient and labour intensive paper-based documentation systems that rely on double or triple data entry to collect clinical and quality-related data.

Essential requirements to support interconnectivity, improve palliative care service and patient outcomes will rely on:

- > a single statewide web-based wireless information technology system for standards-compliant communication and clinical data entry/extraction at point of care, to facilitate efficient and effective service delivery across service catchments, and between government and non-government agencies through careconnect.sa
- > a statewide dataset configured around a single unique record number for all people receiving palliative care services
- > access to reliable, portable wireless computers
- > the training of clinical teams
- > ready access to skilled information technology and data support workers to assist with the extraction and utilisation of data for quality, audit and reporting purposes.

Directions at a glance

Table 6

Statewide initiatives			
1.1	Supporting the work of the Palliative Care Council of SA	1.4	Establishing a statewide palliative care community pharmacy network
1.2	Strengthening service partnering arrangements across the state	1.5	Establishing a statewide palliative care clinical network
1.3	Developing a suite of palliative care packages	1.6	Using a shared model of care and common approach to service delivery across the state
Whole of system initiatives			
2.1	Rolling out an 'Informed Choices Program' across the state	2.2	Developing a statewide health in grief and loss plan
Service Redesign initiatives			
3.1	Development of Level 6 services within CNAHS	3.6	Exploring day hospice options
3.2	Developing Level 4 services in country SA	3.7	Using rapid response teams
3.3	Development of an Aboriginal palliative care service in Pt Augusta	3.8	Differentiating palliative care bed types
3.4	Extending and expanding community based services	3.9	Undertaking capital works
3.5	Reconfiguring bed and hospice units		
Collaborative enablers			
4.1	Supporting new regional aged care teams	4.4	Working differently in the acute setting
4.2	Working with the Aged Care sector to develop their capacity as end of life care providers	4.5	Working alongside pain management teams
4.3	Working alongside chronic disease services		
Workforce initiatives and enablers			
5.1	Developing a statewide palliative care workforce strategy	5.5	Expanding the concept of advanced training
5.2	Growing the established workforce	5.6	Exploring and using the General Practitioner with a Special Interest
5.3	Proliferating advanced practice roles	5.7	Establishing a trained community-based personal care workforce
5.4	Growing a Nurse Practitioner workforce	5.8	Exploring and using new and emerging roles
Quality, data, reporting initiatives			
6.1	Developing an end of life care outcomes surveillance capacity	6.3	Establishing a statewide reporting cycle
6.2	Implementing a statewide quality program	6.4	Putting in place IT solutions & support
Research and education initiatives			
7.1	Reinstating a statewide end of life research collaborative	7.2	Using a statewide approach to education, training support and practice development

Next steps

Responding to changes

The Plan anticipates many of the identifiable challenges that lie ahead. The dynamic nature of reform within a changing health care environment requires systems to be in place to monitor and respond to unanticipated risk or independent trends. This will require the Statewide Palliative Care Clinical Network to adopt a watching brief on developments related to:

- > rates of death at home, proportion of time spent in the out-of-hospital setting, along with the additional identification of barriers and enablers
- > demand, usage and length of stay in the hospices of greater Adelaide
- > the impact of the acuity-based model of care in the major metropolitan hospitals of Adelaide
- > the impact of new supported care options for younger people (under 65 years old) with step-down or slow stream needs
- > the availability, recruitment and retention of palliative care clinicians of all disciplines
- > barriers to role optimisation across advanced practice roles
- > legislative obstacles to the handling or movement of the deceased in the home or community setting, including restrictions on those who can 'declare life extinct' and the possible need to extend certification of death to nurse practitioners
- > forthcoming National Health & Hospital Reform Commission performance reporting requirements
- > the impact of any forthcoming private insurance products that offer community-based end of life care and support options to the privately insured
- > changes in the amount of private practice palliative medicine
- > changes in hospital flows and the role of GP Plus Health Care Centres
- > the level of demand for complex end of life care in country General Hospitals, and barriers to meeting this need
- > the ongoing monitoring of caregiver burden
- > access (or barriers to access) to palliative care services by Aboriginal people and people from cultural and linguistically diverse communities
- > changes in the usage profile and uptake of volunteerism
- > the presence and impact of accessible primary care bereavement services.

Evaluating the outcomes of the Plan

Evaluation will be a core component of implementation and occur at key points across the life of the plan and include:

- > the ongoing piloting and adaptation of system and service-level reforms and innovations
- > a 2012 midpoint report on the progress of the Plan
- > a new statewide strategic plan for the period of 2017 and beyond.

Timeframe for action

The following action timeframe will be implemented by regional health services and the statewide palliative care clinical network over the life of the plan. There are some immediate next steps required to commence the implementation of the plan.

Priority first actions

There are some immediate next steps required to commence the implementation of the plan. The anticipated program of work required in 2009 includes the following areas.

Statewide

- > The establishment of the statewide clinical leadership framework for palliative care (Statewide Palliative Care network).
- > Develop and implement palliative care packages in both metropolitan and country areas. This work will be supported by a statewide project funded from a grant from the National Palliative Care Program.
- > Workforce initiatives to recruit and develop palliative care clinicians, commencing with the Palliative Care Nurse Practitioner Role Transition Program, and the development of pharmacist consultant positions and the associated SA Palliative Care Community Pharmacy Network as well as a range of other advanced practice roles.

Metropolitan specific

- > The formation of the 2 Level 6 services in CNAHS
- > This will require bringing together the separate teams currently located in different hospitals to form regionalised services
- > Develop processes needed to enable clinicians to work across multiple care facilities
- > Establishment of the hospice at The Queen Elizabeth Hospital
- > Extend the capacity of the hospice at Modbury Hospital
- > Determine the resource impact on primary care services of supporting more people with palliative care needs to die at home.

Country specific

- > Development of services in country level 4 sites, with a particular focus on achievement of equity of access across country South Australia
- > Develop the Aboriginal palliative care service based in Pt Augusta.

Table 7

Initiatives and timeframe

	Financial Year							
	08/09	09/10	10/11	11/12	12/13	13/14	14/15	15/16
Transition Initiatives								
- Integrated Service Plans by Health Regions								
1.2 Statewide service partnering								
1.3 A suite of palliative care packages								
1.4 Community Pharmacy Network								
- After hours emergency medications project								
1.5 Statewide palliative care clinical network								
- Next statewide palliative care services plan								
1.6 Development of common tools, protocols, guidelines and pathways								
Whole of system initiatives								
2.1 An 'Informed Choices Program'								
2.2 A statewide health in grief and loss plan								
Service Redesign Initiatives								
3.1 Services consolidation in CNAHS								
- Promotion and launch of new Level 6 services								
- Development of online profile and resources								
3.2 Development of Level 4 services at Country General Hospitals and in peri-urban services								
3.3 Scoping of post-PEPA Aboriginal palliative care service needs and roles								
3.4 Rapid response teams (pilot & evaluation)								
- Death at home rate of 30-40%								
- Death at home rate of 45-55%								
3.5 Bed and hospice unit reconfiguration								
- Nurse-led care options (pilot & evaluation)								
3.6 Day care options (pilot & evaluation)								
3.9 Capital works - telemedicine units								
- Team accommodation - TQEH & Modbury								
- RGH Hospice Expansion								
- Satellite unit refit – Mt Barker and Gawler								

Table 7
Initiatives and timeframe contd.

	Financial Year							
	08/09	09/10	10/11	11/12	12/13	13/14	14/15	15/16
Workforce								
5.1 Statewide workforce strategy group	•	—	—	—	—	—	—	—
- First three-year rolling workforce profile	•	—	•	—	—	—	—	—
5.2 Growth in the established workforce	•	—	—	—	—	—	—	—
- Recruit paediatric psychosocial worker	•	—	—	—	—	—	—	—
5.3 Recruitment of advanced practice specialists	•	—	—	—	—	—	—	—
5.4 First NP role development positions	•	—	•	—	—	—	—	—
5.7 A community-based personal care workforce	—	•	—	—	—	—	—	—
5.8 Recruit new role post-holders	•	—	—	—	—	•	—	—
Quality, Data, Surveillance and IT								
6.1 Outcomes surveillance group	—	•	—	—	—	—	—	—
6.2 Statewide quality program and workgroup	•	—	—	—	—	—	—	—
- Complete accreditation of Level 6 services	—	—	—	•	—	—	—	—
- Complete accreditation of Level 4 services	—	—	—	—	—	—	—	•
6.3 Development of common data set, reporting template and protocols	•	—	—	—	—	—	—	—
6.4 Piloting & development of integrated regionalised service-level IT system	•	—	—	—	—	—	•	—
6.4 Once only entry into service and single record number	•	—	—	—	—	•	—	—
Research and Education								
7.1 SA End of life care research collaborative	•	—	—	—	—	—	—	—
7.2 Statewide Continuing Professional Development program, education and practice development	•	—	—	—	—	—	—	—

Appendix 1: Definition of terms

Terminology

The terms 'palliative care' and 'end of life care' require definition and their use within this Plan needs careful clarification. The way the terms are used is not intended to value one over the other, but to assist in differentiating the roles of specialist and generalist providers of end of life care in ways that clarify the contributions of each, while allowing for consistent use of terms.

Across the international literature, the term 'end of life care' is used inconsistently and without precise meaning. It is sometimes used interchangeably with the term palliative care and is also used specifically to refer to care in the terminal stage of illness (ie the last few hours or days prior to death).

The term palliative care also has wide meaning and attribution and can refer to a philosophy, a reform movement and an area of clinical specialty. In the context of this plan, the term palliative care is used to refer to specialty clinical practice and service delivery. It generally refers to 'the specialty that grew out of the hospice movement'.^{49,50}

For the purposes of this plan, the term end of life care is used to describe care that is planned for, negotiated with, or provided to a person at the end of their life. It is used without specific reference to timeframes and hinges instead on the orientation toward providing care appropriate for a natural life event and the ordinary place of death within a person's lifespan.

End of life care ends in death, but begins at a point that varies according to a range of factors:

- > Personal choice - for example when the person with advanced disease, or organ failure, makes a choice for comfort care only.
- > Professional judgment - when a health professional determines that physiological decline associated with advanced disease or system failure is irreversible, cannot be offset and where death is inevitable or expected. This may be informed by use of the question: *Would you be surprised if this person were to die in the next 12 months?*

In some instances people make the transition to end of life care when diagnosed with an incurable illness.

For others, end of life care is triggered by subtle clinical changes, an event, a revision of prognosis, or a simple recognition that death is coming. In some circumstances end of life care can last for years, and in others only days, or even hours, as can sometimes be the case in an Intensive Care Unit with the withdrawal of life-support.

Providers of end of life care

All health professionals have a responsibility to advocate for and contribute to the care of people at the end of life. Fulfilling this requirement requires a basic level of knowledge and skill in both the philosophy and the practice of palliative care.

End of life care is provided by health professionals who can be located along a generalist-specialist continuum from:

- > those that have occasional or regular involvement with people at end of life, to
- > those that have occasional or regular involvement with people at end of life and incorporate this work in their diverse practice, to
- > those whose scope of practice is solely or substantively focused on the population of people at end of life, largely to the exclusion of other areas of practice, and who are therefore required to develop specialist skill, knowledge and qualification in the field of palliative care.

Generalist providers (providers of end of life care)

Generalist providers refer to all those services and clinicians who have a primary or 'first contact' relationship with the person at end of life.

The use of the term 'end of life care provider' in this context refers to general practitioners, community-based domiciliary nurses, disability sector support workers, disease-specific chronic care coordinators, the clinical staff of residential aged care facilities and GP Plus Health Care Centres.

It also includes other specialist services and clinical staff of emergency departments, acute care hospitals and services, including for example gerontologists, oncologists, renal, cardiac or respiratory physicians, surgeons and other designated clinicians.

These staff, while specialist in their own areas, may undertake an ongoing, occasional or lead role in the support of people at end of life, depending on the circumstances, their capacity and the level of need. Generalists have in the past and will continue to provide the majority of all end of life care in South Australia.

Specialist providers (providers of palliative care)

Palliative care providers have a sole focus on end of life care and are directly involved with people who have complex and unmet physical, emotional, spiritual and social care needs that exceed the capacity of the generalist provider in either primary or acute care sectors.^{51,52,53}

Specialist providers are drawn from a range of biomedical and psychosocial science disciplines and have specialised knowledge and qualifications in the field.

Palliative care services have a major role in building the capacity of the broader health care sector to provide quality care to all people at end of life. Much of the Plan focuses on these services.

Appendix 2: End of life trajectories

Historically the focus of the palliative care sector has been weighted towards those people with a diagnosis of cancer and despite long-standing engagement with a range of non malignant diseases, the incidence of advanced cancer diagnoses cared for by palliative care services remains largely static at around 80-85%.^{54,55,56,57,58} The level of prognostic uncertainty associated with non-cancer disease courses is often cited as the major impediment to palliative care referral.^{59,60}

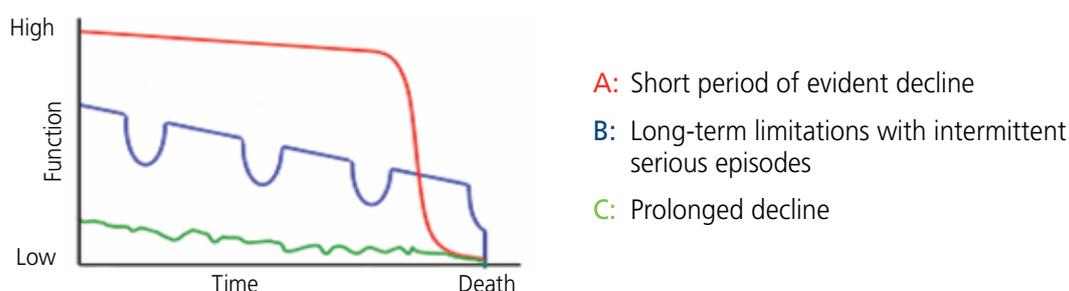
Emerging from the recent research and thinking within palliative care, is an appreciation of the features of a person's end of life trajectory as a significant determinant of need. This is seen as helpful in planning service responses at a whole-of-system level.^{61,62,63,64,65} Consideration of end of life trajectories also helps broaden the scope of planning beyond a focus on the relatively small proportion of people who die with involvement from a palliative care service.^{66,67}

This plan recognises the three typical or characteristic end of life trajectories, excluding sudden death, and seeks to appropriately position palliative care services across these three characteristic groups of people at end of life to ensure their input and resources are most effectively utilised.

These trajectories are outlined in figure 1. It should be noted that they are not intended for use as a fixed template to be applied to individual people.⁶⁸ Rather, the care needs of people at end of life are assessed individually and negotiated on a case-by-case basis using a best practice approach.⁶⁹

Figure 1

Typical end of life trajectories.



Taken from Lynn & Adamson (2003)

Trajectory A: Short period of evident decline

This trajectory is most commonly seen in advanced metastatic cancer and is characterised by:

- > maintenance of relatively good function to a point
- > a relatively short period of plummeting functional status and high symptom burden
- > a short terminal phase.

The pace and service-level responses to the needs associated with this trajectory ideally match the capacity and model of care that has traditionally been associated with palliative care services.

People whose end of life pathway follows this trajectory will have needs that challenge the capacity of generalist providers of end of life care and will benefit from timely referral to a palliative care service. For many people with advanced cancer, direct and continuing palliative care service involvement will be necessary and appropriate.

Trajectory B: Long-term limitations with intermittent serious episodes

Often seen in end-stage organ failure (typically end stage heart failure, liver and lung diseases) and characterised by:

- > progressive decline in overall functional status over time
- > periods of exacerbation or acute illness often necessitating hospitalisation, any of which could result in death
- > most deaths are sudden but few are surprising
- > high levels of prognostic uncertainty.

Both the pace and the types of care needed for people on this trajectory can be met through a shared care model between community generalist care providers with support from the relevant chronic disease service. For example, specialist heart failure nurses and nurse practitioners have been instrumental in anticipating and managing exacerbations of heart failure in the community and in thereby reducing hospital by up to 50%.^{70,71,72}

A proportion of these people will have needs that exceed the capacity of generalist providers and will benefit from timely referral to a palliative care service, leading to a coordinated shared care approach between palliative care services, chronic care managers and primary care providers. A smaller proportion of these people will have complex needs that will see the palliative care service take a lead role in their care. For some people with organ failure or other non-malignant diseases, their clinical course more closely approximates that of trajectory A or Trajectory C, prompting a different level of palliative care response or engagement.

Trajectory C: Prolonged decline

Typically seen in frail elderly people and those with an established dementia, characterised by:

- > slow incremental decline from an already very low functional status
- > minor or subtle clinical changes
- > continuing high-level care needs throughout with transition into terminal phase difficult to identify.

People whose end of life is characterised by this trajectory usually need continuing care in the community and supported care settings such as residential aged care facilities and will have their needs met by aged care providers with support of the local regional aged care team. Only a small proportion of these people need the input of a palliative care service.

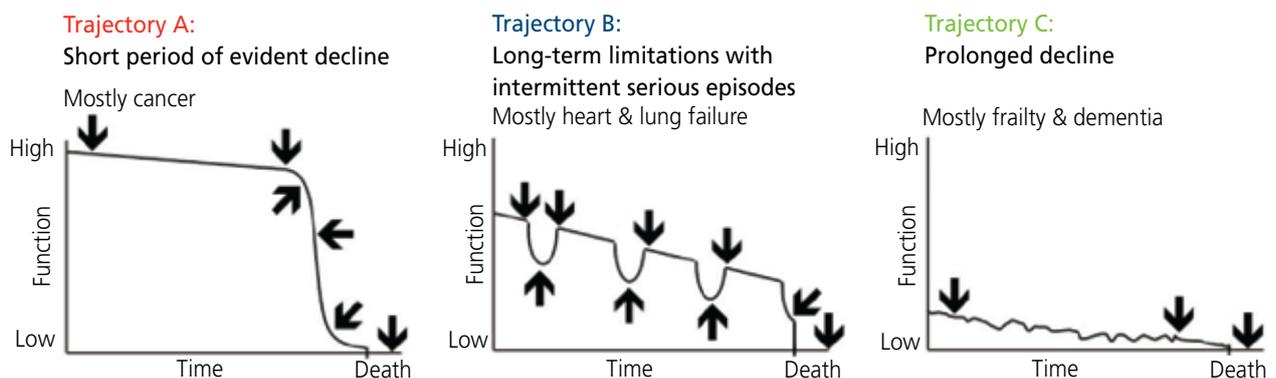
The role of triggers in service delivery and service planning.

The focus on needs-based service planning brings the concept of 'triggers' into sharper focus. The use of 'triggers' does more than assist in promoting timely referral to palliative care services. They help clarify opportunities for intervention, action and review by a wider range of health care providers involved with the care of people at end of life.⁷³

Triggers represent the real and potential opportunities that arise along a person's health journey that can change the nature, direction and outcomes of their care. Across these end of life trajectories, a number of triggers can be predicted and are illustrated in the following manner.

Figure 2

Triggers and Trajectories



Triggers come in many forms, and may include a new diagnosis or revision of prognosis, the advent of a frightening or overwhelming symptom or escalation of symptoms, an indication of distress or despair, a very subtle change, or from a shift in thinking by those involved (see Table 8 for examples).

Table 8
Examples of thought triggers

Source	Trigger
Person at end of life	"I think I'm dying!"
	"I don't want to have to go through [another visit to the ED] ever again!"
	"I just want to go home!"
Caregiver	"I'm exhausted...I don't think I can give any more!"
	"I won't go on without him!"
Clinician	"I'm going to be out of my depth soon!"
	"I don't know what to try next!"

Provision of quality end of life care for people rests in part on all health care providers being alert to and responding appropriately when triggers occur. This requires an informed clinical sector with the capacity, the time and the preparedness to respond to the evolving needs of people at end of life.

Across the health service continuum, clinicians should make use of triggers to:

- > listen to what at end of life, their caregivers, families/kinship groups for changes that lie ahead
- > reflect on or people are saying and asking for
- > review and adapt care plans ceasing ineffective or burdensome treatments
- > prepare people at end of life, their caregivers, families/kinship groups for changes that lie ahead
- > reflect on or review their own capacity to provide care, as well as their own personal and professional responses or feelings about death and dying
- > seek advice from palliative care providers, and where appropriate facilitate timely referral to specialist services.

Rather than 'leaving it all to the last minute' the timely and appropriate response to triggers that arise all along a person's health journey or illness trajectory can:

- > improve people's health literacy
- > help prepare people for death while at the same time improving their quality of living
- > prompt individual tailoring of care to systemically improve the care received
- > aid the transition of caregivers and family through grief and bereavement.

Enhancing the system-wide focus and capacity to respond to the needs of people at end of life, will also yield enhanced clarity about the respective roles and contribution of generalist and specialist sectors in the provision of quality end of life care for all.

Appendix 3: Expanding and reshaping palliative care services

Palliative care services in South Australia

The palliative care services of South Australia are becoming progressively more:

- > Patient-focused - where the person at end of life is the central concern of service planning and service delivery.
- > Community-focused - supporting people, their caregivers, families and communities to achieve social, emotional and spiritual health at the end of life through a commitment to optimising home and community-base care options
- > Delineated - a nationally consistent framework for service types. A single set of national standards are applied in a graduated fashion to each level of service to reflect both the level of expectation placed on each level of service, and the resource allocation necessary to achieve that level of service
- > Health promoting - with a focus on normalising death and dying as part of life and lifting the level of health literacy across all South Australian communities
- > Planned - using population-based planning principles to achieve equity of access, comparable quality of services and outcomes for patients and their families regardless of location
- > Delimited - with a focus on clinical engagement in the care of people with the most complex needs, while also actively engaged in a targeted and sustained consultative effort to support others who care for the dying and people at end of life across all settings, sectors and institutions
- > Regionalised - to provide a spectrum of services, interventions and programs to the palliative care population within their designated service catchment
- > Focused on outcomes - with appropriate quality and governance structures in place
- > Contributors - to the body of biomedical and social science evidence that shapes the practice of palliative care, through the facilitation, utilisation and generation of high quality research
- > Teaching and learning communities of practice, that seek always to learn from mistakes, expand and share knowledge and improve the safety and quality of care
- > Interdisciplinary in nature, drawing on a combination of individuals and disciplines to bring the best available blend of skill sets, experience and capacity to the services they provide
- > Responsive - to change and sustainable in design with a range of strategies in place to ensure that they can maintain and replace their workforce, manage their proportionate and evolving scope of practice and adjust their position in the health system appropriately
- > Networked with each other through a series of formal service agreements to provide/receive support and to achieve a range of shared outcomes
- > Collaborative in their relationships with direct care providers such as GPs, RDNS, Domiciliary Care SA, Regional Aged Care Teams, as well as the care teams of GP Plus Health Care Centres and community and residential aged care services.

Appendix 4: Service delineation

The delineation of services identifies the scope of practice and services provided within these levels and provides important planning, resource allocation and accountability functions. The development of a service delineation profile for palliative care services in SA incorporates two bodies of work:

- > The Clinical Service Delineation for SA Health Facilities.⁷⁴
- > The national palliative care service delineation framework developed by Palliative Care Australia.⁷⁵

While the national framework describes palliative care services using a three tiered framework, the Clinical Service Delineation for SA Health Facilities uses a 6 tiered model to describe patient complexity and the minimum level of support required to resource these needs. To give some capacity for national service comparisons, within this Plan, palliative care services are positioned across only three of the SA delineation levels (levels 6, 4 and 2). This framework aims to:

- > ensure a shared understanding of the expectations of different sized services
- > support parity of funding, benchmarking and comparison of outcomes between similar sized services
- > organise partnering relationships between services across the state
- > account for differing levels of local and statewide responsibilities.

The capability and resource profile of each level of specialist service as well those services that provide end of life care in the primary, acute, community, chronic and aged care settings are set out in Table 9.

Table 9

Delineated services descriptions

Acute, chronic, aged and community providers of end of life care	
Role	<ul style="list-style-type: none"> - Provide quality end of life care to people, caregivers and families. - Up to the level where specialist support or input is required to ensure quality end of life care
Setting	<ul style="list-style-type: none"> - Places of residence - GP practices or GP Plus health care centre - Hospital settings - Residential aged care facility - Anywhere in the state
Staffing	<ul style="list-style-type: none"> - Primary and acute care teams
Services accessible and available resources	<ul style="list-style-type: none"> - Local palliative care service - Local primary care community bereavement services - HACC, aged care & respite care packages - Local community health services - Community pharmacies - Other primary health care providers - Interpreter services - Aboriginal health services - Office of the public guardian - Diagnostic imaging and pathology services
Education of others	<ul style="list-style-type: none"> - Patient, caregivers and family - Nursing students, - Aged care workers - Disability workers - Aboriginal health workers - Students of all health care disciplines
Research involvement	<ul style="list-style-type: none"> - Initiates own research and audit activities if indicated
Quality activities	<ul style="list-style-type: none"> - Participates in quality activities
Level 2 palliative care service	
Role	<ul style="list-style-type: none"> - The provision of palliative care expertise and services - A mobile service to site of care - The service provided may be either direct or via telephone consultation - The service is available 24 hours a day, 7 days a week
Setting	<ul style="list-style-type: none"> - A regionalised rural service catchment, including homes, inpatient or outpatient hospital settings, GP Plus health care centres and residential aged care facilities
Leadership	<ul style="list-style-type: none"> - Rural palliative care nursing coordinator
Staffing	<ul style="list-style-type: none"> - Registered nurses experienced in palliative care and/or with tertiary qualifications
Partnering Relationship	<ul style="list-style-type: none"> - With local Level 4 palliative care service if available - With a designated adult Level 6 service - With SA paediatric palliative care service
Formal Service Links	<ul style="list-style-type: none"> - General practitioners - Domiciliary nursing services - Local GP Plus health care centres - Government-funded organisations - Residential aged care facilities - Allied health service providers - Community and hospital pharmacy services - Indigenous healthcare services - Medical and surgical specialties - Carer respite organisations - Volunteer services - Non-government organisations

Level 2 palliative care service contd.	
Services Accessible	<ul style="list-style-type: none"> - Local community bereavement services - Diagnostic imaging and pathology - Community pharmacies
Education of others	<ul style="list-style-type: none"> - Patient/caregiver education - In-service programs for primary care providers - Clinical teaching to clinicians who provide end of life care including nurses, aged care workers, disability workers, Aboriginal health workers - Clinical teaching to nursing, medical, allied health, students and others engaged in undergraduate programs that prepare health professionals who will provide end of life care
Research Involvement	<ul style="list-style-type: none"> - Collaborates with others to undertake research and incorporate research findings into practice - Contributes to policy development at a state-wide and national level
Quality activities	<ul style="list-style-type: none"> - Leads quality and audit activities within the service - Individual palliative care staff participate in their own ongoing professional development - Fulfils reporting requirements as determined by Country Health SA and SA Health
Level 4 palliative care service	
Role	<ul style="list-style-type: none"> - The provision of palliative care expertise and services - A mobile service to site of care - The service provided may be either direct or via telephone consultation - The service is available 24 hours a day, 7 days a week - Service as a clinical and professional resource to Level 2 services within cluster
Setting	<ul style="list-style-type: none"> - A regionalised rural or peri-urban service catchment, including homes, inpatient or outpatient hospital and hospice settings, GP Plus health care centres and residential aged care facilities
Leadership	<ul style="list-style-type: none"> - Rural palliative care coordinator
Staffing	<ul style="list-style-type: none"> - Registered nurses experienced in palliative care and/or with tertiary qualifications - Nurse Practitioner(s) (as available) - GP with a special interest (as available)
Partnering Relationship	<ul style="list-style-type: none"> - With local Level 2 palliative care service (if relevant through clustering Country Health SA arrangement) - With a designated adult Level 6 service - With SA paediatric palliative care service
Formal Service Links	<ul style="list-style-type: none"> - General practitioners - Domiciliary nursing services - Local GP Plus health care centres - Government-funded organisations - Residential aged care facilities - Allied health service providers - Community and hospital pharmacy services - Indigenous healthcare services - Medical and surgical specialties - Carer respite organisations - Volunteer services - Non-government organisations
Services Accessible	<ul style="list-style-type: none"> - Local community bereavement services - Diagnostic imaging and pathology - Community pharmacies - Outpatient clinics & GP Plus health care centres - Clinical psychology - Acute/chronic pain management services - Volunteer program

Table 9

Delineated services descriptions contd.

Level 4 palliative care service contd.	
Education of others	<ul style="list-style-type: none"> - Patient/caregiver education - In-service programs to primary and acute care providers/teams engaged in end of life care - Clinical teaching to clinicians who provide end of life care including nurses, aged care workers, disability workers, Aboriginal health workers - Clinical teaching to nursing, medical, allied health, students and others engaged in undergraduate programs that prepare health professionals who will provide end of life care - Training of volunteers
Research Involvement	<ul style="list-style-type: none"> - Initiates own research activities and collaborates with others to undertake research and incorporate research findings into practice - Contributes to policy development local and state-wide level
Quality activities	<ul style="list-style-type: none"> - Leads quality and audit activities within the service - Individual palliative care staff participate in their own ongoing professional development - Fulfils reporting requirements as determined by Country Health SA and SA Health
Level 6 Specialist Adult Palliative Care Service	
Role	<ul style="list-style-type: none"> - The provision of palliative care expertise and services - A mobile service to site of care - The service provided may be either direct or via telephone consultation - The service is available 24 hours a day, 7 days a week - Serve as a clinical and professional resource to a number of Level 2 and Level 4 services across the state
Setting	<ul style="list-style-type: none"> - A regionalised metropolitan service catchment, including homes, inpatient and outpatient hospital and hospice settings, GP Plus health care centres and residential aged care facilities
Leadership	<ul style="list-style-type: none"> - Service Director
Staffing	<ul style="list-style-type: none"> - Palliative medicine specialists - Advanced trainees in palliative medicine (as available) - Psychiatrist (where available) - GP with a special interest (as available) - Level 4 nurse clinical services coordinator/or director/or service functional director - Nurse Practitioners - Palliative care NP candidates (as available) - Level 3 nurse clinical coordinators with tertiary qualifications - Palliative care physiotherapist and OT consultants. - Accredited palliative care pharmacist - Social workers, clinical psychologist & other psychosocial support workers - Community network facilitator - Pastoral care staff - Bereavement coordinator and managers - Volunteer coordinators and managers - Coordinator of education, research and practice development - Welfare officer - IT and data support manager
Partnering Relationship	<ul style="list-style-type: none"> - With designate Level 2 and Level 4 palliative care services - With SA paediatric palliative care service

Level 6 Specialist Adult Palliative Care Service contd.	
Formal Service Links	<ul style="list-style-type: none"> - Academic units and research centres of excellence - Divisions of general practice - General practitioners - Domiciliary nursing services - Local GP Plus health care centres - Government- funded organisations - Residential and community aged care services - Allied health service providers - Aboriginal health services - Medical, surgical and radiation oncology services - Gerontology services and regional aged care teams - Rehabilitation services - Chronic disease services - Acute, chronic and complex pain services - Carer respite organisations - Non-government organisations
Services Accessible	<ul style="list-style-type: none"> - Local community bereavement services - Diagnostic imaging and pathology - Community pharmacies - Outpatient clinics & GP Plus health care centres - On site telemedicine unit - Volunteer program
Education of others	<ul style="list-style-type: none"> - As with Level 4 - Leadership role in broader educational activities - Contribution to formalised medical, nursing and allied health programs, curriculum development, delivery and review - Provision and oversight of advanced training in palliative medicine and of NP candidates and graduates - Development and review of training of volunteers and volunteer coordinators. - Demonstrated by faculty membership and joint appointments
Research Involvement	<ul style="list-style-type: none"> - Initiates own research activities and collaborates with others to undertake research and incorporate research findings into practice - Fosters research capacity and research integration of others - Contributes to policy development local and statewide level - Collaborates with others in SA or Australia to build a national/international profile in one or more program areas of research
Quality activities	<ul style="list-style-type: none"> - Leads quality and audit activities within the service - Individual palliative care staff participate in their own ongoing professional development - Fulfils reporting requirements as determined by health region and SA Health
Level 6 Specialist Paediatric Palliative Care Service	
Role	<ul style="list-style-type: none"> - The provision of palliative care expertise and services - A mobile service to site of care - The service provided may be either direct or via telephone consultation - The service is available 24 hours a day, 7 days a week - Serve as a clinical and professional resource all Level 2, 4 and 6 services
Setting	<ul style="list-style-type: none"> - A statewide service catchment, including homes, inpatient or outpatient hospital and hospice settings, GP Plus health care centres and other health care facilities
Leadership	<ul style="list-style-type: none"> - Paediatric Palliative Care Service Manager
Staffing	<ul style="list-style-type: none"> - Paediatric palliative medicine (provided by paediatrician with special interest in palliative care or a local adult palliative medicine specialist with special interest in paediatrics) - Paediatric palliative care NP(s) and or advanced nurse clinical specialist coordinator - Social worker, bereavement counsellor or psychosocial support worker
Partnering Relationship	<ul style="list-style-type: none"> - With all Level 2, 4 and 6 adult palliative care services across South Australia

Table 9

Delineated services descriptions contd.

Level 6 Specialist Paediatric Palliative Care Service contd.	
Formal Service Links	<ul style="list-style-type: none"> - Academic units and research centres of excellence - Divisions of general practice - General practitioners - Domiciliary nursing services - Local GP Plus health care centres - Government-funded organisations - Allied health service providers - Indigenous healthcare providers - Paediatric medicine, oncology and surgical services - Carer respite organisations - Non-government organisations
Services Accessible	<ul style="list-style-type: none"> - Local community bereavement services - Diagnostic imaging and pathology - Community pharmacies - Outpatient clinics and GP Plus health care centres - Clinical psychology - Acute/chronic pain services
Education of others	<ul style="list-style-type: none"> - As with Level 4 - Leadership role in broader educational activities - Contribution to formalised medical, nursing and allied health programs, curriculum development, delivery and review - Provision and oversight of advanced training in palliative medicine and of NP candidates and graduates - Development and review of training of volunteers and volunteer coordinators - Demonstrated by faculty membership and joint appointments
Research Involvement	<ul style="list-style-type: none"> - Initiates own research activities and collaborates with others to undertake research and incorporate research findings into practice - Fosters research capacity and research integration of others - Contributes to policy development local and statewide level - Collaborates with others in South Australia or Australia to build a national/international profile in one or more program areas of research
Quality activities	<ul style="list-style-type: none"> - Leads quality and audit activities within the service - Individual palliative care staff participate in their own ongoing professional development - Fulfils reporting requirements as determined by CYWHS and SA Health

Consistent with this delineation framework, the following table lists current palliative care services and those that will be in place by 2016.

Table 10

Service delineation table of SA Health's palliative care services current and 2016

Current		2016	
Service Name	Service Base	Service Name	Service Base
Metropolitan Services		Metropolitan Level 6 Services	
SA Paediatric	North Adelaide	SA Paediatric	North Adelaide
Lyell McEwin	Elizabeth	Northern Adelaide	Modbury
Modbury	Modbury	Central Adelaide	Woodville
Central Adelaide	Adelaide	Southern Adelaide	Daw Park
Western Adelaide	Woodville	Country Level 4 Services	
Southern Adelaide	Daw Park	Mt Gambier & Districts	Mt Gambier
Country Services		Riverland	Berri
Mt Gambier & Districts	Mt Gambier	Eyre Peninsula	Pt Lincoln
Riverland	Barmera	Whyalla	Whyalla
Pt Augusta	Pt Augusta	Pt Augusta & Far North	Pt Augusta
Whyalla	Whyalla	Periurban Level 4 Services	
Gawler & Districts	Gawler	Gawler & Districts	Gawler
Barossa & Districts	Angaston	Adelaide Hills	Mt Barker
Adelaide Hills	Mt Barker	Southern Fleurieu	<i>Victor Harbor</i>
South Coast	Victor Harbor	Country Level 2 Services	
Lower Eyre Peninsula	Pt Lincoln	Barossa & Districts	Tanunda
Port Pirie Regional	Pt Pirie	Pt Pirie Regional	Pt Pirie
Murray Mallee	Murray Bridge	Mallee Coorong	Murray Bridge
Yorke Peninsula	Walleroo	Yorke Peninsula	Walleroo
Lower North	Clare	Lower North	Clare
Naracoorte	Naracoorte	Naracoorte	Naracoorte
West Coast	Ceduna	West Coast	Ceduna
Kangaroo Island	Kingscote	Kangaroo Island	Kingscote

The configuration of hospices by 2016

Planning the number and distribution of palliative care beds and units for South Australia has involved balancing the issues raised in the planning principles. An interdisciplinary team of clinical experts with sufficient FTE and bed-throughput is required to sustain advanced skills in inpatient palliative care.

Expert opinion across the Australian palliative care sector suggests that a minimum number of 16 beds are required to sustain this expertise.^{76,77} Expert opinion also suggests that 16 beds or more are required to maintain and sustain units over the long term.

The continuing trend toward outer metropolitan and peri-urban population growth supports a rationale for positioning a number of new hospices in key outer metropolitan suburbs or peri-urban population centres. This will reduce the travel time for increasing numbers of people requiring inpatient palliative care and their families who would otherwise have to travel to inner metropolitan hospices.

Set against this, is the need to establish only the number of hospices that can be reasonably sustained over the long-term given the anticipated workforce pressures that are anticipated over the next 8 years and beyond.

Table 11 records the difference in bed utilisation practice between the regionalised service in Southern Adelaide and the way overnight admitted care has been managed in the acute hospitals associated with each of the palliative care services of CNAHS. The four services of CNAHS have a bed utilisation pattern that reflects a one-hospital-one-service-catchment configuration, which tends toward the fluctuating level of palliative medicine bed-card activity within an acute hospital that meets the varying level of need for overnight admitted care arising from that hospital's catchment.

The Plan directs a shift in bed utilisation by 2016 the will see the hospice units of greater Adelaide being the places where most of the overnight admitted care provided by each palliative care service will take place.

The plan also directs services towards supporting an optimal amount of care at end of life in the home and community setting.

To support these twin outcomes, palliative medicine resources will need to be invested in community-based care and primary care capacity building, and the amount of palliative medicine bed-card activity that takes within the major metropolitan hospital setting will reduce.

The plan relies on a consistently operationalised model of care, and a range of service-level and clinical-led initiatives to support this system-level change.

Table 11

2008 publicly funded hospice beds and palliative medicine bed card activity across metropolitan hospitals.

Health Region	Metropolitan Hospitals	Dedicated hospice beds	Average bed card activity (usual range)
Central Northern Adelaide Health Service	Lyell McEwin Hospital		10 (10 – 12)
	Modbury	14	2 (0 – 4)
	Queen Elizabeth		8 (6 – 12)
	<i>(contracted at Philip Kennedy Centre Hospice)</i>	12	
	Royal Adelaide Hospital		4 (2 – 12)
	Calvary Hospice Mary Potter Hospice	6	-
Southern Adelaide Health Services	Repatriation General Hospital	15	0
	Flinders Medical Centre		0
	Noarlunga Health Service		0
Total Average Palliative Medicine Bed Card Activity		47	24(18 – 40)

Nurse-led care options

The palliative care plan allows for the piloting and evaluation of a nurse-led model of inpatient care. In instances when expert nursing care is the primary therapeutic intervention preferred and required by an inpatient, the presence of appropriately costed and differentiated beds types enables services to better match needs and preferences with resources.

This innovation represents a potential option for:

- > uncomplicated terminal care
- > periods of step-down care for stable younger inpatients who live alone or cannot realistically be cared for at home
- > planned and unplanned periods of respite care
- > inpatients whose stated preference is for 'comfort care only'.

When evaluated and costed, the incorporation of a small cluster of nurse-led beds into the overall compliment of beds for each Level 6 service safely allows for expanded choice and an increase in the overall number of beds.

The option of nurse led care may address a well-described and persistent gap in services for people under 65 years of age with either continuing high care needs or requiring a step-down and slow stream care approach that is not satisfactorily or appropriately provided in the residential aged care setting.

The option also accommodates the need for short periods of planned or unplanned overnight admitted respite care.

Other nurse-led care options will also be explored in the community and transitional care settings, drawing on the shared residential housing model that is used at Cheltenham House⁷⁸ to meet supported care needs of people with advanced HIV/AIDS.

Other components of palliative care service

The scope of palliative care services extends well beyond clinical service provision, and includes a number of domains and activities that are summarised in the section below.

Research

The palliative care community is charged with the primary responsibility for asking and answering a range of questions related to clinical, philosophical, technical and operational issues related to end-of-life care and the needs of the palliative care population. This community bears the responsibility for building the knowledge- and evidence-base that frames future practice and innovation.

Level 6 services have particular research responsibilities and are expected to develop a purposeful targeted program of research which both achieves a 'best fit' between the skills, interests and capacity of expert clinicians within that service and the targeted areas of established need or knowledge deficit.

Establishing research priorities and program areas are negotiated via statewide and national research networks. A statewide end of life care research collaborative is proposed.

Education and teaching

Undergraduate

Curriculum offered in health sciences courses that prepare the health workforce that will provide end of life care in the future will, as a minimum, need to incorporate an introduction to the principle and philosophy of palliative care. National curriculum initiatives are available to support this.

Palliative care services demonstrate their contribution to education through the development of relationships with undergraduate faculty at University and TAFE to design, deliver, review and evaluate palliative care-related curriculum, and by recognition of participation through membership of academic faculty.

Palliative Care services provide clinical placements opportunities for undergraduate students and have established agreements that support the development of shared teaching and learning relationships and activities with faculty partners.

Postgraduate

A range of postgraduate topics and awards are already available to provide for the entry-in-specialty and advanced practice needs of the specialist workforce.

The Department of Palliative and Supportive Studies at Flinders University and the Discipline of General Practice at Adelaide University both offer different but well-established graduate programs.

Experienced expert clinicians working in Level 6 services contribute to the continuing design, delivery, review and evaluation of both graduate-level palliative care-related curriculum and discipline-specific graduate curriculum. They also gain recognition for their contributions by way of academic status and in some instances joint appointments. Their profile and their activities within the teaching faculty of universities is indicative of the extent to which Level 6 services are recognised for their tertiary level expertise.

All palliative care services provide clinical placements opportunities for post-graduate students and have established agreements that support the development of shared teaching and learning relationships and activities with faculty partners.

Clinical teaching across settings

Opportunities to provide clinical teaching arise on an ad hoc and daily basis and represent the principle mechanism for capacity building amongst primary care providers regardless of setting.

Beyond ad hoc and ongoing clinical teaching, Level 6 services provide a targeted range of clinical teaching opportunities and take responsibility for the continuing teaching/learning needs of their own team members, as well as contributing to formal teaching opportunities (such as grand-rounds, clinical teaching and tutorial calendars) within the acute care hospitals and community agencies with which they have service agreements.

A statewide approach to training support, continuing professional education and practice development across palliative care services will assist in enhancing the quality and diversity of opportunities that can be provided to, and by the palliative care community of practice.

Health promotion

The palliative care sector has an evolving interest in the promotion of health through the 'normalisation of death'.

Through a range of targeted public health promotional approaches designed to shift the level of community anxiety about death and dying, palliative care services seek to redress the concerns of those that feel that assisted suicide is a more dignified response to impending death than the path that lies through illness and dependence on others.⁷⁹

Appendix 5: Equipping teams for change

The new and emerging roles within palliative care teams

A range of new and emerging roles will be incorporated into expanded palliative care teams.

The palliative psychological medicine specialist and the palliative care clinical psychologist

This plan anticipates the need for Level 6 services to enhance their capacity to provide psychological and psychiatric support to better assess and meet the needs of people with emergent or continuing mental health needs at end of life, those whose mental health is at risk, and to caregivers and families experiencing anxiety, distress, psychological dysfunction or mental health crises.

Palliative Psychological Medicine Specialists will be incorporated into the specialist medical complement of each adult Level 6 service to achieve this.

Each Level 6 service will also utilise a clinical psychologist specialising in psychological support and therapeutic counselling to people, caregivers and families experiencing anxiety, existential distress and difficult adjusts that are common at end of life.

These two post-holders will augment both the psychosocial support and medical components of Level 6 teams and will take up leadership roles in clinical teaching, curriculum development, undergraduate and post graduate education, and clinical research within their respective disciplinary fields. They will serve as a key resource to all providers of mental health and psychosocial therapy and support at end of life across the state.

The GP with a special interest

The use of the general practitioner with a special interest in palliative care have been identified as a potential source of medical practitioners who can 'fortify' the provision of palliative medical services, particularly across community settings.^{80,81,82}

The varying distribution of general practitioner services and after hours locum service cover across the community setting, leaves large structural gaps in primary medical care services.

This will limit the capacity of SA Health services to increase the amount of adequately supported end of life care in the outer suburbs of Adelaide.

The use of the GP with a special interest in palliative care will be explored:

- > in the hospice setting and in GP Plus Centres
- > when working alongside nurse practitioners in the community, and with a particular focus on supporting people at end of life with multi-system illness
- > as a key component of palliative care service provision in country general hospitals
- > to extend specialist skills and expertise into the general practitioner workforce.

GPs with a special interest will require clinically supervised training through the Clinical Diploma of Palliative Medicine.

Depending on need and availability, they could be employed on a sessional basis, with a pro-rata allocation of additional sessions per month for continuing professional development.

The efficacy and effectiveness of the role of the GP with a special interest will be evaluated by the midpoint evaluation, and will inform the ongoing workforce strategy for palliative care.

The caregiver network facilitator

This novel role utilises a health visiting approach to engage with caregivers to assist them to identify and mobilise their own local network of friends, relatives, neighbours, work colleagues and acquaintances to assist with caregiver support.

A key aspect of the role involves addressing social barriers as well as knowledge deficits that inhibit the utilisation of a willing and able network of people and local organisations to provide material and practical assistance to caregivers.

The facilitator maintains extensive knowledge and entree to the full spectrum of local community resources that exist (including local government, community groups, sporting associations and the faith or cultural communities that are relevant and significant to the caregiver).

Harnessing appropriate and practical and emotional support from non-professional sources is not designed to substitute the role of clinical professionals in caregiver support. It serves to strengthen community capacity and build social capital and lay the foundations of effective support in bereavement.

A strong weight of published evidence also suggests that early social reintegration and support through existing networks of social support may represent the most effective and therapeutic mechanism to reduce complicated grief reactions and offset the increased risk of caregiver morbidity. In this context, the facilitator works to prime the caregiver support network to recognise and respond usefully to the emotional (as well as the practical) needs of that caregiver as they experience grief and loss after the death.

To ensure the optimal development and utilisation of this role it may benefit from being relocated to a more appropriate service other than palliative care. On the basis of mid point evaluation (due in 2012) these roles may be sponsored by, or transferred to, primary care services in GP Plus networks or Commonwealth carer respite service or even local councils, and take up a wider role in community network facilitation to a broader range of target groups (possibly even those identified through locally generated health improvement plans.

The personal care worker in community palliative care

This plan anticipates the need for a workforce of personal care workers with accredited skills and training in the provision of end of life care.

Their role in personal care workers within community palliative care teams is described elsewhere.⁸³

The palliative care sector will have a leadership role in the development of training, accreditation and supervision of practice of this workforce.

The development of this personal care worker role for use in palliative care packages will require planning and a comprehensive workforce strategy. This strategy will need to incorporate not just recruitment and role promotion, but will also require a careful mapping of opportunities for workers to progress through a well-described career path involving role consolidation and progression through an articulated program of training and credentialing opportunities.

By this means, those aspiring to a career in community-based end of life care work can move along a path from an entry point characterised by casual employment and heavily supervised practice in an unregulated role through to a fully credentialed and professional role.

Optimising contributions through advanced practice roles

Advanced practice roles:

- > have extended and expanded scopes of practice
- > incorporate innovative, non-traditional tasks
- > take responsibility for aspects of care previously undertaken by another health professionals.

Advanced practice, however involves more than transferring tasks or functions from one member of a team to another. What makes a practice role 'advanced', is the application of advanced knowledge required to safely perform those services or tasks.

The other requirement for these roles is the maintenance of high-level collaborative interdisciplinary model of teamwork and a shared approach to clinical governance.

An advanced practice professional is a recognised expert in their field. They have special knowledge, skills, and years of experience related to the care of a specific patient population and in the delivery of expert, specialised clinical services.

Their roles involve expanded practice, across multiple domains related to clinical practice, education, research, professional development and leadership, and they have a pre-established minimum level of post-basic education, and an appropriate level of clinical supervision required for safe practice at an advanced level.

A number of advanced practice roles have been planned for palliative care services in South Australia.

The palliative care consultant physiotherapist and occupational therapist

Rather than seek additional allied health workers, the intent of this strategic plan is to utilise the contribution of therapists for higher-level effect.

A physiotherapist and an occupational therapist will be employed by each Level 6 service with the expectation that these clinicians will engage in graduate level palliative care education, develop advanced clinical expertise and serve as clinical leaders within their respective disciplines.

These clinical leadership roles will serve as consultant clinicians. Through the development of their own roles, and engaging a shared program of advanced practice and role development, they will fully explore and optimise the contribution that physiotherapy and occupational therapist roles can make to:

- > the comprehensive functional assessment
- > community-based support of palliative care patients (including in the GP Plus Health Care setting)
- > maintenance of functional independence
- > palliative rehabilitation from reversible decline in function
- > the management of asthenia.ⁱ

Consultant therapists will serve as statewide resources and lead their services in the capacity building of other therapists who work in primary and acute care settings to support quality end of life care. They will be expected to contribute to curriculum development, education and training within and beyond their own disciplines, and will bring new focus and capacities to the research agenda.

The palliative care consultant pharmacist

Through the Pharmacy Reform Program, accredited consultant pharmacists will be positioned in each Level 6 service and in Country Health SA to take up leadership roles in clinical practice, teaching/education curriculum development, and clinical research within the field of palliative care pharmacotherapeutics.

A fully optimised advanced practice pharmacy role in palliative care would play a critical role in the ongoing management, monitoring and titration of complex drug regimens, and serve as an expert resource for all prescribers providing end of life care.

These roles will facilitate a program of close engagement and capacity building between Level 6 services and community and hospital pharmacies across the state, and through the development of a statewide community palliative care pharmacy network. The pharmacist based in country will work across all country areas.

A self-sustaining SA Palliative Care Community Pharmacy Network will:

- > Facilitate a quality use of palliative medicines approach across community, aged care, disabilities and acute care settings.
- > Expand the number and the capacity of community pharmacists across the state providing home medicine reviews for palliative care patients in the community
- > Ensure the optimal prescription and dispensing of palliative care medications around the clock to those who need them, and the safe disposal of those drugs when no longer required
- > Explore and overcome barriers that inhibit greater contribution to the planning and delivery of coordinated multidisciplinary palliative care by community pharmacists in the community setting
- > Bring together community pharmacists with an interest in palliative care to explore and develop opportunities for increased community pharmacy involvement in quality end of life care in the community.

The palliative care nurse practitioner

The number of nurse practitioners working in Level 4 and 6 palliative care services will need to rise from two to 20 or more by 2016 in order to meet the projected demand arising from:

- > substantially increased proportion of complex care at end of life provided in the community setting
- > nurse-led care options in the hospice, transitional care facilities and community shared housing arrangements
- > comprehensive after hours 'on call' and rapid response initiatives, and
- > increasing complex care in country general hospitals and periurban services.

By 2016 Nurse Practitioners will be the most common senior specialist nursing role within palliative care services and will have established a profile across the community, ambulatory and acute care settings.

ⁱ Asthenia is a clinical term that refers to weakness, debility or lack or loss of bodily strength and energy.

When fully optimised, these advanced practice roles will enable comprehensive clinical assessment care coordination and clinical management for people at end of life with complex needs.

They will:

- > work closely with general practitioners and other primary end of life care providers
- > provide the 'first on call' for after hours advice and support
- > provide the bulk of triage and rapid response roles within each Level 6 and 4 service across SA
- > serve as an exemplar clinical leader and teacher in nursing at end of life.

The advanced practice social worker

The palliative care workforce strategy will need to overcome the underdeveloped social work career path to ensure a fuller utilisation of the range of skills and contributions inherent in the social work role through the development of advanced practice social worker roles.

This plan recognises that experienced social workers with additional qualifications, training and skills (beyond that of entry level social work practice) can be more fully utilised within palliative care services in particular aspects of service delivery such as:

- > therapeutic one-on-one and group counselling and interventions
- > community capacity building, health promotion at end of life, and partnership development
- > the coordination, education, training and support of volunteers, and bereavement programs
- > a clinical leadership role to provide advocacy, policy development, academic and clinical teaching, and research to build the evidence, design curriculum and change practice in psychosocial care at end of life.

Appendix 6: Supporting end of life care providers

To further improve the quality of this care, in the face of an overall increase in the demand for end of life care requires:

- > an informed community
- > an informed health sector
- > the 'right' support for generalist providers of end of life care by the palliative care sector
- > a particular focus on supporting 'living-in-place/dying-in-place' in the residential aged care setting
- > a 'whole of population evaluation' of end of life care.

An informed community

South Australia's health reform program is being underpinned by a range of strategies that systematically increase the level of health literacy across all sectors of the community.

In general terms health literacy refers to the ability of an individual to make decisions and act in favour of their health in daily life.

Health literate people have increased control over their health; they take responsibility and participate in activities such as actively seeking out health information, navigating complex systems, changing behaviour that puts their health and wellbeing at risk and negotiating health care options for themselves.

Health literacy at end of life has a particular focus on:

- > open honest communication around prognosis
- > fully informed and realistic appraisal of treatment choices, their benefits and their burdens
- > timely, sensitive and continuing engagement with people, their caregivers and families to elicit and explore their preferences
- > facilitation of those choices through Advance Care Planning
- > recognising that people can and do change their minds.

To date uptake of advance care planning under the Consent to Medical Treatment and Palliative Care Act 1995⁸⁴ has been relatively low. The development of an informed choices program as a statewide approach to achieve effective promotion of Advance Care Planning across SA Health is an important feature of the health literacy agenda.

A statewide Informed Choices Program will support health workers facilitate timely conversations between people and their family members, caregivers, friends and the health care teams working in both community and hospital settings to ensure that people's choices about treatments are both known in advance and are respected.

This is particularly important in situations where a person is unable to speak for themselves.

Advance care planning gives people the opportunity to exert greater control over health related decision-making at the end of life.

Written and signed advance care plans serve as a record of a person's choices ahead of time, and a consistent and coordinated informed choices program will help to ensure health providers respect people's choices at critical moments in the clinical decision-making process. By exposure to an informed choices program, individuals and families increase their health literacy.

In South Australia, The Queen Elizabeth Hospital has championed the uptake of Advance Directives through the Respecting Patient Choices program. Since 2004 the Respecting Patient Choices team at has built up considerable capacity and experience in this area, and has demonstrated strong uptake of advance directives across western Adelaide.

Advance Care Planning has become routine practice in many residential and community aged care services, and a number of hospitals are currently developing local advance care planning programs to ensure uptake of Advance Directives, suggesting the need for coordination and consistency of approach.

The SA Government is currently engaged in a review of the laws, regulations and conventions that relate to Advance Care Planning and Advance Directives to determine potential changes needed to ensure advance directives can be made and respected. This review will result in legislative changes and new documentation to record Advance Directives in SA.

An Informed Choices Program should be applied across South Australia using a well-coordinated and consistent approach to lift the capacity and skills of targeted front-line health workers in facilitating timely conversations about care choices and procuring advance care plans. This will require a staged program of training and support to a range of health care workers in the community, in residential aged care facilities, in hospitals and health clinics across the state.

While the palliative care sector has been identified as having a lead role in the development of this health service innovation, the community primary care setting has been suggested as the most appropriate clinical venue for the timely and sensitive facilitation of conversations about care choices and the generation of Advance Care Plans. There are a range of key frontline workers (practice nurses, GPs, community and hospital-based chronic disease care coordinators, lifestyle coordinators, etc) who are positioned 'upstream' where critical 'triggers' that serve as timely and appropriate opportunities to initiate Advance Care Planning occur. These workers will be key agents in the efficacy and success of the Informed Choices Program.

Statewide planning that seeks to meet the care needs of healthy older people and to best manage the care of people living with chronic disease, both represent key opportunities to maximise the delivery and impact of an Informed Choices Program. With this in mind, the operationalisation of an informed choices program will overlap a range of planning initiatives and draw in a range of partner programs, agencies and services to achieve effective and sustainable results.

An informed health profession

To further lift the quality of care provided to South Australians at end of life requires:

- > service-level and clinician-level capacity to adapt to changes in practice informed by evidence and a best-practice approach
- > the incorporation of the principles and philosophy of palliative care into foundation-level educational curriculum of all social and clinical health disciplines involved in the provision of end of life care.

Beyond foundation training, each discipline, and each specialty and advanced training program should address quality care at end of life and ensure that specialist curricula and continuing profession development programs reflect contemporary required knowledge and skills.

All clinicians involved in the care of people at end of life across public and private health sectors will need to:

- > maintain a contemporary understanding of the ethics and duties that underpin the change from curative to palliative strategies, including an appreciation of relevant legislative and professional standards of practice, the appropriateness of and justifications for withholding or withdrawing treatments and respect for the informed choices of people at end of life, their advance directives and the decision-making capacity of their legally appointed proxies
- > maintain skills in advanced care planning, breaking bad news, and in honest and open communication around prognosis, supporting informed consent through realistic interpretation of the benefits and burdens of treatment, and spend time listening and understanding peoples concerns, preferences and aspirations at end of life
- > reflect on their own mortality and their feelings and responses to death, loss and grief
- > understand the scope of palliative care services in meeting the needs of people at end of life maintain contemporary expectations about their own level of involvement in end of life care, and
- > understand the needs-based referral criteria and new mechanisms to achieve timely and appropriate referral to specialist services.

Support for generalist providers of end of life care

End of life care providers continue to benefit from an expanding body of high quality, evidence-based resources, guidelines and clinical pathways to inform and support their clinical practice and decision-making. Though the National Palliative Care Program and at a state level, these include but are not limited to:

- > Caresearch: Palliative Care Knowledge Network.⁸⁵
- > APRAC⁸⁶ and COMPRAC.⁸⁷
- > The Rural Palliative Care Program.⁸⁸
- > MAPCARE.⁸⁹

As the terminal care phase approaches, end of life care pathways including the Liverpool Care Pathway⁹⁰ and the Gold Standards Framework⁹¹ have both been promoted internationally as a means of systematically improving the outcomes of end of life care provided by generalist clinicians in acute and community settings.

Local adaptation of these approaches will continue in a limited fashion until high level evidence confirms the efficacy and sustainability of their perceived outcomes.

These initiatives underpin and support the capacity of all generalist providers to better meet the needs of people at end of life, their caregiver and families/kinship groups.

Supporting end of life care across the aged care sector

The concept of 'ageing in place' has driven the development of a range of services aimed at supporting people to remain in their place of residence as they grow older.

Following on from this concept, 'dying in place' has emerged as an important principle for the planning and delivering of services to support people to not only live well at the end of their life, but to die where they have lived.

The concept of 'dying in place' represents an important social response that serves to enhance choice and reinforce personal and social continuity. In this respect, it reinforces death as a normal part of life.

For the majority of frail and disabled older people, their place of residence becomes a residential aged care facility. However:

- > The age of Australians living in residential aged care facilities is increasing with over 50% of all residents now over 85 years and more than a quarter over the age of 90 years (while only 4% are 65 years or younger)
- > Their level of acuity and care needs are increasing with the proportion of those assessed as requiring high level care has risen over the last decade from under 60% to approximately 70%
- > Length of time from admission to death is also increasing with an average completed length of stay for permanent residents rising from 131 to 146 weeks over the last decade.⁹²

For providers of care in the residential aged care setting, this requires high level and ongoing commitment to the twin concepts of 'living in place' and 'dying in place'.^{93,94} Providing end of life care for people living in a residential aged care facility is an integral part of the work of the aged care sector.

A number of enablers and strategies have contributed to the enhanced capacity of all aged care services in South Australia to provide high quality end of life care.

These include or are reflected in:

- > The recently implemented Aged Care Funding Instrument which now includes palliative care in its funding classification criteria.
- > The considerable investment of educational resources, training and support through the National Palliative Care Program⁹⁵ and the Encouraging Best Practice in Residential Aged Care Program⁹⁶ to systematically build up the capacity of residential and community aged care services to provide quality end of life care.^{97,98,99,100}
- > A number of initiatives rising from the older peoples' health reform agenda, as outlined in the Health Service Framework for Older People. One element of this wide-ranging reform is the advent of Regional Aged Care teams working across aged care services and settings. These interdisciplinary teams will have a continuing presence and impact on the quality of care for older people both in their homes and in supported care settings. This initiative will lead to greater integration, an improved capacity for timely intervention in the trajectory of 'at risk' elderly, and greater continuity of care for older people at end of life. Through close partnerships the regional aged care and palliative care teams will work together to identify triggers and optimise their respective contributions to the care and support needs of older people at end of life.
- > The proven impact and efficacy of the 'link nurse model'.^{101,102,103}
- > Around the clock access to advice and support from a local palliative care service, and access to overnight admitted care in a hospice on the basis of need.
- > The introduction of new palliative care service reporting requirements that detail support activities
- > A whole of population surveillance approach, that will capture key aspects of outcomes related to end of life care across residential and community aged care settings, and will need to include a shared quality and audit capacity across regionalised aged care services and palliative care services.

Evaluating end of life care

The reforms heralded by the National Health and Hospital Reform Commission align with the reform agenda underway through South Australia's Health Care Plan.¹⁰⁴

Performance targets and benchmarks as well as regular reciprocal public performance reporting of health performance across all Australian jurisdictions will become a more prominent feature of future Australian Health Care Agreements.

'Patient-level' data that links family experiences, service utilisation and outcomes, along with 'number of emergency department visits and hospital days in last 30 days of life per person' have both been mooted as possible performance benchmarks for incorporation in Australian Health Care Agreements by 2010-11.

End of life care surveillance is a coordinated and ongoing planning and quality activity designed to establish and analyse an inventory of existing databases and additional and required data that helps answer key 'what', 'how' and 'where' questions about the end of life care provided in South Australia.

More specifically surveillance of this kind seeks to describe, from a population-wide perspective, the places of end-of-life care, care transitions, levels and types of caregiver involvement, the actual treatments and care provided to people at end of life. It also seeks to identify and refine potential indicators or proxy measures of the quality of end-of-life care that are to be found within available data.

Although the term implies a 'policing' function, its purpose is to inform planning and resource allocation. It will result in a greater capacity to plan and equitably deliver care across service catchments and areas of the state that vary considerably in terms of demographics and the distribution of health determinants.

This focus on population-wide end of life care outcomes rather than just the outcomes of those referred to palliative care services, is consistent with the reform agenda of both the National Health and Hospital Reform Commission and SA Health. Palliative Care Australia has recently been involved in bringing together a national 'quality end of life care alliance' to progress this agenda.

Integral to this focus is the reliable capture of high quality relevant data from a range of sources that when combined, yield a comprehensive picture of outcomes of care at end of life for the whole of population.^{105,106,107}

Appendix 7: Improving access and equity

People living in rural and remote settings

Currently 15 palliative care services operate across periurban, rural and remote South Australia. Based in larger population centres across the state, they each provide support to primary care providers in smaller population centres and their surrounding districts.

A Palliative Care Coordinator will lead each rural and peri-urban palliative care service. These positions serve to ensure:

- > the provision and coordination of high quality care for palliative care patients in each service catchment
- > the continuing provision of education and capacity building to primary and acute care providers of end of life care in the primary care and acute care settings across the service catchment
- > a close and ongoing relationship with the Level 6 service partner.

Drawing on the role of Country General Hospitals as outlined in the Strategy for Planning Country Health Services in SA, Level 4 services will have greater capacity to support one or more neighbouring Level 2 services that operate within their cluster arrangement.

The Nurse Practitioner role will be a key element in the provision of expert palliative care by Level 4 services across the state. Within the framework set out by the Nurses Board of South Australia nurse practitioners working in Level 4 palliative care services would be banded as 'rural and remote' with either a palliative care-specific scope of practice, or a more general community health scope of practice which includes chronic disease and end of life care as a combined specialty scope of practice. These Nurse Practitioners will need access to palliative medicine specialists and to regular periods of clinical time in a Level 6 service through their candidature and on an ongoing basis.

To meet the end of life care needs of people who will increasingly be receiving care for advanced disease at local Country General Hospitals rather than travelling to the metropolitan hospitals, the plan anticipates the need for designated medical roles within rural Level 4 services. In the absence of staff medical officers employed at Country General Hospitals, the role of the General Practitioners with a Special Interest in palliative care will be explored.

The General Practitioner with a Special Interest in palliative care will undertake additional training through the Clinical Diploma of Palliative Medicine. Along with nurse practitioners and other members of the Level 4 clinical team they will be supported to locally manage the care of people at end of life with complex needs though the provision of a program of regular visitation as outlined below.

The incorporation of hospices in key periurban centres in the outer north suburbs and the Mt Lofty Ranges will also consolidate specialist capacity in the periurban areas and allow for specialist inpatient care for people from across the greater Adelaide area and beyond, based on need.

A staged program of new hospice development will support the development of these two units and consolidation of local specialist workforces to staff these units. The program of experience in the palliative approach will be also be used to augment this local staff training and capacity building program.

The key features of the partnering relationship between Level 6 services and their respective Level 2 and 4 services partners is the calendared program of visits and support.

The features of partnering include provision of 24-hour phone advice and support to Level 2 and Level 4 service providers, and through them to primary and acute care service providers across the state requiring assistance with clinical care at site of care.

A year-round calendar of multidisciplinary visits to support ongoing face-to-face clinical teaching by key members of the Level 6 team including:

- > palliative medicine specialists (funded though Medical Specialist Outreach Assistance Program in those rural areas targeted by this program)
- > palliative care nurse practitioners and nurse consultants
- > service directors
- > social workers, palliative care clinical psychologists, pharmacists, physiotherapists and occupational therapists
- > palliative care volunteer and bereavement coordinators
- > regular and ad hoc clinical and professional development support conferencing via Telemedicine, with telemedicine facilities available at each Level 6 service base

- > funded release to participate in a structured program of periodic clinical training and professional development time in the Level 6 service for all rural coordinators and clinical staff working in Level 2 and Level 4 services
- > access to Level 6 continuing professional development program activities, and to an ongoing remote group clinical supervision program.

Infants, children and adolescents

There is a statewide paediatric palliative care service. This palliative care plan focuses on:

- > consolidating the service to ensure long-term sustainability
- > addressing paediatric-specific workforce planning within the wider workforce strategy
- > integrating paediatric palliative care capacity within partnering and clustering arrangements, and through community capacity building
- > ensuring the needs of the paediatric palliative care population are reflected in sector reporting, quality, surveillance, research and development programs
- > the need for expansion of paediatric palliative care-specific psychosocial support and bereavement counselling services
- > the pathway of transition for older adolescents and young adults from child-centred to adult-orientated services

The end of life care needs of infants, children and adolescents, their parents, siblings and families are unique, and so too is the palliative care service designed to meet their needs.^{108,109}

The key features of Paediatric Palliative Care Services include:

- > specialist respite, emergency, palliative and terminal care (that can be offered within the hospital, hospice or the family home)
- > bereavement counselling and support (offered as individual home support, in groups and with siblings)
- > information, advice and practical assistance
- > around the clock telephone support
- > a volunteer support service (that ensures families are supported)
- > collaborative working arrangements with other agencies and individuals to ensure a continuum of care and support is available to the children and families, and that the families have choices about care and the place of death
- > provision of information, expert help and guidance for others involved with the child and family.

The five most significant differences between adult and paediatric palliative care services are:

- > The level of expertise and skill required for the clinical management of a diverse range of rare or uncommon conditions that led to death in infancy, childhood and adolescence. For this reason, the continuing central role of the child's paediatrician is essential
- > The incidence of 'life limiting' illness in children in developed countries is estimated to be 0.1% of children.¹¹⁰ The relatively small numbers of referrals per year in South Australia supports only a small clinician team of expert specialists. The training and replacement of specialist workers represents a continuing challenge, as is the need for high level coordination and integration by the statewide paediatric and local adult services
- > Parents often serve as the key decision-makers and caregivers
- > The level of psychosocial and emotional distress for parents, siblings, families, neighbourhoods (including school communities) are profound and lead to increased potential for complicated grief reactions, impaired long-term adjustment and long-term measurable impacts on health and wellbeing
- > The referral criteria for paediatric palliative care service have traditionally been broader than those of adult services and include infants, children and adolescents with:
 - Conditions for which curative treatment has failed, such as cancer, or irreversible organ failure
 - Conditions where long periods of intensive treatment may prolong the length and improve the quality of life, but where premature death is still probable or inevitable, such as Cystic Fibrosis and Duchenne muscular dystrophy
 - Progressive conditions for which treatment is exclusively palliative and may commonly extend over many years, such as Batten's disease, CJD, Mucopolysaccharidoses
 - Severe neurologically disabling diseases, which although not progressive, lead to vulnerability and increased susceptibility to complications and premature death, such as severe Cerebral Palsy.^{111,112,113}

With improvements in clinical science and practice some conditions that were once considered fatal have increasingly become chronic in nature, to the extent that death can be forestalled well into early adulthood and beyond. For some adolescents and young adults a transition pathway from child-centred to adult orientated health care systems is required.

This plan anticipates progress by the Australian Paediatric Palliative Care Reference Group in the development of a purposeful, planned transition pathway that addresses the medical psychosocial and educational/vocational needs of adolescents and young adults with chronic medical conditions and physical disabilities as they make the move from paediatric palliative care services to appropriate adult services.¹

Bereavement support surrounding the expected death of an infant, child or adolescent is currently provided on an 'ad hoc' basis. A skilled counsellor or social worker with expertise in loss and grief to serve as a statewide resource and leader has been identified as a high priority recommendation arising from sector feedback, role demand and gap analysis.

A statewide paediatric palliative care psychosocial support and bereavement worker position based at Women's and Children's Hospital will:

- > Provide paediatric palliative care bereavement services and counselling
- > Utilise early intervention strategies targeted to parents, siblings, families and friends to therapeutically alter bereavement course and outcomes
- > Engage with key workers in schools, faith communities and other community groups to advance health in grief and loss
- > Provide expert advice consultancy, support and education related to children's grief and bereavement to metropolitan, peri-urban, regional and rural palliative care services
- > Build capacity of adult palliative care services and other end of life care providers to provide bereavement counselling to children and adolescents who have been affected by death of a family member.

The issue of workforce replacement within small teams of sub-specialty experts is a particularly challenging one. With this in mind, the long-term sustainability of the paediatric service will be better served by replacing the nurse coordinator position with a second Nurse Practitioner position and shifting the service management role to the psychosocial support and bereavement worker.

The family General Practitioner, the child's Paediatrician and a local adult palliative medicine specialist each have a role in providing medical input into the end of life care of infants, children and adolescents.

In each instance their contributions need to be clarified and coordinated with an emphasis on right balance of continuity, accessibility and expertise to meet the assessed needs of each child and family.

The consolidation of the medical contribution to the paediatric service hinges on:

- > the continuity of the role of the GP and the primacy of the child's paediatrician
- > the continuing ad hoc role played by local adult palliative medicine specialists
- > the use of two sessions per week of clinical consultation at the Women's and Children's Hospital by an adult palliative medicine specialist from the Central Adelaide Palliative Service, in the absence of a paediatric palliative medicine specialist or paediatrician with a special interest and training in palliative care.

Aboriginal people

Aboriginal people in South Australia are a diverse population group made up of different clan and language groups. More than 50% of Aboriginal people in the state live in rural and remote areas.

Research confirms that as the terminal phase of the end of life journey approaches, getting home to country is the highest priority for many Aboriginal Australians.

The palliative care plan supports improved access for Aboriginal people to their local palliative care service and directs all mainstream services providing end of life care to do so in ways that respond to the cultural needs of Aboriginal people at end of life, their families and extended kinship groups.

Within the SA Country Health Care Plan, Pt Augusta has been identified as the location for a centre of excellence of Aboriginal Health for the state.

Aboriginal and Torres Strait Islander peoples experience significantly more ill health than other Australians. They typically die at much younger ages and have higher rates of diabetes, cardiovascular disease and cancer. They are more likely to experience disability and reduced quality of life because of ill health.¹¹⁴ At both national and state level, closing the gap in health outcomes between Aboriginal and other Australians has been identified as a high priority.

Several projects have been working to improve the end of life care journey for Aboriginal people:

- > A National Indigenous Palliative Care Needs Study¹¹⁵ undertaken by the Australian Government Department of Health and Ageing in 2002, led to the development of practice principles and educational resources^{116,117} to support mainstream health care workers to provide culturally appropriate end of life care to South Australian Aboriginal people
- > The Program of Experience in the Palliative Approach (PEPA) has an expanded brief to provide experiential learning opportunities for Aboriginal Health Workers to spend time in a palliative care service. Until 2010, an Aboriginal PEPA Manager will be working to develop sustainable networks of collaboration and support between local palliative care services and Aboriginal Health Services and Aboriginal Community Controlled Health Services. These networks will serve to enhance access to and quality of, care provided 'in country' to Aboriginal people at end of life. Evaluation of this project will inform the needs for and scope of addition or ongoing support programs for end of life care to Aboriginal people in South Australia.

Where necessary cultural safety training opportunities for palliative care practitioners will be provided.

In those hospitals where it is anticipated that Aboriginal people will require inpatient end of life care, the facilities need to be designed to adequately account for the cultural needs and practices of Aboriginal people.

Design emphasis will be placed on:

- > Significantly increasing the size of rooms to encourage and accommodate extended family and kinship groups over long periods of time
- > Providing direct bed access to adjacent outdoor areas to enable care to be provided outside (day and night) over extended periods of time. These outdoor spaces need to be purposefully designed
- > Providing unencumbered capacity for ceremonial and cultural activities before and after death (with specific reference to smoking ceremonies and aspects of sorry business).

People from diverse cultural backgrounds or linguistic traditions

Health services and professionals that provide care at end of life require, at a minimum, the capacity to engage in culturally safe practice, by recognising the extent to which culture and language influence and frame responses to:

- > beliefs and understandings about death and dying, the purpose of the human experience and the virtue, if any, of human suffering
- > the transaction of information, 'truth telling' and consent
- > the provision and receipt of services
- > the negotiation of professional/therapeutic and interpersonal relationships

Equally, the needs or preferences of individuals cannot be presumed on the basis of their membership of a community that is identifiable on the basis of culture, language or skin colour.

Through migration, the diversity of cultural and linguistic groups present in the South Australian community is expanding, and each palliative care service will need to identify the cultural and linguistic profile of the population living in their respective service catchment.

Palliative care services will report on these profiles and the activities and programs undertaken to best meet the needs of people at end of life within their service catchment who are marginalised or at risk of reduced access to services due to cultural or linguistic difference.

Palliative care services will utilise the Cultural Competency in Health: A Guide for Policy, Partnerships and Participation¹¹⁸ to inform the care of individuals and service-level responses to cultural and linguistic communities.

Rather than reproducing palliative care services for every cultural and linguistic community, service responses will be directed toward collaborative partnerships with community leaders and key workers within cultural and linguistic groups across service catchments, and work with them to build the capacity of communities to provide their own culturally- and linguistically-specific care at end of life.

ⁱ Based on the UK-based Association of Children's Palliative Care Transition Care Pathway

Older people

South Australia has one of the fastest growing populations of older people in Australia. The exception to this marker of progress is the Aboriginal and Torres Strait Islander population that has a significantly lower life expectancy.

Older people deserve access to quality, safe, complete and affordable health care.

The ageing of SA's population, and the relative growth in the number and proportion of older South Australians brings with it significant challenges. Not least of which can be measured in terms of significant increase in demand for general health care and a shift in orientation of many age-specific services and programs to support a healthy ageing approach to care.

The Health Service Framework for Older People 2009-2016 sets out how SA Health will respond to this challenge. These predictable demographic changes will also test health service responses targeted at meeting the end of life care needs of an expanding proportion of the population, many of whom also have ongoing complex or multiple health care needs, and fewer available caregivers.

A key initiative of the Health Service Framework for Older People is the development of Regional Older People's Health Services. These teams will provide a range of clinical services and take up a leadership role in collaboration within the wider aged care sector to achieve improved care for all older South Australians. Regional Older People's Health Services and palliative care services are committed to working in partnership to ensure older people and their families are supported through the end of life journey with access to quality end of life care when required.

Younger people needing supported care in the community

Residential aged care facilities are not regarded as an appropriate setting to best meet the needs of people under 65 years of age who:

- > have a slowly progressing or extended end of life care trajectory
- > require continuing input by palliative care services
- > require continuing supported care in a suitable medium term accommodation.

This nationally acknowledged gap in service requires a structured, cost effective response to ensure equitable access to sustainable high quality supported care options to meet their continuing care needs.

The plan proposes exploration and piloting of alternative options for these people and for a broader category of people requiring step-down or slow-stream palliative care.

Palliative care in the private sector

Over recent years support for out-of-hospital end of life care by private health insurers in South Australia has declined to a minimum.

Changes at national policy level or arising through industry reform are required to overcome the barriers that currently limit privately insured South Australians' options for home-based care and support at end of life. These changes would impact on the demand for publicly-funded palliative care services.

Any opening up of support and care options for privately insured South Australians will also create market opportunities for those private and not-for-profit providers of care to extend their services beyond acute inpatient care and oncology services and allow them to offer more integrated inpatient and community-based end of life care programs.

In South Australia, Calvary Health Care, through Mary Potter Hospice is recognised as a specialist provider of inpatient palliative care.

People with interventional pain management needs

Interventional pain management techniques (beyond continuous subcutaneous infusions) are indicated in instances where pain or excessive side effects persist despite the optimisation of analgesia.

The proportion of palliative care patients who would require such intervention has been quantified with the international literature suggesting that 8-10% of people with advanced cancer require or benefit from interventional approaches to pain control.^{119,120}

Outcomes in people with pain management needs will be supported through:

- > The presence of a mechanism to formalise service agreements and referral pathways between palliative care services and tertiary level pain services through regional health services to ensure that people at end of life with acute, chronic and complex pain syndromes receive timely and appropriate access to specialist pain services
- > A program of audit and evaluation to determine quantify and cost the optimal appropriate use of procedural pain control interventions within the palliative care population
- > The incorporation of workforce and resource requirements into future service planning.

Health in grief and loss

Palliative care has had a traditional and philosophical commitment to after-death care and the provision of bereaved support. This is not the case for many other clinical services that provide care to people who die. Consequently, many who experience the loss of a relative, friend or colleague, do so without routine screening for bereavement risk, or offers of bereavement support and follow up.

It is not surprising then to find that palliative care services, particularly those in rural settings, are frequently called upon to provide bereavement support to people who are thought to be at risk through sudden death associated with sudden infant death syndrome, miscarriage and other causes of unanticipated peri-natal death, as well as from acute illness and deaths arising from sudden or traumatic causes.

A substantial and growing body of research evidence confirms that grief and loss are important and under-recognised contributors to mortality and morbidity.¹²¹ Although the experience of grief and loss at the death of a relative, friend or colleague are universal experiences that will touch everyone at some point in life, 'complicated grief' is strongly associated with poor outcomes. The effects can be wide-ranging and result in long-lasting health, social and economic costs.

As mentioned elsewhere, the greatest enabler to health in grief and loss is found along a path of reintegration back into life with the thoughtful open support of existing social networks of family, friends, neighbours and colleagues.

Accumulative and compounded grief and loss impact on the health and welfare of Aboriginal South Australians and need particular attention and culturally appropriate and integrated responses.

This plan recognises the established track-record of the palliative care sector in the areas of risk assessment and in the careful and appropriate positioning of their role and contribution to care along the specialist and primary care provider continuum.

On this basis, the palliative care sector appears well positioned to take a leadership role in progressing a whole of population health in grief and loss response.

A separate plan to scope and implement a statewide health in grief and loss agenda across the health and welfare sectors is called for.

The key elements of a successful whole-of-population health in grief and loss agenda are:

- > The formation of a new community of practice built around a coalition of clinicians, advocates, researchers, academics and other stakeholders who will take up leadership responsibility and build clinical practice capacity in appropriately targeted model of care and evidence-based bereavement care interventions and ensure their application across the health and welfare system
- > A peak body to steer development of community services and provide advice to SA Health, Family and Community Services and (at a federal level, with others) to the Commonwealth Department of Health and Ageing in the area of health in grief and loss
- > The development of the right mix of specialist and generalist community-based Loss and Grief Services to operate across the state in community health or welfare sector, GP Plus Networks and centres to address current gaps ie traumatic and sudden deaths, children and adolescents, indigenous health and community services, and across cultural and linguistic communities.
- > The use of a health promotion – community development framework and other public health approaches to build community capacity over a 10-year time frame
- > Consideration of the introduction of the role of a Chair of Health in Grief and Loss to aid the development of undergraduate and post-graduate educational curriculum, and progress a coordinated program of research that builds evidence to support quality and efficacy in both direct therapeutic interventions and in the area of community capacity building
- > Development of strategies to build capacity of general practitioners and other primary health care workers to understand uncomplicated / complicated grief and access to appropriate referral sources.

Appendix 8: Enhancing quality and measuring performance

The palliative care assessment

A key feature of referral for palliative care is the Palliative Care Assessment, which starts with an initial triage by a designated triage officer (usually an advanced practice nurse) to assess appropriateness of referral, complexity and urgency of response.

A comprehensive assessment process, using a standardised systematic multidisciplinary assessment tool is then initiated to ensure early identification of physical, social, spiritual and emotional needs, develop and individualise care plans, and tailor service responses to meet need.

The level of urgency dictates the time-frame for response to both triage and the initiation of the palliative care assessment process.

Using a common process and agreed criteria, the levels of service responsiveness across all services can be benchmarked against a best-practice standard.

Ongoing assessment and revision of care plans requires the continuing input of an expanded range of disciplinary perspectives and contributions.

System integration in palliative care

System integration can be illustrated by the concept of single entry into palliative care. This ensures that once referred, assessed and accepted into a palliative care service, a person and their caregivers will not be required to progress through multiple repeated admissions to other palliative care services as they move around the acute care or community care services and across private and public sectors.

Furthermore, single entry means that they will not be required to tell their story over again to different clinicians because their relevant clinical history is accessible to any palliative care provider at point of care (in any hospital, at home, in the GP Plus Health Care Centres or outpatient clinic).

With this level of connectivity and integration, a comprehensive palliative care assessment and plan can accumulate over encounters within and across different teams.

Using shared processes, clinical assessment and screening tools and an agreed set of criteria for entry, clinical teams across the state and across relevant government and non-government agencies will collect the same data in the same manner. They will also require the necessary level of direct access rights to medical records of people referred to their service.

This also enables palliative care specialists to provide effective remote 'on call' advice and support to clinicians at point of service. Secure web-based data warehousing enables specialist clinicians to access and interpret securely held patient records and effectively contribute to care planning and clinical decision-making.

This can be done remotely or at the point of care as dictated by circumstances.

Effective collaboration with others across clinical settings and services, across disciplines and across the public and private sectors are hallmarks of system integration. Palliative care services will be increasingly orientated toward building and sustaining the capacity of others to provide quality end of life care, rather than attempting to provide all end of life care to all South Australians.

Reporting and evaluating outcomes

The National Hospitals and Health Reform Commission place significant emphasis on open transparent reporting and indicate that regular reporting by governments to the Australian people will be a prominent feature of all future Australian Health Care Agreements.

The commission suggests that:

"...state governments would be responsible for regular reporting against agreed performance indicators for public hospitals, including at a whole of state level, at a geographic area level, at a the level of individual hospitals, and showing outcomes for particular populations for whom the system has not been equitable" (p.27).

Palliative care services funded by SA Health will participate in regular and ad hoc reporting that encompasses both activities and outcomes. Reporting will focus on a range of service level activity data elements including:

- > De-identified demographic data about those South Australians referred to palliative care services, and their needs and circumstances at time of referral
- > Data that describes the utilisation of hospice beds including purpose of admission, length of stay access and transfer issues
- > Rate of death at home, rate of death at preferred site of care and proportion of time spent, by those referred to palliative care services in over-night admitted care
- > Clinical teaching, education, research, quality activities and advanced training activities
- > Teleconferencing, out of region visiting and other activities in support of partnering arrangements
- > Staffing and workforce data in support of the palliative care workforce agenda

Consistent with the agenda set by the National Health and Hospital Reform Commission, SA Health will seek to evaluate population-wide end of life care outcomes.

A palliative care clinical network will facilitate the coordination of service development and research including the shared teaching, learning, training, resource development and research opportunities. Practice development, knowledge transfer and the translation of evidence into practice across the sector will be facilitated where possible, on a statewide basis. A state-wide end of life care research collaborative will be reinstated, with an expanded focus on collaborative cross-specialty research.¹²²

Demonstrating performance and continuous improvement

National Standards Assessment Program¹²³ funded by the Australian Government Department of Health and Ageing under the National Palliative Care Program provides a national approach to continuous quality improvement in palliative care service delivery.

This program will form a critical element in the SA palliative care quality framework. It is also a means by which palliative care services in South Australia can contribute to the national quality agenda.

The plan sets out a timeframe for the national palliative care specific accreditation for Level 6 services (by 2012) and Level 4 services by 2016.

The Palliative Care Outcomes Collaborative¹²⁴ also provides South Australian palliative care services with an opportunity to participate in a national continuous quality improvement project by the standardised collection and analysis of routine outcome measures which support a national benchmarking system designed to improved palliative care outcomes.

Research and development

The palliative care sector continues to benefit from a national program of research and development funded through the National Palliative Care Program. The directions of this program will guide the research and development agenda for palliative care services in South Australia.

Through the upcoming Australian Health Care Agreements, and through a range of intergovernmental forums, those elements of the local end of life care reform agenda that benefit from a national approach will be addressed.

Appendix 9: The workforce profile

Each year a three year rolling workforce profile will be generated to guide the palliative care workforce strategy through to 2016.

The workforce strategy will also be informed by ongoing analysis of the impact and efficacy of new roles and the optimisation of others (both those inside and those outside palliative care services).

The level of uptake of new roles and their impact on others within the team, along with the overall performance and responsiveness of teams will also be monitored.

Additional work has been planned that will refine the 2009 three year workforce profile and ensure it accounts for the differing levels of out-of region activity that each service participates in to meet their respective partnering obligations.

With specific reference to the planned incorporation of 20 or more nurse practitioners with palliative care services by 2016, a coordinated program of preparation and role transition involving three cohorts of six Nurse Practitioner candidates is proposed.

The key elements of this program include set funding allocations to:

- > Each of the Level 6 services that will providing clinical training support for candidates
- > Those services where Nurse Practitioner roles are being incorporated, to support service-level role mapping and evaluation, clinical governance development and specific stakeholder consultation
- > Each candidate as scholarship support for the post-graduate study requirements that lead to endorsement as a nurse practitioner
- > To facilitate shared training opportunities and the coordination and support for each cohort.

Each of these elements are critical enablers to the successful incorporation of the Nurse Practitioner roles as set out in this plan, and have been modelled on the palliative care Nurse Practitioner program underway in Victoria.

Workforce planning to align the disciplinary roles to the needs of services is an ongoing challenge that will be taken up by the palliative care clinical network as it pilots and evaluates role innovations and monitors trends in retention, recruitment and workforce supply.

Over the life of the plan, the workforce profile of palliative care services will be reviewed and amended.

Workforce Issues

Some new or advanced practice roles will be built into the first workforce profile at 1.0 full time equivalent per service.

This approach is calculated to ensure sufficient minimum full time positions to embed them into each service, facilitate their optimisation and to support their capacity to develop as whole-of-state resources.

Roles in this category include the caregiver network facilitator, the advanced practice roles in pharmacy, physiotherapy, occupational therapy, and the welfare officer and business manager positions.

A number of disciplines (namely medicine, nursing and social work) are already well established within palliative care and represent specialty workforces that require a more systematic and long-term workforce planning view to optimise the maintenance and replenishment of their number.

To ensure the long-term sustainability of these disciplines a dynamic workforce planning strategy will be required.

Through an ongoing iterative process that involves the production of three year rolling workforce profiles, the strategy will need to appreciate and absorb the impact that new roles have on the traditional division of labour within the interdisciplinary team, as well as the impact on others when existing roles are expanded and fully optimised.

By reviewing the needs of services, and analysing the scope and function of each role using efficacy and utilisation data, population-based formulae will be developed to enable workforce planning of roles across the team.

A base formula is derived from:

- > a realistic estimate of current workforce availability
- > presumptions about future workforce availability
- > predictions about the impact of new and renegotiated roles on the work done by current established roles, and the impact of new and different roles in sectors beyond palliative care
- > predictions about the impact of substantial changes in the amount of palliative care work taking place in homes and in other community care setting
- > a 'best fit' approach that incorporates new strategies to test the capacity of new or optimised roles and some 'pump priming' of roles that are instrumental to addressing longer-term workforce challenges across health.

Appendix 10: Glossary

Aboriginal health workers	Aboriginal and Torres Strait Islander health workers provide clinical and primary health care for individuals, families and community groups. They deal with patients, clients and visitors to hospitals and health services and assist in arranging, coordinating and providing health care in Aboriginal community health services.
Advance care directives	A written record of a person's instructions regarding their consent to, or refusal of, the future use of specified medical treatments. It becomes effective in situations where the patient no longer has the capacity to make treatment decisions.
Critical conversations	Critical conversations arise out of ordinary communication opportunities with others and lead to breakthrough changes in attitudes, behaviour and practice that are sustained over then long term. They are a key indicator of clinical leadership at any level and are demonstrated by the ability and preparedness to identify the attitudes and behaviours that lie behind the actions of others and address these barriers in ways that lead to change informed by an evidence-based and best practice approach.
Clinical networks	Multidisciplinary groups working on a collegiate basis to provide leadership and strategic planning for clinical service development across the continuum of care and across all regional health services - both country and metropolitan.
Clinical Senate	A key decision-making and advisory body of SA Health comprising senior clinicians across the health sector.
Full time equivalent (FTE)	FTE is based on the total hours worked by the health professional divided by the hours in a standard working week for that profession. A person employed on a full-time basis has an FTE of 1.0. Likewise, someone working only 2 full days a week is employed at 0.4 FTE. This varies for different professions. For the medical workforce, 45 total hours per week is equivalent to one FTE. For all other disciplines, one FTE is calculated at 38 total hours per week.
Health literacy	Health literacy is described as the capacity of individuals to obtain, process, and understand basic health information and their ability to make decisions and act in ways that enhance or protect their health in daily life ¹²⁵
Hospice	An inpatient unit providing palliative care through a fully constituted interdisciplinary team of experienced and qualified specialists. Over-night care in the beds of the hospice are quarantined and access is based on need. An established set of criteria is used to determine access and admission. These units serve as a statewide resource.
Medical Specialist Outreach Assistance Program (MSOAP)	A federally funded and indirectly managed program that enables some medical specialists to provide outreach services to rural and remote centres.
National Palliative Care Program	A national program funding by the Australian Government Department of Health and Ageing to develop and enhance research, education and clinical practice in palliative care across the country.

Palliative care	A specialty that grew out of the hospice movement. Palliative care seeks to improve the quality of life of people at end of life through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of physical symptoms and supportive interventions to address psychosocial, emotional and spiritual care needs
Palliative care service	An integrate clinical service funded by SA Health that operates across a population and is exclusively focused on the provision of specialised and expert care to people at end of life.
Service catchment	A described geographical area and the population that resides within it and for which a palliative care service is commissioned to provide care.
Statistical local areas (SLAs)	The base spatial unit for the purpose of collection, dissemination and analysis of population statistics in Australia. In 2007 there were 1,426 SLA's defined under the Australian Standard Geographical Classification system. They cover the whole of Australia without gaps or overlaps.
Terminal stage	That period of the terminal illness in which death is imminent (usually measured in hours or days).
Triggers	An event or point along a pathway that indicates or initiates an opportunity for intervention, action and review.
Unique Record Number (URN)	An allocated number that links each person to their medical record. People who have an episodes of care with a range of hospitals, primary and community health services accumulate a number of URNs.

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